

THE UNIVERSITY OF HULL

**Psychosocial Outcomes after Moderate to Severe
Acquired Brain Injury**

**being a Thesis submitted for the Degree of
Doctor of Clinical Psychology
in the University of Hull**

by

Julia Katharine Loomes,

**BSc (Hons) Psychology
PGCert Mental Health Care**

July 2009

Acknowledgements

Special thanks are extended to Dr Catherine Derbyshire and Dr Selen Selvachandran, for their invaluable help, support and advice. Thank you both for everything you have done throughout the course of the project. My appreciation is also extended to Prof Dominic Lam for his contributions. Thank you to Dr Eric Gardiner for his valued specialist advice and input.

My family and close friends have all helped me immeasurably throughout this process. Thank you for keeping me smiling! Thanks especially to Kat and Sarah, for being with me every step of the way and for never underestimating the importance of a coffee and a chat. Thanks to my parents and Monica, for your constant encouragement and faith, even when mine was wavering.

Thanks to Matt for always believing in me, reminding me what is truly important, making me laugh and making me tea.

I would like to dedicate this thesis to the people who really made it: the participants and their families who shared their time, effort and experiences with me.

Overview

This portfolio thesis focuses on psychosocial outcomes following moderate to severe Acquired Brain Injury and is presented in three parts: a literature review, an empirical study and a set of appendixes. Please note, 'Acquired Brain Injury' is used in this thesis as an umbrella term to cover all types of brain injury, from both internal causes (e.g. stroke, subarachnoid haemorrhage) and external causes (e.g. traumatic brain injury).

Part one is a systematic literature review of empirical studies examining social support after Traumatic Brain Injury. An introduction to the social support literature is presented, followed by justification for its importance as an area for study after brain injury. The methodology of the review is presented, and then included studies are reviewed and discussed.

Part two is a cross sectional study of post-traumatic growth following Acquired Brain Injury. Post-traumatic growth can be simply defined as positive changes following a traumatic event. Correlates and predictors of post-traumatic growth were hypothesised: specifically illness perceptions, social support and social functioning. The limitations and clinical implications of the study are discussed at the end.

Part three is the appendixes, containing a reflective account of the research process and supplementary materials.

Contents

Overview	3
Lists of Tables and Figures	5
<hr/>	
Part 1: Systematic Literature Review	
Abstract	7
Introduction	8
Method	13
Results	16
Discussion	24
References	31
<hr/>	
Part 2: Empirical Paper	
Abstract	36
Introduction	37
Method	44
Results	50
Discussion	58
References	64
<hr/>	
Part 3: Appendices	
1: Reflective Statement	70
2: Brain Injury ó Instructions for Authors	79
3: Ethical Approval and Research Governance Documentation	93
4: Supplementary Materials for Systematic Literature Review	94
5: Supplementary Materials for Empirical Paper	97
6: Participant Information Sheet and Consent Form	98
7: Summary of Statistical Analyses	103
<hr/>	

List of Tables

Part 1

Table 1: <i>Characteristics of the included studies.</i>	17
--	----

Part 2

Table 1: <i>Numbers of participants for types of brain injury in the sample.</i>	50
Table 2: <i>Mean scores on measures of distress.</i>	51
Table 3. <i>Mean scores (and standard deviations) for overall Post-traumatic Growth (PTG) and PTG domains.</i>	52
Table 4: <i>Correlations between PTG, level of disability and level of distress.</i>	53
Table 5. <i>Correlations between PTG, perceived social support and illness perceptions.</i>	54
Table 6. <i>Summary of regression analysis for variables predicting overall PTG.</i>	55
Table 7. <i>Summary of regression analysis for variables predicting social functioning.</i>	56
Table 8. <i>Regression analysis for demographic and clinical variables.</i>	57

List of Figures

Part 1

Figure 1: <i>The literature search process.</i>	16
---	----

Part 1: Systematic Literature Review

Social support after Traumatic Brain Injury: a systematic review of the literature

This paper is written in the format ready for submission to *Brain Injury*. Please see Appendix 2 for the Guidelines for Authors.

Social Support after Moderate to Severe Traumatic Brain Injury: A systematic review of the literature.

Abstract

Primary Objective:. The aims of the study were to 1) systematically search for literature on social support after brain injury; 2) provide an overview of the existing literature; 3) identify areas for further research.

Method: A systematic literature search was performed using search terms for Traumatic Brain Injury (TBI) and Social Support (SS). The quality of the literature was appraised using an adapted critical appraisal checklist. Inclusion criteria were: studies including adult participants with diagnoses of moderate to severe TBI.

Results: 12 studies were identified which met the inclusion criteria. 2 explored social networks, and 10 explored perceived support. Social networks were found to decrease after TBI; this was found to be associated with depression and ability to initiate social interaction. Relationships were reported between perceived social support and age, time since injury, Quality of Life and vocational outcome. Studies reported mixed findings regarding the relationship between perceived social support and emotional distress.

Conclusions: Social support has been found to be associated with a number of different factors and outcomes. It is difficult to draw conclusions from the existing literature and future research needs to use clearly defined constructs and a more standardized approach.

Introduction

Social Support – Concepts and definitions

Social support has been shown to be an important factor in recovery from health conditions and to be associated with health outcomes in a number of different conditions [e.g. 1]. Social support has been hypothesized both to have direct links to health outcome (e.g. practical help given to administer medication, support given around appraisal of diagnosis) and indirect links to health outcome. Cohen and Wills [2] proposed the stress-buffer hypothesis to explain the mechanism for indirect links. This theory postulates that social support can have an effect on health, both during a highly stressful time, and in times of low stress, through the knowledge and associated reassurance that social support is available if required.

Social support is not a unitary concept. For example, there needs to be a distinction made between the amount of social contacts someone has (their *social network*) and the *perceived* amount of social support and satisfaction a person has with their available social support. Social networks are usually measured quantitatively, and take into account how many social contacts a person has and how dense the network is (i.e. how many people within the network are linked to each other). In addition, a distinction can be made between the formal networks of support provided by professionals or organizations, and informal support networks consisting of personal relationships. Perceived social support is more subjective and is usually measured with a self-report questionnaire or observation.

A commonly reported definition of perceived social support was developed by Cobb [3, p. 7]: "information leading the subject to believe that he or she is loved, esteemed and belongs to a network of mutual obligation"

Social support may be categorised into different types: emotional support, informational support, tangible/instrumental support and appraisal support [4]. Emotional support consists of positive affect such as empathy, trust and love. Informational support is providing information or guidance that helps the receiver to respond as required to a stressor or situation. Tangible or instrumental support is the practical help provided by the supporter, such as assisting with money or helping with a practical task. Appraisal support is providing constructive feedback to the receiver which helps them to achieve their goal. It may be hypothesised that each of these different types of support is involved in distinct ways in health outcomes and recovery from a traumatic health event.

Different perspectives on social support raise issues for consideration in clinical practice and research. Cohen et al [5] present an overview of three theoretical approaches to the study of social support: the stress and coping perspective, the social constructionist perspective and the relationship perspective.

As previously mentioned, the stress and coping perspective postulates that social support acts as a buffer to reduce the effect of stressful life events on a person's health. From this perspective, the type of support may need to correspond to what the person needs in order to cope with the stressor and be from an acceptable source, for example where a stressor has mainly emotional consequences but no financial impact,

an empathic response from a friend would be more helpful in mediating stress than receiving money from an organisation.

The social constructionist perspective suggests that a person's perception of social support is based on experience, meaning that there may be no clear consensus across individuals or groups as to what constitutes supportive behaviors [5, p. 36]. A person's perception of social support is linked to the perception of self, and shaped by the way that others view them and their experience of the social world. Therefore, a person already holds pre-existing beliefs about social support and may interpret others' actions as more or less supportive in order to make them fit with these beliefs. Cohen et al [5] discuss the literature exploring the mechanism by which a high level of perceived social support is related to good self-esteem, which in turn leads to positive health outcomes.

The third perspective discussed by Cohen et al [5] is the relationship perspective, where support is viewed as part of relationship processes. This approach hypothesizes that it is beliefs about the quality of relationships which are measured rather than beliefs about social support, or the actual help provided during or after a stressor. Cohen et al hypothesise that measures of social support cannot be discriminated from closely associated concepts such as low conflict, companionship, intimacy and social skills [5, p. 42] and that effects of social support could be accounted for by relationship processes. They propose that definitions of these concepts overlap with definitions of social support on factors such as positive and negative ties between people; personality trait characteristics (e.g. extraversion and agreeableness) and attachment styles.

The concept of social support can, therefore, be viewed from many perspectives. It is difficult to distinguish the impact of 'social support' on coping as a concept without considering the person's social context, relationship processes and personality factors. DeLongis and Holtzman [6] used a daily process approach (observing naturally occurring stressful events) to monitor stress, coping and social support, and found that contextual and personality factors were involved in the interplay between stress and coping. Personality factors such as level of Neuroticism (as defined by the Five-Factor model of personality [7]), seems to have an impact on a person's ability to elicit social support, to engage in support and to choose effective coping strategies [6].

Social support and recovery from TBI

TBI has physical, social, emotional and cognitive consequences [8], Personality changes are common, and social adjustment may still be taking place many years after the head injury [9].

The importance of social support is highlighted in the NICE guidance on early management of head injury [10]. In the early stages of recovery, particularly if confusion is present, the guidance states that the presence of close family and friends can be very helpful. It suggests that family members could be part of the recovery process by assisting with simple care tasks and that they should be encouraged to talk and have physical contact with the patient. However, it is also acknowledged that the hospital environment can be distressing for family members and the guidance encourages the provision of information about the consequences of brain injury and the linking of families with voluntary agencies for support, particularly where

statutory services are lacking. The emphasis on the involvement of family and carers in the long-term management of the consequences of their head injury continues in the NSF for long-term neurological conditions [11], with Quality Requirements focussing on supporting patients and their families effectively.

In her classic paper on the experience of living with someone with Acquired Brain Injury, Lezak wrote about the "characterologically altered" person and the challenges faced by family in adjusting to the altered patterns of family interactions. [12] It is recognised that brain injury places a significant burden on family and friends and has been associated with depression and anxiety in those close to the individual [13]. Behavioural disturbance following brain injury is particularly problematic as it is associated with higher levels of stress, depression and increased distress in families [13].

Due to the difficulties experienced by those close to the person with brain injury, the provision of social support may be difficult, and it is important to understand the outcomes associated with social support in order to consider the full picture as to why caregivers should be supported to provide support after TBI.

Aims of the Current Study

The current review aimed to explore previous research findings on the role of social support after brain injury. Specifically, the aims were to: 1) systematically search for literature on social support after brain injury; 2) provide an overview of the existing literature; 3) identify areas for further research.

Method

Search Criteria

A systematic literature search was conducted to identify published papers by using two electronic databases: PsycINFO and MEDLINE.

The search terms included were combinations of the following:

1. (HEAD INJURY), (BRAIN INJURY), (TRAUMATIC BRAIN INJURY), (TBI), (CLOSED HEAD INJURY) or (CHI)

∓AND∅

2. (SOCIAL), (SOCIAL SUPPORT) or (INTERPERSONAL SUPPORT).

Manual searches were also conducted of articles included in the review to identify any further papers.

Inclusion Criteria

The following criteria were used to determine suitability of papers for inclusion in the review:

- Articles published in peer-reviewed journals until June 2009. No start date for publications was chosen, although it was anticipated that studies would only be identified from the late 1980s onwards, as the emphasis on the role of social support in health conditions increased.
- Studies where participants have a diagnosis of moderate to severe traumatic brain injury, as defined by Glasgow Coma Scale score.
- Studies with adult participants, as the type and function of social networks and perceived support is likely to be very different between adults and children.
- Studies including perceived social support or social network as an independent or dependent variable.

Exclusion Criteria

- Any study only including participants with mild traumatic brain injury or post-concussional syndrome (studies with mixed severities of brain injuries were included).
- Studies only examining caregivers' social network or perceived social support.
- Studies published in a language other than English.
- Studies which did not contain exploration of perceived social support or social network either as a dependent or independent variable.

Study Quality Assessment

The included studies were rated on the quality of the methodology and reporting, based on the published report. A quality checklist was constructed to appraise studies

systematically. Due to the cross-sectional design of the studies, no published checklist was found that could be usefully applied without adaptation, as all that were found were designed for intervention studies (e.g. [14]). The checklist was based on the Foukes and Foulton [15] guidelines for appraising published research, and adapted to match the type of article. This is included in Appendix 4.

Studies were rated between 0 and 2 for each aspect of the study and report, from the abstract to the conclusion. There was also the option to rate as 'not applicable'. A percentage score was then calculated.

Data Extraction

A data extraction form was specifically designed to structure the extraction of relevant information from the studies. This was completed for each of the studies included in the review. For an example of this, see Appendix 4.

Data Synthesis

The data was not subjected to quantitative analysis due to the heterogeneity of studies regarding research aims and measures used. A qualitative approach was utilised to systematically evaluate the findings of the studies included in the review.

Results

The searches resulted in 2570 overall hits (including duplicates). After screening the titles of these and removing duplicates, 70 abstracts were obtained and examined. Where it was not possible to determine suitability of the study from the abstract, the full article was examined. 58 articles met one or more of the exclusion criteria and were not included in the study. 12 studies met all of the inclusion criteria and were included in the review. See Figure 1 for the literature search process.

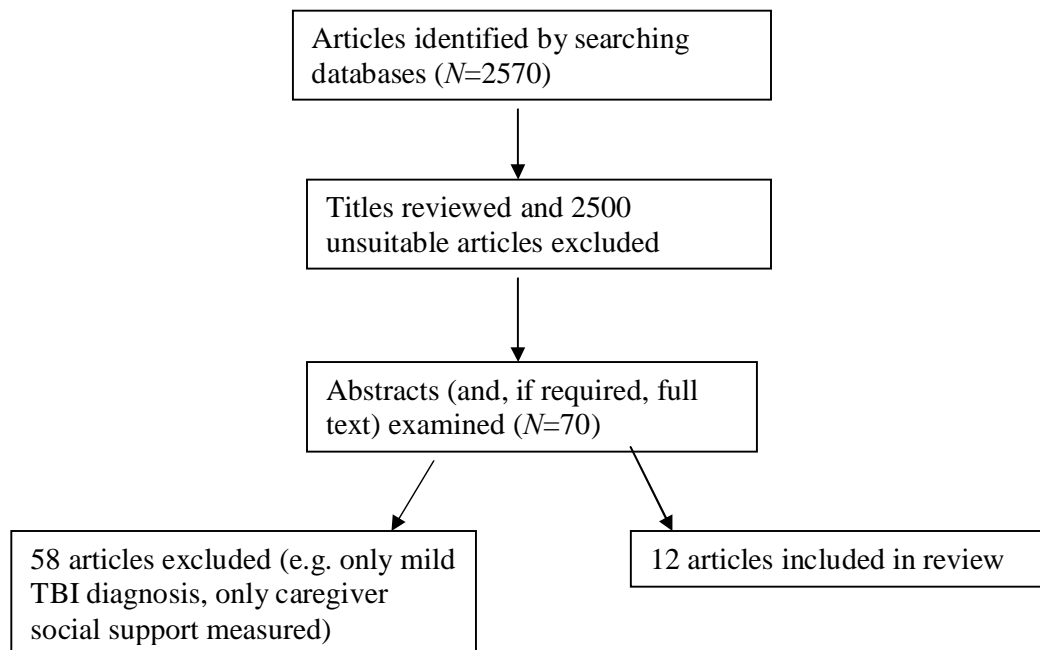


Figure 1. Flowchart of literature search process.

12 studies were identified for inclusion in the review, published between 1989 and 2008. Table 1 outlines the details of each study along with the main findings related to social support.

Table 1. *Characteristics of reviewed studies.*

Study	Design	Quality Rating	Participants	Social Support measure used	Other variables explored	Main Findings
Holosko & Huege (1989) [16]	Cross-sectional	83%	20 TBI, mild-severe.	5 questions devised from Davidson et al (1981) [17]	Life Satisfaction, Self-esteem, Level of disability, Life adjustment, social & leisure activities	SS positively correlated with self-esteem, life satisfaction, severity of disability. Negative correlation between SS and age.
Kaplan (1990) [18]	Cross-sectional	72%	36 ÷severeø TBI, 10-30 months since TBI	SSQ	Emotional distress, Vocational outcome	Negative correlation between SS satisfaction and emotional distress. Positive correlation between SS Satisfaction and vocational outcome.
Leach et al (1994) [19]	Cross-sectional	83%	39 TBI (5 ÷mildø 6 ÷moderateø 28 ÷severeø). 2.75-24 years since TBI.	SSQ-short form	Depression, family coping	SS not correlated with/ predictive of Depression.
Finset et al (1995) [20]	Cross-sectional	72%	77 consecutive admissions to rehabilitation. TBI less than 9 months prior.	Social Network Index (constructed by authors)	Functional status, subjective symptoms	Participants had reduced social networks. Depression negatively correlated with size of network. Ability to show initiative correlated with size of network.

Zencius & Wesolowski (1999) [21]	Cross-sectional; comparison with non-matched controls	67%	70 residents of rehabilitation facilities. Included stroke and tumour diagnoses along with TBI. 20 non-injured controls.	Social Network Inventory	None	TBI persons had smaller social networks than controls.
Bechtold & Chwaliz (2000) [22]	Cross-sectional	50%	27 moderate-severe TBI in post-acute rehab.	Not specified	Depression (NB. measure not specified), time since injury.	Negative correlation between SS and time since injury. SS not significant predictor for depression.
Douglas & Spellacy (2000) [23]	Cross-sectional	83%	35 TBI. >3.5 years post-injury	Instrumental-Expressive Social Support Scale	Depression, Level of disability	Social support was significant predictor of depression.
Pelletier & Alfano (2000) [24]	Cross-sectional	67%	13 pairs of TBI patients and family member. Consecutive admissions to rehab centre.	Not specified (construct: perceived SS \emptyset)	Depression, perceived stress, family coping, family stress (NB. measures not specified)	Negative correlation between perceived SS and depression.

Farmer et al (2003) [25]	Cross-sectional	89%	56 TBI that required medical attention >6 months post-injury.	Social Support Scale (adapted from Family Support Scale)	Author constructed Hesitation scale to explore beliefs about seeking SS, Quality of Life.	Positive correlation between beliefs on Hesitation scale and SS. Positive correlation between SS and QoL, but SS not significant predictor for QoL.
Tomberg et al (2005) [26]	Cross-sectional, comparison with age/education/gender matched controls.	90%	85 TBI (25% severe, 75% moderate). 9 months-3 yr post TBI. 68 controls.	Estonian Brief SSQ.	Health Related QoL, Coping, Life orientation (optimism).	HRQoL positively correlated with SS Satisfaction.
Tomberg et al (2007) [27]	Longitudinal: follow up to 2005 study.	83%	31 TBI. 5.7 years after Time 1 (above).	As above	As above	HRQoL still positively correlated with SS satisfaction. Overall decrease in SS Satisfaction since Time 1.
Izaute et al (2008) [28]	Cross-sectional	83%	46 TBI (58.7% severe, 21.74% moderate, 13.04% mild).	SSQ-6	Locus of Control, High vs. Low rehab needs.	Compared with published norms, High rehab group had greater SS satisfaction. Low rehab group did not significantly differ from norms.

Designs of studies

9 out of the 12 studies used solely a cross-sectional design [16, 18, 19, 20, 22, 23, 24, 25, 28]. 2 studies used a cross-sectional design but also included comparisons with healthy controls [21, 26]. One study was a longitudinal follow up 5.7 years after a previous cross-sectional study (also included in the review) [27].

Types of participants

Sample size ranged from 13 [24] to 85 [26]. All studies mainly focused on TBI patients (as this was an inclusion criteria). However, the severity of TBI included in the studies was varied. 5 out of the 12 studies did not adequately report the severity of brain injuries [20, 21, 23, 24, 25] 3 studies included participants with mild, moderate or severe TBI [16, 19, 28]. 3 studies included participants with moderate-severe TBI [22, 26, 28]. One study only included solely participants with severe TBI [18].

Time since injury was not reported in 5 out of the 12 studies [16, 21, 22, 24, 28]. For the studies which did report, time since injury ranged from less than 9 months since TBI [20] to 24 years post-TBI [19].

For the healthy controls, one comparison group was non-matched to the sample [21] and one comparison group was matched on age, gender and educational level [28]

Overview of Empirical Findings

As previously outlined, a distinction should be made between social networks and perceived social support. Therefore, the findings pertaining to social networks will first be presented, followed by the findings for perceived social support.

Social Networks

Measures used

2 out of the 12 studies examined social networks [20, 21]. Finset et al [20] constructed a 3 item Social Network Index to explore the amount and nature of interaction with and support from family, neighbours and other friends. Zencius & Wesolowski [21] used the Social Network Inventory [29] which asks the patient to list the people they know and then state whether they are alive, over 18, live within 50 miles and have been in verbal contact during the past three months. If the listed person meets all four criteria, then they are considered to be part of the person's network and can be counted as such.

Findings of studies

Finset et al [20] found that the social networks of participants had significantly decreased in size from prior to brain injury and that most patients had greater interactions and support from family as opposed to friends. Zencius and Wesolowski [21] compared social networks of people after TBI to those of healthy non-matched controls and found that patients with TBI have smaller networks with a different composition, including family and staff members rather than friends and colleagues.

Correlates with Social Network size

Finset et al [20] found a negative correlation between size of network and level of depression ($r=-0.38$, $p<.01$, $N=77$). A positive relationship was also found between size of network and ability to show social initiation, where greater ability to initiate was associated with a larger network ($r=0.42$, $p<.01$, $N=77$). Furthermore, vocational status was not found to be correlated with social network size (no r value reported).

Perceived Social Support

Measures used

The remaining 10 studies assessed perceived social support. The social support measure used was not specified in 2 studies [22, 24]. Five studies [22, 24, 18, 19, 26, 27] used a form of the Social Support Questionnaire [30] which asks patients to identify people who provide social support and then rate their satisfaction with the support. Douglas and Spellacy [23] used the Instrumental-Expressive Social Support Scale [31] which asks patients to rate themselves on items relating to excess responsibilities and demands, lack of money and lack of involvement and also includes a calculation of strong-tie involvement which is a perception of adequacy of support. Finally, two studies constructed their own scales by adapting previous measures [16, 25]

Correlates with Social Support and Variables predicted by Social Support

The findings have been divided into a number of different types of associated variable: Demographic variables, TBI-related variables, Psychological Distress, Quality of Life and Life Satisfaction, Functional Outcome and Cognitive Beliefs. The findings pertaining to each of these factors will be presented in turn.

- *Demographic factors*

Age was found to be negatively correlated with perceived social support by Holosko and Huege [16] (no r value reported).

- *TBI-related factors*

Time since injury was found to be negatively correlated with social support by Bechtold and Chwaliz [22] ($r=-0.34$, $p<.05$, $N=27$) Severity of TBI was found to be positively correlated with social support by Holosko and Huege [16] ($r= 0.43$, $p<.05$, $N=20$).

- *Psychological distress factors*

A negative correlation was found between social support and depression by Pelletier and Alfano [24] (no r value reported) and Bechtold and Chwaliz [22] ($r=-0.35$, $p<.05$, $N=20$). In Kaplan's study [18] a negative relationship was identified between social support and emotional distress, which Kaplan describes as an anxiety dimension (no r value reported, but $p<.01$). However, Leach et al [19] did not find a significant correlational relationship between depression and social support ($r=-0.15$, $p>.05$, $N=29$).

Social support was not found to be a predictor for depression either by Leach et al [19] or Bechtold and Chwaliz [22].

- *Quality of Life and Life Satisfaction*

Tomberg et al [26, 27] found positive correlational relationships between social support satisfaction and the majority of the Health-Related Quality of Life domains.

This relationship remained constant over time (In 2005, r value range=-0.35-0.46, $p<.05$, $N=85$; In 2007, $r=-0.46$, $p<.05$, $N=31$). A positive relationship was also found between social support and Quality of Life by Farmer et al [25] ($r=0.28$, $p<.05$, $N=56$), although regression analysis then found that social support was not a predictor for Quality of Life in this study.

Holosko and Huege [16] explored the relationship between social support and life satisfaction and found that they were positively correlated ($r=0.45$, $p<.05$, $N=20$).

- *Functional Outcome*

Social support satisfaction was found to be positively correlated with vocational outcome by Kaplan [18] ($\chi^2(1, N=36)=6.44$, $p<.05$).

- *Cognitive Beliefs*

Farmer et al [25] found a negative correlation between scores on their hesitation scale and social support ($r=0.34$, $p=.01$, $N=56$). This scale was designed by the authors to investigate a person's beliefs about seeking support (their hesitations). The results indicated a relationship between negative beliefs about support seeking, and lower perceived social support. However, this finding needs to be interpreted with caution as the scale is not standardized.

Discussion

The study aimed to 1) systematically search for literature on social support after brain injury; 2) provide an overview of the existing literature, including methodological

details and quality assessment; 3) identify areas for further research and discuss the clinical implications of the findings.

Social Support after TBI

The review found that twelve studies have explored the role of social support, but the results were varied. It is also difficult to draw conclusions because of the limited number of studies exploring each outcome and the occasionally poor methodological quality and/or reporting of studies.

It may be the case that there appears to be differences in the level of support provided by supporters (i.e. people who provide social support) dependent on their perception of the severity of the TBI. [16, 22, 27]. The provision and reception of support is an interactive process, between two or more people, influenced by characteristics of the stressor and of the people involved. Interestingly, one study found that the younger the age of the person with TBI, the higher the level of perceived social support [16]. This was particularly true for provision of support by family members. Two studies also found a relationship between time since injury and perceived social support [22, 27]. This raises the question of whether this reflects the actual provision of social support (possibly due to difficulties experienced by the caregiver in providing sustained support over long periods of time [e.g. 12, 13] or changes in the individual's perception of the social support provided by others.

Four studies explored the relationship between social support and psychological distress. However, there are differences both in the measurement instruments used, and in the types of distress explored, which make the interpretation of results and forming

conclusions difficult. In terms of quantity of social support, Finset et al [20] found that the size of the social network was negatively associated with depression. There was mixed evidence for the association between perceived social support and psychological distress, which was explored by four studies. There is a lack of information in two studies about the measurement instruments used [22, 24]. The remaining two studies both use the Social Support Questionnaire [30] (one uses the short form) but the distress variables measured are different. Kaplan [18] explores the effect of social support on a multi-dimensional assessment of emotional distress, which is reported as anxiety and Leach et al [19] explore the effect of social support on depression. Further research is required to explore the role of social support in Psychological distress, including better designed studies of the relationship with anxiety and depression, as well as expanding the definition of psychological distress to incorporate recovery after trauma.

Positive relationships were found between perceived social support and Quality of Life/ Life Satisfaction [16, 25, 26, 27]. However, social support was not found to be a significant predictor of Quality of Life [25].

Limitations

The factors limiting the current review may be considered in two categories: the limitations of individual studies that were included in the review, and the limitations of the review itself. These two categories will be explored separately.

Limitations of Included Studies

The methodological quality assessment of the 12 studies included in the review indicated a number of problems with the quality of the studies.

Two articles did not outline the measures used to assess perceived social support or other factors, [22, 24] therefore the quality and suitability of the measures cannot be determined, and interpretation is limited. In addition the studies cannot be replicated. Future reporting of studies into social support after TBI needs to ensure that measures are clearly described and referenced.

Full details were not always provided regarding participant demographics and injury details. In particular, reporting of severity of TBI, and time since injury, was not consistent across studies. It is important that these details are reported, due to the effect of time on recovery after TBI and the differences between recovery processes and outcomes in mild, moderate and severe TBI. This is not only important for clinicians to apply the research findings in practice, but also to allow for comparisons to be made across studies.

The lack of clear definition of theoretical constructs and underlying theoretical orientations was judged to be a weakness for a number of the included studies. Within the articles in this review, different theoretical constructs were examined, as two of the studies utilised social network size as an indication of support networks [20, 21], whereas others were concerned with perceived availability of social support and satisfaction with that support. Of the 12 papers included in the review, only three included a discussion of theoretical definitions of social support [18, 23, 26].

Limitations of the Review

A limitation of the review is the small number of studies included, and the even smaller numbers exploring individual variables associated with TBI. For some correlates, only one study explored that particular factor, so the results must be interpreted with caution. It was surprising that only 12 studies were identified exploring social support after TBI. Given that there were no time limits placed on the search, and that the first identified paper was published in 1989, and the most recent was published in 2008, there seem to have been surprisingly few investigations into the role of a factor which is often quoted as highly important in recovery after brain injury [e.g. 10]

However, it should be noted that given the poor psychosocial outcomes that are often reported after TBI [e.g. 8], additional studies may have included variables which could possibly be conceptualised as social support at times, but are not reported as such (e.g. social integration), and thus were not included in this review. This may be considered a limitation of the review, as search terms may not have sufficiently included these broader concepts. This was a difficult balance to strike, due to the broad and varied theoretical conceptualisations used to define social support.

The review focused on associations with social support only for outcomes relating to the individual with the TBI, rather than considering the literature on outcomes for other family members, the family system, marital relationships etc. This review aimed to explore the role of social support from one perspective and to highlight any evidence on which types of social support might be helpful to the individual with TBI,

but the limitation of this is that it is clearly an overly simplistic approach if attempting to consider how to best support individuals after TBI, and the available literature on family and caregiver outcomes would need to be evaluated.

The assessment of methodological quality in the review was subjective and only one researcher carried out the quality assessment. An improvement on the methodology of the current review would have been for multiple raters to complete the checklist, and degree of inter-rater agreement determined.

Areas for Future Research

On the surface, the concept of social support has face validity and may seem easy to define when used as a qualitative descriptor (e.g. in clinical practice). However, existing definitions of social support generally acknowledge it as being multi-dimensional in nature, including emotional support, tangible support, informational support and appraisal support. [4] Therefore, researchers need to be clear about which aspects of support they wish to evaluate, so that valid conclusions can be drawn from the findings of studies. A problem with this is the lack of valid and reliable measurement instruments to quantitatively assess individual aspects of social support, and the lack of research into which aspects of support is assessed by different existing measures. This is an issue both for established measures of social support, and for researchers wishing to design their own questionnaires, or adapt existing ones, as was the case in two studies in this review [16, 25]. This is an area for future research to explore, both in the general assessment of social support, and specifically in the assessment of people with TBI.

As previously mentioned, the role of social support in psychological distress is an important area for further study. The findings of this review highlight inconsistencies in the literature for determining the relationship between social support and psychological distress factors such as depression and anxiety. Furthermore, no studies were found which explore the role of social support in PTSD after TBI. For many years, it was considered that patients who had experienced TBI would not experience post-traumatic stress symptoms, due to patients' amnesia for the event, and the serious impairments that result (e.g. lack of awareness of difficulties). However, research has now shown that this is not always the case, and post-traumatic stress can result following brain injury [32]. It therefore seems pertinent to also consider post-traumatic growth in this population. Ehlers & Clark's cognitive model of PTSD [33] suggests that adjustment after a traumatic event relies upon two processes: cognitive appraisal of the event and its sequelae and autobiographical memory processing. Social support may be considered a mediating variable after a traumatic event in helping the person reappraise their lives, and facilitating memory processing.

Conclusions

This review provides an overview of the empirical literature base on social support after Traumatic Brain Injury. The literature has examined some factors associated with social support after TBI, and there are mixed findings. Interpretations made are tentative due to difficulties in cross-study comparisons. There are still a number of gaps in the literature, and issues with the measurement of social support, which future research needs to address.

References

1. Van Dam, H., van der Horst, F., Knoop, L., Ryckman, R., Crebolder, H, Bart, H. Social support in diabetes: a systematic review of controlled intervention studies. *Patient Education and Counseling* 2005; 59: 1-12.
2. Cohen, S., Wills, T. Stress, social support and the buffering hypothesis. *Psychological Bulletin* 1985; 98: 310-357.
3. Cobb, S. Social support as a moderator of life stress. *Psychosomatic Medicine* 1976; 38: 300-314.
4. House, J . Work, stress and social support. 1976. Reading MA: Addison Wesley.
5. Lakey, B., Cohen, S. Social support theory and measurement. In: Cohen S., Underwood L., Gottlieb B, editors, *Social support measurement and intervention: a guide for health and social scientists* 2000; OUP, USA.
6. DeLongis, A., Holtzman, S. Coping in context: The role of stress, social support and personality in coping. *Journal of Personality* 2005; 73 (6): 1-24.
7. Costa, P., McCrae, R. *The NEO Personality Inventory Manual* 1985; Odessa FL: Psychological Assessment Resources.
8. Lezak, M., O'Brien, K. Longitudinal study of emotional, social and physical changes after traumatic brain injury. *Journal of Learning Disabilities*. 1988; 21: 456-463.
9. Oddy, M., Coughlan, T., Tyerman, A. Jenkins, D. Social adjustment after closed head injury: a further follow up seven years after injury. *Journal of Neurology, Neurosurgery and Psychiatry*, 1985; 48: 564-568.

10. NICE . Head injury: triage, assessment, investigation and early management of head injury in infants, children and adults. 2007. National Collaborating Centre for Acute Care.
11. Department of Health. National Service Framework for long-term conditions. London, UK.
12. Lezak, MD . Living with the characterologically altered brain injured patient. *The Journal of Clinical Psychiatry*. 1978; 39: 592-598.
13. Marsh, N., Kersel, D., Haril, J., Sleight, J. Caregiver burden at 6 months following severe traumatic brain injury. *Brain Injury* 1998; 12: 225-238.
14. Downs, S. Black, N. The feasibility of creating a checklist for the assessment of the methodological quality both of randomised and non-randomised studies of health care interventions. 1998; 52: 377-384.
15. Foukes, F. Foulton, P. Critical appraisal of published research: introductory guidelines. *British Medical Journal*. 1991; 302: 1136-40.
16. Holosko, M. Huege, S. Perceived social adjustment and social support among a sample of head injured adults. *Canadian Journal of Rehabilitation*. 1989; 2: 145-154.
17. Davidson, T.N., Bowden, L.M., Feller, I. Social support and post-burn adjustment. *Archives of Physical Medicine and Rehabilitation* 1981; 62: 274-278.
18. Kaplan, S. Social support, emotional distress and vocational outcomes among persons with brain injuries. *Rehabilitation Counseling Bulletin*. 1990; 34.
19. Leach, L. Frank, R. Bouman, D. Farmer, J. Family functioning, social support and depression after traumatic brain injury. *Brain Injury*. 1994; 8: 599-606.

20. Finset, A. Dyrnes, S. Krogstad, J. Berstad, J. Self-reported social networks and interpersonal support 2 years after severe traumatic brain injury. *Brain Injury*. 1995; 9:141-150.
21. Zencius, A. Wesolowski, M. Is the social network analysis necessary in the rehabilitation of individuals with head injury? *Brain Injury*. 1999; 9: 723-727.
22. Bechtold, K. Chwaliz, K. The relationship among level of depression, social support, and time since injury in individuals recovering from traumatic brain injury. *Archives of Clinical Neuropsychology*. 2000; 15: 810-811.
23. Douglas, J. Spellacy, F. Correlates of depression in adults with severe traumatic brain injury and their carers. *Brain Injury*. 2000; 14: 71-88.
24. Pelletier, P. Alfano, D. Depression, social support and family coping following traumatic brain injury. *Brain and Cognition*, 2000; 44: 45-49.
25. Farmer, J. Clark, M. Sherman, A. Rural vs. urban social support seeking as a moderating variable in traumatic brain injury outcome. *Journal of Head Trauma Rehabilitation*. 2003; 2: 116-127.
26. Tomberg, T. Toomela, A. Pulver, A. Tikk, A. Coping strategies, social support, life orientation and health related quality of life following traumatic brain injury. *Brain Injury*. 2005; 19: 1181-1190.
27. Tomberg, T. Toomela, A. Ennok, M. Tikk, A. Changes in coping strategies, social support, life orientation and health related quality of life following traumatic brain injury: a longitudinal study. *Brain Injury*. 2007; 21: 479-488.
28. Izaute, M. Durozard, C. Aldigier, E. Teissedre, F. Perreve, A., Gerbaud, L. Perceived social support and locus of control after a traumatic brain injury. *Brain Injury*; 2008; 22: 758-764.
29. Wesolowski, M. *Social Network Inventory 1983*; Morgantown, WV: West Virginia University.

30. Sarason, IG., Sarason, BR., Shearin, EN., Pierce, GR. A brief measure of social support: Practical and theoretical implications. *Journal of Social and Personal Relationships* 1987; 4: 497-510.
31. Ensel, W., Woelfel, M. Measuring the instrumental and expressive functions of social support. In: Lin N, Dean A, Ensel W, editors, *Social Support, Life Events, and Depression* 1986; Orlando: Academic Press: p. 129-152.
32. Turnbull, S., Campbell, E., Swann, I. Post-traumatic stress disorder symptoms following a head injury: does amnesia for the event influence the development of symptoms? *Brain Injury* 2001; 15 (9): 775-785.
33. Ehlers, A., Clark, D.M. A cognitive model of post-traumatic stress disorder. *Behaviour Research and Therapy* 2000; 38: 319-345.

Part 2: Empirical Paper

Post-traumatic growth, illness perceptions, perceived social support and social functioning following moderate to severe Acquired Brain Injury

This paper is written in the format ready for submission to *Brain Injury*. Please see Appendix 2 for the Guidelines for Authors.

Post-traumatic growth, illness perceptions, perceived social support and social functioning following moderate to severe Acquired Brain Injury

Abstract

Primary Objective: To determine factors associated with positive psychological change in people with moderate to Acquired Brain Injury (ABI), including illness perceptions and perceived social support.

Design: The study employed a cross-sectional design, with a sample of 40 people with ABI at least 3 years post-injury.

Methods and Procedures: The Posttraumatic Growth Inventory (PTGI), Brief Illness Perception Questionnaire, Perceived Social Support from Family and Friends Scale, Abilities and Participation sections from the Mayo-Portland Adaptability Inventory-4 (MPAI-4), Hospital Anxiety and Depression Scale (HADS), Impact of Event Scale-Revised (IES-R), Section F25 of the Structured Clinical Interview for DSM-IV (SCID) and DEX questionnaire were administered.

Main Outcomes and Results: No factors were found to be significantly correlated with overall post-traumatic growth, and no predictors for positive change were identified. Post-traumatic growth did not predict level of social functioning.

Conclusions: The study found no evidence for psychological or social factors that predict positive change after ABI. Future research is required to explore psychosocial aspects of post-traumatic growth.

Introduction

The consequences of brain injury can be severe and bring about major change to a person's life, which require a significant amount of physical and psychological adjustment. Furthermore, brain injury is usually unexpected and has the potential to cause death or serious disability. An Acquired Brain Injury can be caused by an external event, such as an assault or a road traffic accident, or can be due to an internal health event, such as a stroke or heart attack. The suddenness, and often the circumstances under which the injury occurs can be traumatic in itself; according to DSM-IV criteria, a traumatic event involves actual or threatened death or serious injury. Therefore, the experience of moderate or severe brain injury can be regarded as a traumatic experience, both in terms of the event itself and the physical and cognitive sequelae. However, there is growing evidence that positive, as well as negative, psychological consequences may result from traumatic experiences.

Post-traumatic Growth

In literature, religion and philosophy there has long been the idea that the experience of a traumatic event can lead to positive change for an individual. Psychological theorists have recently begun to conceptualise this as 'post-traumatic growth' (PTG), which may be defined as 'the experience of positive change that occurs as a result of the struggle with highly challenging life events'[1]

Post-traumatic growth is not the same as physical recovery after a trauma, nor is it equivalent to psychological adjustment. The individual who experiences PTG has not simply returned psychologically to where they were prior to the event, but has moved on a step or two from that and perceives themselves as better off in some way. It has been proposed that PTG occurs in five domains [2]: ‘Appreciation for Life’, ‘Personal Strength’, ‘Spiritual Change’, ‘New Possibilities’ and ‘Relating to Others’. A person who has experienced growth in the domain of ‘Appreciation for Life’ will have a greater appreciation for the value of their life and will have changed or strengthened their sense of what is important. Growth in the domain of ‘Personal Strength’ is a perceived increase in ability to handle difficulties, but also being able to accept that one is sometimes vulnerable and needs others. ‘Spiritual Change’ is strengthened or changed spiritual beliefs. Growth in the domain of ‘New Possibilities’ means that the person changes the path of their life, feels they can achieve better things and experience new opportunities which would not otherwise have been available. ‘Relating to Others’ is characterised by an increased sense of closeness and compassion for other people.

A model of post-traumatic growth has been proposed [1] which equates the trauma to a ‘seismic event’ that shakes the person’s world, leaving them with the challenge of managing their emotions, and coping with the ‘shake-up’ of their schema and life narrative. It is suggested that these challenges are addressed through a process of rumination, which is initially automatic and intrusive, but becomes more deliberate as the person disengages from previous goals and develops new schema that can assimilate the traumatic event. It is believed that this process is aided by ‘self-disclosure’ in the early stages (e.g. talking, praying or writing) and social support from

others. The model does not assume that individuals will be left with no negative consequences from the event, and suggests that the enduring distress also can contribute to PTG.

Empirical studies of PTG have included a wide range of traumatic events and PTG has been investigated following health events such as rheumatoid arthritis, HIV infection, cancer, bone marrow transplantation and heart attack. Currently, there is limited research into post-traumatic growth following brain injury.

The first empirical investigation of PTG after brain injury was a pilot study using 21 participants [3]. It was demonstrated that post-traumatic growth can occur after brain injury and a comparison of PTG based on time since injury suggested that it increases over time. Similarly, Powell, Ekin-Wood and Collin [4] conducted a study into post-traumatic growth after traumatic brain injury (TBI). The study found that post-traumatic growth occurred following traumatic brain injury and that participants in the late group (10-12 years previously) were found to have experienced more PTG than those in the early group (1-3yrs previously).

A longitudinal study (with data collected at 6 months and 10 years post-injury) aimed to explore predictors of PTG after head injury [5]. Injury variables (such as age at injury, severity of injury, abnormal CT scan) and scores on outcome measures at 6 months were not good predictors for positive changes in outlook at 10 years.

Therefore, further research is needed to explore whether other variables contribute to post-traumatic growth after brain injury.

McGrath [6] outlines the important benefits of positive rehabilitation practice for patients with brain injury. As previously discussed, there is evidence that growth can occur after head injury. The process of PTG requires the person to assimilate the traumatic event and to move on from it, looking toward the future. McGrath [6] likens this to effective rehabilitation, which is focused upon looking to the future and building on the person's strengths but also recognising the loss that the person has experienced. Therefore, the study of PTG has implications for rehabilitation practice after brain injury.

Illness Perceptions and PTG

The term 'illness perception' refers to the cognitive representations held by a patient about their illness or the health event which they have experienced. The self-regulatory model of illness representations [7] proposes that they are formed by a combination of internal and external factors (for example, the person's individual history of health events and their social environment). When a health threat is experienced, the illness representations affect the way in which the patient perceives the identified components of illness perceptions (namely identity, consequences, timeline, control/cure, emotional representation and cause). It is clinically important to consider a patient's illness perceptions after a health event and there is evidence for links between illness

representations and recovery from medical events [e.g. 8] whereby a person's ability to cope with illness is affected by the beliefs they hold about the illness and their potential for recovery.

There is a limited literature exploring illness perceptions after Acquired Brain Injury and the role they may play in recovery, and no studies have explored Traumatic Brain Injury or made comparisons between different types of brain injury. Sheldrick et al [9] used a longitudinal design to investigate illness perceptions and post-traumatic stress disorder (PTSD) symptoms after Myocardial Infarction and Subarachnoid Haemorrhage. The study found a correlation between PTSD and some illness perception factors (specifically those of identity, timeline, consequences and emotional representation) at three time points of 2 weeks, 6 weeks and 3 months after hospital admission.

There is evidence that an individual's perception of a health event can impact upon PTG. [10] suggested that cancer patients' subjective appraisals of threat were more important in PTG than objective measures of cancer severity. PTG is postulated to occur following a seismic event which shakes one person's world enough for them to re-evaluate their schema. There will however be differences between the ways in which individuals respond, and coping after different health events may be influenced by different illness perception factors. It therefore seems important to consider perceptions of brain injury and this study aims to explore the relationship between illness perceptions relating to brain injury and PTG.

Social Support and Acquired Brain Injury

The role of social support in post-traumatic growth is highlighted in the model by Tedeschi and Calhoun [1]. It is also an important factor in illness representations [7], as the model highlights that the person's social context is important, including the support that is given by others when a health threat is experienced.

Linley & Joseph [11] conducted a review of variables which are significantly associated with growth and found that social support in general tended not to be associated with growth, but social support satisfaction was positively associated. Therefore, it may be that the individual's perception of their social support (rather than size of social network) is an important variable to consider in post-traumatic growth.

There is evidence which explores the relationship between recovery after acquired brain injury and social support. Emotional support may be particularly important. Glass & Maddox [12] examined the impact of emotional, instrumental and informational support on recovery of functional capacity after Stroke, and found that the level of emotional support was a predictor of the shape (i.e. changes in functional status over time) and extent of recovery. A review to support this empirical study explored social support after Traumatic Brain Injury, and found that social support may correlate with and predict outcome after TBI. Given that the post-traumatic growth literature emphasises the importance of perceived social support, and that there is evidence for social support as a predictor of recovery from brain injury, the role of

social support in achieving post-traumatic growth after brain injury needs to be considered and therefore the relationship between perceived social support and PTG will be explored in the current study.

Social Functioning after Acquired Brain Injury

Morton and Wehrman [13] reviewed the literature on psychosocial functioning after Traumatic Brain Injury and concluded that individuals who experience TBI lack opportunities for building new social networks and get involved in fewer leisure activities that they did prior to their injury.

Teasdale and Engberg [14] followed up patients 5, 10 or 15 years after they had experienced a Stroke, and found that participants had psychosocial difficulties at all time points. The outcome measures explored a number of areas of psychosocial functioning, including employment, household family relations, other social relations and leisure activities.

The research therefore suggests that people with acquired brain injuries can experience difficulties in social functioning. It has also been found that social impairments can affect recovery following Stroke [15]. The contribution of post-traumatic growth to social functioning after acquired brain injury has not previously been explored and therefore the relationship between social functioning and PTG will be examined using a self-report measure of social behaviour.

Aims and Hypotheses

1. Aim: to examine factors correlating with PTG in a population with Acquired Brain Injury. Hypothesis: Illness perception factors and perceived social support would correlate with PTG and PTG components.
2. Aim: To determine predictors of PTG after brain injury. Hypothesis: perceived social support and the illness perceptions factors of personal control, consequences and understanding would predict the level of post-traumatic growth.
3. Aim: To explore the relationship between PTG and social functioning following brain injury. Hypothesis: that level of PTG would predict social functioning, when level of disability was controlled for.

Method

Participants

40 participants were recruited from a NHS Neuropsychology service. They had all experienced a type of moderate to severe acquired brain injury at least three years previously, as defined by a Glasgow coma scale of 12 or less at the time of injury and post-traumatic amnesia of greater than or equal to one hour. Participants had all undergone cognitive assessment while on the caseload of the service, although the majority had subsequently been discharged. All participants were over 18 and spoke English as a first language. People with severe cognitive impairment, meaning they

were unable to give informed consent, or who had language impairment meaning that they could not complete the questionnaires, were excluded, as were people who had received extensive therapy focussing on adjustment as this could impact upon a person's cognitive appraisal of the event and have affected PTG.

Sample size estimation was based on a 'rule of thumb' of 10 cases per independent variable for the regression analysis, therefore a total of 40 participants were needed for the study to achieve sufficient power, because it was planned to use the four following independent variables in the regression: 1) overall perceived social support, and the illness perception factors of 2) personal control, 3) concern and 4) understanding.

Between January and May 2009, 110 potential participants were identified from current and past Neuropsychology NHS records. Of these, 40 people consented to take part, 7 declined, 1 consented but did not complete the procedure and the remainder either did not have up to date contact details or could not be contacted within the timescale. The participant who was unable to complete the questionnaires became emotionally distressed during the procedure and the decision was made to discontinue.

Measures

The assessment instruments used in the study were selected on the basis of their relevance to the research questions, as well as suitability for completion by people with brain injuries by taking into account factors such as the length of the questionnaire and the complexity of questions. The measures used were as follows:

Post-traumatic growth. Post-traumatic growth was assessed using the Post-traumatic Growth Inventory (PTGI; [2]). This is a 21-item scale designed to measure positive outcomes for people who have experienced a traumatic event. Five factors are assessed by the scale: "New Possibilities", "Relating to Others", "Personal Strength", "Appreciation of Life" and "Spiritual Change". Participants are presented with a list of statements and asked to rate how applicable they are on a 6-point Likert scale, ranging from "I did not experience this change as a result of my crisis" (0) to "I experienced this change to a very great degree as a result of my crisis" (5). The scale has good internal consistency ($\alpha = .90$) and test-retest reliability of .71 (over a two month period). The scale is scored by summing responses on the scales, meaning the scale has a range of 0-105.

Illness Perceptions. These were assessed using the Brief Illness Perception Questionnaire (Brief IPQ; [16]). This is a quantitative measure of the components of illness representations (identity, consequences, timeline, personal control, treatment control, emotional response and understanding), based on Leventhal's model [7]. The questionnaire is a 9-item measure which requires participants to rate answers on a 10 point likert scale. The Brief-IPQ correlates with the full IPQ, and test-retest reliability was calculated for each illness perception and individual correlations were between .42 and .75 [16]. Sheldrick et al [9] used the full IPQ-Revised measure [17] with patients who had experienced a subarachnoid haemorrhage. A factor analysis was completed and found that the measure was appropriate and valid for use with an acute medical trauma population. However, participants commented that the wording of the questionnaire did not make it easy to complete, as they did not see their haemorrhage as an illness, but rather as a single event. Therefore, in line with recommendations made by Moss-Morris et al [17] and Broadbent et al [16], the questionnaire was

adapted for use with people who have acquired brain injury by referring to specific diagnoses rather than the general term 'illness'. A score is not generated for the scale as a whole, but rather the response on each illness perception factor. Thus, each factor has a range of 0-10.

Social Support. The Perceived Social Support from Family and Friends scale [18] was used to assess social support. This measure comprises of two 20-item questionnaires (investigating perceived family support and perceived support from friends) which require simple 'yes', 'no' and 'don't know' responses. The scale has been stated to have predictive and construct validity due to correlations with psychopathology and distress measures, with correlation co-efficients of 0.88 for family support and 0.90 for support from friends [18]. The scale is scored by summing the number of responses which indicate social support is present, and thus the scale range is 0-20 for the friends scale, 0-20 for the family scale, and 0-40 for the overall scale.

Social Functioning. The Participation Index from the Mayo-Portland Adaptability Inventory-4 [19] was used. The MPAI-4 aims to assess 'the range of physical, cognitive, emotional, behavioural, and social problems that people may encounter after ABI' [19]. The Participation Index explores societal participation, including initiation, social contact, leisure/recreational activities, self-care, residence, transportation, work and money management. This index has been shown to have good item reliability of 0.98 [19]. Participants' level of functioning is rated on a 4-point likert scale, depending on level of independence in completing each activity. After completion, two items are re-scored, meaning that the range for the Participation Index is 0-30. [20]

Emotional Distress. Mood was assessed using the Hospital Anxiety and Depression Scale [20]. This measure is included to gain a better understanding of sample characteristics, in terms of psychopathology. This is a 14-item scale, divided into two subscales: one for depression and one for anxiety. The internal consistencies of the two subscales (assessed by Cronbach's alpha) were 0.93 for anxiety, and 0.90 for depression [21]. Items are rated on a 4-point Likert scale ranging from no distress (0) to unbearable distress (3). Therefore, the scores range from 0-21 for depression and 0-21 for anxiety. These scores can be categorised into 'normal', 'mild', 'moderate' and 'severe', but a recent study found these not to be useful predictors for caseness of depression and anxiety after TBI [22], and therefore, these categories will not be used, but the scores reported instead.

Post-traumatic Stress. The Impact of Events Scale- Revised. [23] is a questionnaire which is used to determine the extent to which an event has had a negative impact upon a person. The participant will be asked to consider their brain injury as the 'event' when completing the measure. The scale generates scores in three domains: hyperarousal, intrusions and avoidance. Internal consistencies for the three subscales ranged from 0.79 to 0.92 [23].

Level of disability. The Abilities Index of the Mayo-Portland Adaptability Inventory-4 [19] was included as a measure of level of disability. This index explores mobility, use of hands, vision, audition, motor speech, communication, attention/concentration, short-term memory, fund of information, novel problem-solving, visuo-spatial abilities and dizziness. Item reliability for this index was found to be 0.99 [19]. After administration, one item is re-scored, meaning that the range is 0-47.

Previous experiences of trauma. Section F25 of the Structured Clinical Interview for DSM-IV (SCID; [24]) was included to explore participants' previous experiences of trauma.

Self-awareness. The DEX Questionnaire from the Behavioural Assessment of Dysexecutive Syndrome [25] was completed by participants who were able and willing to identify an independent rater. This measure was included as a control measure to assess the level of insight that participants have into their difficulties. It is a 20-item questionnaire with two versions: one for the brain injured individual, and one for their relative or carer. The scale asks for a rating on a 4-point likert scale to indicate how often each difficulty is experienced. A discrepancy score is obtained, ranging between -80 and 80.

Procedure

Ethical approval was obtained from the Local Research Ethics Committee. Consent was obtained and each participant was seen individually in a private room. The abilities and participation subscales of the Mayo-Portland inventory was completed with participants, along with the PTSD section F25 of the SCID. The questionnaires were administered with assistance as required (e.g. reading the items aloud, recording the responses).

Results

Descriptive Statistics

Mean time since brain injury was 9.75 years ($SD=5.10$). Types of brain injury included were Traumatic Brain Injury, Stroke, Subarachnoid Haemorrhage, Encephalitis and Hypoxic Brain Injury. Numbers of participants with each diagnosis are shown in Table 1.

Table 1.

Numbers of participants (and percentages) for types of brain injury in the sample (N=40).

Type of Brain Injury	Number of participants (percentage)
Traumatic Brain Injury (assault, fall, RTA, other)	26 (66.6)
Stroke	5 (12.8)
Subarachnoid Haemorrhage	5 (12.8)
Encephalitis	2 (5.1)
Hypoxic Brain Injury	1 (2.6)

Participants were asked about previous experiences of trauma, and 6 participants (15%; $N=40$) identified a traumatic event prior to the brain injury. Self-reported levels of anxiety and depression were calculated using the Hospital Anxiety and Depression Scale [20]. Self-reported post-traumatic stress symptoms relating to the brain injury (not to previous experiences of trauma) were recorded using the Impact of Event

Scale- Revised [23], and scores calculated on the three individual subscales (avoidance, intrusions, hyperarousal). Levels of distress (anxiety, depression, PTSD) and mean scores are shown in Table 2 below.

Table 2.

Mean scores (and standard deviations) on measures of distress (Anxiety, Depression, PTSD and PTSD subscales) (N=40).

Distress type	Mean score (Standard deviation)
Anxiety	7.13 (4.51)
Depression	4.58 (3.60)
Impact of Event	2.84 (2.50)
Avoidance	0.92 (0.93)
Intrusions	0.91 (0.76)
Hyperarousal	1.00 (1.09)

Note: Scale ranges are 0-21 for Anxiety, 0-21 for Depression, 0-4 for Impact of Event, Avoidance, Intrusions and Hyperarousal.

Level of disability was measured using the Abilities subscale from the Mayo-Portland Adaptability Inventory-4 (MPAI-4; [19]). Mean level of disability was 7.20 (SD=5.92). Social functioning was measured using the Participation subscale from the MPAI-4 [19]. The mean score for MPAI-4 participation was 8.15 (SD=8.39).

Post-traumatic Growth

The mean score for overall PTG and mean scores in the five PTG domains are shown in Table 3.

Table 3.

Mean scores (and standard deviations) for overall Post-traumatic Growth (PTG) and PTG domains (N=40).

PTG Domain	Mean score (Standard deviation)
Overall PTG	45.2 (25.6)
Relating to Others	17.4 (9.8)
New Possibilities	8.35 (6.2)
Personal Strength	7.95 (5.2)
Spiritual Change	2.47 (3.6)
Appreciation for Life	8.32 (5.08)

Note: Scale ranges are 0-105 for Overall PTG, 0-35 for Relating to Others, 0-25 for New Possibilities, 0-20 for Personal Strength, 0-10 for Spiritual Change and 0-15 for Appreciation for Life.

The mean level of overall PTG reported by participants in the current study was considered in relation to reported levels of PTG on the Post-traumatic Growth Inventory in the previous two studies including participants with Acquired Brain Injury [3, 4]. McGrath and Linley [3] reported a median score of 80 (range 22-101) in their late sample (mean time since injury: 9.83 years). The current study found a lower level of PTG (mean 45.2), for a sample with a similar mean time since injury (9.75 years). Powell et al [4] reported mean level of PTG as 36.5 for the early sample (1-3 years post-injury) and 68 for the late group (9-12 years post-injury). These levels of PTG seem comparable with the current findings, as participants were included in the current study 3-17 years post-injury.

No significant correlations were found between PTG and age or time since injury. Association between PTG and other factors was measured using bivariate correlations. The Pearson r values for the associations between PTG and variables of distress and disability are shown in Table 4.

Table 4.

Correlations between overall PTG or PTG components, level of disability and level of distress. (N=40).

	Post-traumatic Growth					
	Overall Growth	Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation for life
<u>MPAI</u>						
Abilities	.16	.26	.17	-.10	.21	.25
Participation	-.01	.12	.10	-.22	-.04	-.03
<u>HADS</u>						
Anxiety	.12	.01	.17	-.00	.02	.15
Depression	.22	.18	.20	.02	.16	.18
<u>Impact of Event</u>						
Overall	.12	.11	.20	-.02	.16	.09
Avoidance	.03	.06	.18	-.12	.00	.04
Intrusions	.12	.09	.20	.01	.23	.13
Hyperarousal	.16	.14	.18	.04	.20	.09

Correlations were also calculated for PTG and the variables of perceived social support and illness perceptions. These Pearson r values are shown in Table 5.

Table 5.

Correlations between overall PTG or PTG components, perceived social support and illness perceptions. (N=40).

	Overall Growth	Relating to Others	New Possibilities	Personal Strength	Spiritual Change	Appreciation for Life
<u>Social</u>						
<u>Support</u>						
Overall	.05	.26	.02	.00	.18	-.05
Friends	.11	.27	.04	.09	.20	.00
Family	-.03	.20	.00	-.09	.14	-.09
<u>Illness</u>						
<u>Perception</u>						
Consequences	.22	.20	.29	.09	.18	.32*
Timeline	-.18	-.17	-.03	-.10	.06	-.12
Personal Control	.13	.04	.12	.32*	.22	-.09
Treatment Control	.17	.17	.14	.14	.31	.11
Identity	.15	.09	.20	.04	.12	.23
Concern	.27	.32*	.16	.13	.27	.26
Understanding	.18	.06	.33*	.13	.02	.09
Emotional Response	.27	.21	.27	.10	.19	.29

*denotes statistical significance ($p < .05$)

No significant correlations were found between overall PTG and other factors. Four significant correlations were found between components of PTG and illness perception factors. Significant correlations were identified between the illness perception –consequencesø and the PTG component –appreciation for lifeø ($r=.32$, $N=40$, $p<.05$), the illness perception –personal controlø and the PTG component –personal strengthø ($r=.32$, $N=40$, $p<.05$), the illness perception –concernø and the PTG component

relating to others ($r=.33, N=40, p<.05$) and the illness perception understanding and PTG component new possibilities ($r=.33, N=40, p<.05$).

McGrath [6] suggests that patients who have problems with self-awareness may achieve high PTG scores. Level of self-awareness was measured for as many participants as possible, determined by how many participants were able and willing to identify someone else to rate their difficulties, and how many questionnaires were returned via the post if the independent rater was not able to be present ($N=22$). For this sub-sample, no significant correlation was found between level of insight and overall PTG ($r=.12, N=22, p>.05$).

Predictors of PTG

The dependent variables of overall social support, personal control, concern and understanding were used in a linear regression model to determine whether these are factors which predict overall PTG. None of the factors were significant predictors of PTG, so the hypothesis was not supported, as shown in Table 6.

Table 6.

Summary of Regression Analysis for Variables Predicting Overall PTG (N=40).

	B	SE B		P
Overall social support	0.36	0.46	.13	.43
Personal control	1.12	1.25	.14	.38
Concern	2.19	1.10	.32	.06
Understanding	1.32	1.17	.18	.27
Constant	12.76	17.43		

Note: $R^2=.14$

Secondly, the effect of PTG on participants' level of social functioning was also explored using a multiple regression model. No evidence was found to support the hypothesis as PTG did not predict social functioning when level of disability was controlled for. The possibility of Type II error needs to be considered when interpreting these findings. See Table 7.

Table 7.

Summary of Regression Analysis for PTG Predicting Social Functioning, Controlling for Level of Disability (N=40).

	B	SE B		P
<u>Step 1</u>				
Level of disability	0.94	0.17	.66	.00**
Constant	1.39	1.60		
<u>Step 2</u>				
Level of disability	0.97	0.18	.68	.00**
Overall PTG	-0.04	0.04	-.11	.37
Constant	2.87	2.28		

Note: $R^2=0.44$ for Step 1, $R^2=0.45$ for Step 2 ($p>.05$). ** $p<.001$.

Post Hoc Analyses

A multivariate Analysis of Variance using the dependent variables of overall PTG and PTG components was conducted to examine the effect of participants' prior experience of trauma on PTG. Using Pillai's Trace, there was not a significant effect of prior trauma on overall PTG or the dimensions of PTG, Pillai's Trace=0.05, $F(6, 33)=0.30$, $p>.05$.

A regression model was used to explore whether PTG could be predicted by the demographic and clinical variables of level of disability and level of distress. Neither level of disability or distress factors predicted PTG, as shown in Table 8.

Table 8.

Summary of Regression Analysis for Demographic and Clinical Variables (N=40).

	B	SE B		P
Level of disability	0.22	0.89	.05	.80
Anxiety	-0.54	1.52	-.09	.73
Depression	2.26	2.29	.32	.33
PTSD	-0.82	2.48	-.08	.74
Constant	39.40	8.44		

Note: $R^2=0.06$

Participants were categorised into 'external' cause of brain injury (i.e. TBI) and 'internal' cause (i.e. stroke, SAH, encephalitis, hypoxic). 27 participants were placed into the external cause group, and 13 were placed into the internal cause group. A multivariate Analysis of Variance was used to explore the effect of internal and external cause on PTG. Using Pillai's Trace, there was a significant effect of cause on PTG, where internal cause was associated with higher levels of PTG, $V=0.42$, $F(6, 33)=3.98$, $p<.01$. Separate between subjects T-tests were conducted to determine the effect of cause on overall growth and on the individual components of PTG. There was a significant effect of cause on overall growth, where participants with internal cause of injury experienced greater levels of growth, $t(38)=-2.59$, $p<.05$. There was also a significant effect of cause on the component of relating to others, $t(38)=-3.41$, $p<.05$. A significant effect of cause was also found on the component of appreciation of life,

although the assumption of equal variance was not met so reported p-values are for equal variances not assumed, $t(38)=-3.54$, $p<.001$. This result needs to be interpreted with caution as it is a post hoc analysis. For the remaining PTG components (personal strength, new possibilities, spiritual change), no significant effect of cause was found ($p>.05$).

Discussion

The study's aims were firstly to explore whether social support and illness perception factors were correlated with PTG. Secondly whether these factors were statistical predictors for PTG, and finally, whether level of PTG statistically predicts social functioning. There were no correlates or predictors found for overall PTG. However, the correlational analysis revealed significant relationships between some illness perception factors and PTG components. Social support did not predict or correlate with overall PTG or PTG components, and this remained the case for family support, support from friends and overall support.

The results raise the question of whether there are consistent predictors of overall PTG after Acquired Brain Injury, as none were found. It is possible that the varied nature of brain injury may mean that predictors of growth are unique to the person and it is not possible to identify predictors of growth that can be generalised to a population of people with brain injuries (especially when including varied types of brain injury: stroke, SAH, other medical conditions, and TBI for example). PTG requires schema change [1] and therefore there will be differences based on the person's life experiences and how the experience of brain injury fits with their schema. It may also be that predictors cannot be determined for overall growth, but that there are factors

which help facilitate the components of growth. Some relationships were found between factors in the current study, and these will now be discussed.

There was a positive moderate correlation between the perception of consequences (i.e. how much the person's brain injury affects their life) and the person's appreciation of life, suggesting that the greater the perceived consequences of brain injury on one's life, the more one appreciates life as a result. This is consistent with Linley & Joseph [26], who report that the greater the perceived threat of an event, the greater the level of PTG.

A positive moderate relationship was also found between the perception of personal control over the brain injury or its effects, and perceived personal strength. This relationship cannot be assumed to be causal but is important, as the nature of brain injury means that patients often experience changes in physical and cognitive abilities which could be perceived as loss of control. Prior research has also found that locus of control after brain injury is associated with functional outcomes, such as returning to employment (e.g. [27]). The challenge and implications for rehabilitation are upon helping patients to develop and maintain personal control as much as possible. Further investigation is needed to determine whether it is the retention of control over the brain injury which fosters growth, or whether growth occurs naturally in the patients whose brain injuries do not lead to loss of control.

Level of concern about the brain injury was moderately associated with growth on the Relating to Others subscale of PTG. Again, the nature of this relationship cannot be determined due to the correlational design. It is hypothesised that participants who were more concerned about their brain injury either had a more severe brain injury,

and therefore required greater levels of support from family and friends, or shared concerns with family and friends and therefore became closer to other people in the process. This is an area for future research to explore.

Post hoc analysis in the current study found an effect of cause on level of PTG, with participants experiencing an internal health event, such as stroke or encephalitis, having higher levels of overall PTG than participants whose brain injury was caused by external factors. There may be a number of differences between these two groups which could account for these differences. The cause of injury could account for differences in how individuals process the meaning of the event. A traumatic brain injury is usually sudden and unexpected and may be associated with risk taking behaviour, whereas strokes and illnesses may have associations with previous internal health events such as diabetes and heart disease [28]. Furthermore, the type of people who are most likely to experience traumatic brain injury compared with stroke may be different. TBI is most common in young people (especially males) between the ages of 15 and 24 [29]. This is different to the stroke population, for example, in which 80% of strokes occur in people over the age of 64 [28].

A significant effect of cause was found on the PTG component of relating to others, where participants with an internal cause of injury experience greater levels of growth in this domain. It is possible that members of this group are more likely to experience closer relationships with others, while those with TBI do not, because of the personality and cognitive changes that often occur after TBI and the detrimental impact these can have on close relationships.

Contrary to the hypothesis, perceived social support was not found to be a significant correlate or predictor of PTG in the current study. This finding is unexpected as social support is a central part of the model of PTG [1]. This result is also contrary to findings from a recent meta-analysis conducted by Barskova & Osterreich [30] that perceived social support is associated with PTG in serious medical conditions (although not brain injury specifically). Therefore, the question is raised of whether the role of social support in PTG is different after acquired brain injury compared to other medical conditions. There may be a possible difference in types of support provided after brain injury. This difference may be due to patients' personality changes and cognitive changes after brain injury, which would not necessarily be a part of other conditions such as cancer or HIV, and the resulting effect of these changes on relationships with others [31]. Furthermore, there may be differences between public understanding of recovery from brain injury and other medical conditions, and the experiences of social support, as brain injury is sometimes described by patients as a "hidden disability".

Post Hoc Analyses did not find a significant effect of level of distress on PTG. A meta-analysis of correlates with benefit-finding, concluded that benefit finding was related to lower levels of depression, but higher levels of intrusive and avoidant thoughts about the stressor [32]. Due to the length of time since brain injury in the current study, it may be that participants are no longer experiencing the levels of distress and intrusive thoughts which are associated with PTG. A longitudinal design would be more useful to explore the relationship between psychological distress and PTG, and to monitor changes in PTG and distress over time. The model of PTG [1] suggests that rumination processes and continued level of distress are involved in the process of positive growth. It is possible therefore those participants with high levels of PTG have

experienced high levels of distress in the past, leading to PTG, but their distress has since subsided.

In order to consider the importance of PTG on functional outcomes after health events, measures of functioning need to be included in studies. Therefore, the current study aimed to explore the relationship between social functioning and PTG. The hypothesis that these would be related was not confirmed, and PTG did not predict or correlate with social functioning. An interesting area for consideration is whether PTG is an outcome in itself, or part of the process of adjustment after a stressor. Helgeson et al [32] discuss whether the nature and role of growth changes with time after a stressor. It is proposed that soon after the event, benefit finding is a cognitive strategy employed short-term to reduce stress [33]; whereas when time has elapsed since the event, measures of benefit finding are exploring actual growth. Following this criterion, due to the length of time since brain injury, the current study should measure actual growth, but this simplistic temporal criterion may be complicated by cognitive impairment after brain injury, and the lengthy recovery and adjustment process that patients undertake, when compared to a single one-off stressor with no lasting effects.

Limitations and Future Research

A limitation of the current study is the cross-sectional design used. Although the study had enough power to determine statistical predictors, a longitudinal design would allow for better determination of predictors. This would be particularly helpful given that a longitudinal investigation of demographic and injury factors were not predictors for PTG at 10 years post-injury [5].

The questionnaire measures used in the study were chosen for their applicability to the research questions, and their suitability for use with this population. However, it needs to be considered whether the choice of questionnaire has affected the results of the study. For example, the Brief Illness Perception Questionnaire [16] was chosen as it is much less tiring for participants to complete, and fatigue is common after ABI. However, this only asks one question per factor, and it may be that illness perceptions were not explored in adequate depth to determine whether relationships between PTG components and illness perceptions exist. Furthermore, the perceived social support measure [18] has not previously been used with an ABI population. It would be beneficial to explore its suitability as a measure with this population before it is used in future research.

The current study found significant positive correlational relationships between certain illness perception factors and PTG components. However, these were only moderate correlations and design limitations do not allow for the nature of these relationships to be determined. It is proposed that future research explore these relationships further.

A recent systematic review reported that personality traits have an effect on PTG in serious medical conditions [30]. Specifically, positive relationships were found between PTG and the personality characteristics of self-efficacy, self-esteem and optimism. This is an area for future research to explore. It is possible that participants' level of PTG is due more to trait characteristics and general patterns of coping than to individual illness perception. Barskova & Osterreich [30] discuss the importance of considering personality characteristics and raise the issue that prior research has demonstrated that personality is important in maintaining both physical and

psychological health. Therefore, future studies into PTG after brain injury should take personality variables into account.

Post hoc analysis in the current study found an effect of internal vs. external cause of brain injury on level of PTG. A methodologically sound investigation, focused on exploring the differences between these two groups would be beneficial to advance understanding of PTG after brain injury, controlling for factors such as age and prior/concurrent experiences of health events.

References

1. Tedeschi, R.G, Calhoun, L.G. Posttraumatic Growth: Conceptual Foundations and Empirical Evidence, *Psychological Inquiry* 2004; 15 (1): 1-18.
2. Tedeschi, R.G, Calhoun, L.G. The Posttraumatic Growth Inventory: measuring the positive legacy of trauma. *Journal of Traumatic Stress* 1996; 9 (3): 455-71
3. McGrath, J.C, Linley, P.A. Post-traumatic growth in acquired brain injury: A preliminary small scale study, *Brain Injury*, 2006; 20 (7): 767-773.
4. Powell, T., Ekin-Wood, A., Collin, C. Post-traumatic growth after head injury: A long-term follow up. *Brain Injury* 2007; 21(1): 31-38.
5. Hawley, C., Joseph, S. Predictors of positive growth after traumatic brain injury: A longitudinal study. *Brain Injury* 2008; 22 (5): 427-435.
6. McGrath, J. Recovery from brain injury and positive rehabilitation practice. In: Joseph S, Linley A, editors. *Trauma, Recovery and Growth: Positive*

Psychological Perspectives on Posttraumatic Stress, Wiley & Sons Ltd, New Jersey, USA; 2008.

7. Leventhal, H., Nerenz, D.R., Steele, D.S. Illness representations and coping with health threats. In: Baum A, Taylor S, & Singer J, editors. Handbook of Psychology and Health. Vol. IV. Hillsdale, NJ: Erlbaum; 1984. p. 2196252.
8. Cherrington, C, Moser, D, Lennie, T, Kennedy, C. Illness representation after acute myocardial infarction: impact on in-hospital recovery. American Journal of Critical Care 2004; 13: 136-145
9. Sheldrick, R., Tarrier, N., Berry, E., Kinsey, J. Post-traumatic stress disorder and illness perceptions over time following myocardial infarction and subarachnoid haemorrhage, British Journal of Health Psychology 2006; 11: 3876400
10. Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., Andrykowski, M. A. Posttraumatic growth following cancer: A controlled comparison study. Health Psychology 2001; 20(3): 176-185.
11. Linley, P., Joseph, S. Positive Change Following Trauma and Adversity: A Review. Journal of Traumatic Stress 2004; 17(1): 11-21.
12. Glass, T., Maddox, G. The quality and quantity of social support: stroke recovery as psycho-social transition. Social Science and Medicine 1992; 34: 1249-1261.
13. Morton, M., Wehrman, P. Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. Brain Injury 1995; 9 (1): 81-92.

14. Teasdale, T.W., Engberg, A.W. Psycho-social consequences of stroke: A long-term population-based follow-up. *Brain Injury* 2005; 19: 1049-1058.
15. Robinson, R., Murata, Y., Shimoda, K. Dimensions of Social Impairment and Their Effect on Depression and Recovery Following Stroke. *International Psychogeriatrics* 1999; 11: 375-384.
16. Broadbent, E., Petrie, K., Main, J., Weinman, J. The Brief Illness Perception Questionnaire. *Journal of Psychosomatic Research* 2006; 60: 631-637.
17. Moss-Morris, R., Weinman, J., Petrie, K. J., Horne, R., Cameron, L.D., Buick, D. The Revised Illness Perception Questionnaire (IPQ-R). *Psychology and Health* 2002; 17: 1-16.
18. Procidano, M. E., Heller, K. Measures of perceived social support from friends and from family: three validation studies. *American Journal of Community Psychology* 1983; 11(1): 1-24.
19. The Mayo-Portland Adaptability Inventory [Internet]. Malec, J. The Center for Outcome Measurement in Brain Injury; 2005 [cited 2009 January]; Available from: <http://www.tbims.org/combi/mpai>.
20. Zigmond, A.S., Snaith, R.P. The Hospital Anxiety and Depression Scale, *Acta Psychiatrica Scandinavica* 1983; 67: 361-370.
21. Moorey, S., Greer, S., Watson, M., Gorman, C., Rowden, L., Tunmore, R., Robertson, B., Bliss, J. The factor structure and factor stability of the Hospital Anxiety and Depression Scale in patients with cancer. *British Journal of Psychiatry* 1991; 158: 255-9.

22. Whelan-Goodinson R, Ponsford J, Schönberger M. Validity of the Hospital Anxiety and Depression Scale to assess depression and anxiety following traumatic brain injury as compared with the Structured Clinical Interview for DSM-IV. *Journal of Affective Disorders* 2009; 114 (1): 94-102
23. Weiss, D., Marmar, C. The Impact of Event Scale -Revised. In: Wilson J, Keane T, editors. *Assessing psychological trauma and PTSD*. New York: Guildford; 1997.
24. First, M., Spitzer, R., Gibbon M, Williams, J. *Structured Clinical Interview for DSM-IV-TR Axis I Disorders, Research Version, Patient Edition. (SCID-I/P)* 2002. New York: Biometrics Research, New York State Psychiatric Institute.
25. Wilson, B.A., Alderman, N., Burgess, P.W., Emslie, H., Evans, J.J. *Behavioural assessment of the dysexecutive syndrome*, 1996. St Edmunds, UK: Thames Valley Test Company.
26. Linley, P. A., Joseph, S. Posttraumatic growth. *Counselling and Psychotherapy Journal* 2002; 13: 14-17.
27. Lubusko, A., Moore, A., Stanbrock, M., Gill, D. Cognitive beliefs following severe traumatic brain injury. *Brain Injury* 1994; 8 (1): 65-70.
28. Carroll, K., Murad, S., Eliahoo, J. Stroke incidence and risk factors in a population-based prospective cohort study, *Health Statistics Quarterly* 2001; 12, Office of National Statistics.
29. Kraus, J., Rock, A., Hemyari, P. Brain injuries among infants, children, adolescents, and young adults. *American Journal of Diseases of Children* 1990; 144: 684-691.

30. Barskova, T., Osterreich, R. Post-traumatic growth in people living with a serious medical condition and its relations to physical and mental health: A systematic review. *Disability and Rehabilitation* 2009; 31: 1-25.
31. Lezak, M., O'Brien, K. Longitudinal study of emotional, social and physical changes after Traumatic Brain Injury. *Journal of Learning Disabilities* 1988; 21(8): 456-463.
32. Helgeson, V., Reynolds, K., Tomich, P. A meta-analytic review of benefit finding and growth. *Journal of Consulting and Clinical Psychology* 2006; 74(5): 797-816.
33. McFarland, C., Alvaro, C. The impact of motivation on temporal comparisons: Coping with traumatic events by perceiving personal growth. *Journal of Personality and Social Psychology* 2000; 79: 327-343.

Part 3: Appendices

Appendix 1: Reflective Statement

Appendix 2: Brain Injury – Instructions for Authors

Appendix 3: Ethical Approval and Research Governance Documentation

Appendix 4: Supplementary Materials for Systematic Literature Review

Appendix 5: Supplementary Materials for Empirical Paper

Appendix 6: Participant Information Sheet and Consent Form

Appendix 7: Summary of Analyses

Appendix 1
Reflective statement

Reflective Statement

Introduction

This statement reflects on the research process and aims to highlight what I have learnt from each stage in the project. In particular, throughout the statement, I have considered how my learning will be applied to future research endeavours. First I will reflect upon the different stages in the empirical research process, followed by personal reflections. I will then reflect upon the process of conducting the Systematic Literature Review and conclude with some final comments on how my learning will help in the future.

The early stages

From the start, the most important aspect of producing a thesis for me was to achieve a well-designed study. From my undergraduate research experience at the University of York where I studied a topic not on the curriculum, I was not daunted by beginning research in an area I knew little about, as this learning experience was something I had previously relished. However, I had also learnt from choosing a topic for my undergraduate dissertation that I have broad interests, and a strong interest in research more generally, and therefore I was aware that it would be advantageous to narrow down my choices early on in order to focus. I therefore decided that I would like to complete my research with participants who have cognitive deficits, and began searching for a theoretically interesting and clinically relevant topic.

Throughout my clinical experience, and in my personal life, I have always been struck by the resilience and strength of people, and interested in how people manage to assimilate the trauma and continue their lives after traumatic events. Therefore, the concept of PTG interested me. I had mixed feelings about pursuing a study into PTG after ABI because I had discovered a large gap in the literature, and was concerned that the background literature on PTG was not as theoretically sound as I had hoped. However, despite reading about other topics (which did interest me), I kept coming back to PTG and I set out with an (perhaps overly) optimistic, yet enthusiastic attitude. I approached a potential supervisor with an initial proposal, keen to get started.

This enthusiasm and the fact that, as far as I am aware, this is the first study exploring psychosocial factors in PTG after ABI, meant that there were many possible research questions for the study, and many different ways of exploring them (e.g, quantitative or qualitative design). The result was that the proposal was over-ambitious in the time frame, and this was reflected back after the peer review process. It felt uncomfortable having to remove parts of the study after this, but it did mean that I could focus more on a smaller number of factors. I still wonder whether I made the right decisions at this time, but I do feel that this study has been a good 'first step' into exploring the topic, and will provide a base for future research to build upon, despite the limitations.

Practical Issues

During the process, I have changed supervisor twice, due to changes in staffing. The first change took place at the end of the second year of training (when one member of staff left the department), and the second change was a few months afterwards (when a new member of staff joined). These changes have had both positive and negative

aspects. On a positive note, the advantages of this was gaining additional perspectives on the design, and developing my understanding of how research supervision is carried out by different supervisors. However, this also presented some challenges, which I have been reflecting upon throughout the course of the project. The additional perspectives gained meant that it felt as though the research questions were constantly changing, and subsequently, the process of refining the design took much longer than expected. At times, early on, it felt as though there was no consistency. However, I soon realised that the initial idea for the project was my own, and that this consistency needed to be provided by me, and I began to take back the ownership and control over the project from this point forward, using supervision in a more constructive way.

The most frustrating time during the research process was waiting for R&D approval to be granted. I received my LREC approval in July 2008, but the R&D approval was not received until just before Christmas. This five month hold-up was due to issues obtaining an Honorary Contract in the Hull and East Yorkshire Hospitals NHS Trust as there were difficulties in the responsible department. After numerous attempts from myself and my field supervisor, and involvement from her management, I eventually received my honorary contract and R&D were able to grant approval. I began data collection in January, and managed to meet with 40 participants in the end, which allowed the sample size estimation to be met. However, given the research questions and exploratory nature of the project, it would have been a significant improvement on the study to have included larger numbers of participants, and I believe that this would have been possible if this unfortunate hold-up had not occurred. I had taken a systematic approach to my planning for data collection, and had aims for the numbers of participants I wanted to meet each month. It was extremely disheartening to see these numbers diminish week by week, without knowing when data collection could

begin. From this experience, I have learnt that sometimes during research, events are beyond your control and that planning needs to take account of this and be flexible enough to cope with setbacks.

Choice of Journal

The decision was made to write the articles for submission to *Brain Injury* for a number of reasons. Firstly, the journal aims to publish on all aspects of brain injury.

The website states that:

Manuscripts address emergency and acute medical care, acute and post-acute rehabilitation, family and vocational issues, and long-term supports. Coverage includes assessment and interventions for functional, communication, neurological, and psychological disorders.

Due to this broad focus, the readership of the journal is wide, including basic scientists, neurosurgeons or rehabilitation specialists, and all other rehabilitation professionals such as physical and occupational therapists, speech pathologists, neuropsychologists, rehabilitation psychologists, social workers and rehabilitation nurses. I feel that it is important for Psychologists researching and working in ABI rehabilitation to disseminate their findings across the range of professionals who are involved in a person's care. The emphasis of effective rehabilitation needs to be upon care addressing all aspects of the person's needs, and my clinical experience of working in this area has taught me the necessity of team working and information sharing, including mutual educating on different perspectives, in order to achieve this. Finally, the journal has published on PTG in ABI before, and most of the papers that I

have read during the research process were published here. Thus, people who are interested in learning more about this topic may look here first.

Ethical issues

Conducting research with participants who have cognitive impairments is always going to be fraught with ethical considerations. Some of these simply required a protocol to be developed and/or for me to rely upon my clinical judgement, which I feel was appropriate. For example, deciding whether a participant has understood the information sheet adequately to be able to give informed consent. However, other ethical issues were not so simple to resolve, and influenced the design of the study. We decided to set a limit on the number of questionnaires that would be administered, in consideration of how tiring some participants would find the procedure (due to fatigue which is a common long-lasting effect after brain injury, and potential cognitive overload). This limited the number of variables that could be explored in the study. Furthermore, as this was a first study investigating a number of different variables, the decision was made to use the shortened form of questionnaires where possible. Whilst this addressed the ethical dilemma, I did reflect upon whether the choice limited the quality of the data which was gathered, and whether a more focused study with the more in-depth questionnaires would have been a more useful approach. I feel that the answer to this lies in the aims of the study and the research questions and returning to these will help me to make similar decisions in the future.

An ethical issue which I regularly faced was the number of participants who I met that had no current involvement with services, despite continuing to experience difficulties. There is a lack of local services generally for people after brain injury, something

which professionals are aware of and applying for funding to develop. Specifically in Neuropsychology, only one Neuropsychologist is employed in the service to work with both the inpatients and outpatients, and there is no Neuropsychological input for stroke during the inpatient stay. For a number of participants, it felt necessary to discuss their difficulties in supervision and to consider a Neuropsychological referral. Many participants asked questions about where they could find further information about brain injury, or whether there were any support services they could access. I found myself signposting people to the local Headway organisation on an almost daily basis, and I plan to include details of Headway when I disseminate the findings amongst participants.

Personal Reflections

At times, meeting with participants was difficult and I felt a range of negative emotions when hearing their experiences, from frustration at the lack of support, to sadness at some participants' isolation and loneliness. At these times, supervision was very important to me and I reflected upon how vital it is to have support structures in place during research as well as in clinical practice. However, there were also times when my feelings were more positive and I felt inspired by the resilience of the people I was talking to. I was also touched by the way that people would give up their time so willingly and put in a huge amount of effort to ensure that they were completing the questionnaires well enough, even when they found it tiring or tedious (and even after I offered them the chance to withdraw or take a break). Although it was a quantitative study, I met with every participant, and most of the time people talked me through their responses and would talk about their experiences. People often spoke with great respect and gratitude of the staff who had helped them through the recovery process,

and were genuinely glad to be able to give something back to professionals. At the time, I was on placement in the Neuropsychology department, so it was very inspiring to hear these accounts and believe this improved my clinical work, as I learnt what people consider helps them through the recovery process. I welcomed the opportunity to meet with so many more people than I would normally see on placement, and learn from them.

Systematic Literature Review

The process of conducting a Systematic Literature Review was daunting, but I embraced the opportunity to learn the skills. I first began trying to decide on a topic during my first year of training, and I conducted initial pilot searches at this time. The final decision was not made until my final year, and during this time I cycled between topics which were too specific or too new, where there was not sufficient literature to review, and topics which were too broad. I anticipated that there would be much more literature on social support than was found during the final review, and was surprised when only 12 papers were identified. I have wondered whether it would have been more clinically useful to broaden out the focus of the review, to include social support for caregivers, or to study group interventions, but I do believe that the current review is more closely linked to the empirical area of study and has helped to enhance my understanding. I have also worked clinically with people who have brain injuries, and feel that it is important that Clinical Psychologists do review the literature on psychosocial aspects of brain injury, identify gaps and conduct research in order to ensure that patients' well-being is considered during rehabilitation, beyond the physical aspects of care (although clearly this is a priority in the early stages of recovery). On reflection, I feel that I have learnt about some of the challenges during

the early stages of a Systematic Literature Review, and will be more prepared to accept that this is part of the process and that perseverance is the key.

Conclusion

I feel that I have learnt so much from the process of completing this research, particularly from the inevitable ups and downs along the way. I set out with great ambitions, and do feel some disappointment that the resulting thesis is much more humble than this, and with more flaws than I had hoped. However, this has inspired me to continue with research so that I can improve my skills and I feel that I have learnt from my mistakes and the setbacks along the way. I will be able to move forward and embark upon my future research endeavours with a greater appreciation of the challenges faced when conducting clinical research, and most importantly, be better at planning for and coping with these challenges. In addition, I feel that my experiences have prepared me for potential future roles as a research supervisor, both in terms of providing informal comment and guidance, and in a more formal capacity.

Appendix 2
Brain Injury ó Instructions for Authors

BRAIN INJURY

Instructions for Authors

General Guidelines

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

Contacting the Editors:

Jeffrey S. Kreutzer, Department of Physical Medicine & Rehabilitation, Virginia Commonwealth University, Medical College of Virginia Campus Richmond, VA 23298-0542, USA.

Nathan D. Zasler, Concussion Care Centre of Virginia, 3721 Westerre Parkway, Suite B, Richmond, VA 23233, USA.

Associate Editor:

William W. McKinlay, Case Management Services Ltd, 14a Main Street, Balerno, Edinburgh, EH14, 7EQ, UK.

Managing Editor:

Jennifer H. Marwitz, Virginia Commonwealth University, Department of Physical Medicine and Rehab, Box 980542, 1200 East Broad Street, Room 3-102, Richmond, VA 23298-0542, USA. Tel: +1 804 828 3704; Fax: +1 804 828 2378; Email: jhmarwitz@vcu.edu

Contacting the Publishers:

Brain Injury -Journals Editorial, Informa Healthcare, Telephone House, 69-77 Paul Street, London, EC2A 4LQ, UK

Submitting a paper to *Brain Injury*

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

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

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

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

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

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

Abstracts

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

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

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

The abstract should not exceed 200 words.

Electronic Processing of Figures

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

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

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

Declaration of interest

It is the policy of all Informa Healthcare to adhere in principle to the Conflict of Interest policy recommended by the International Committee of Medical Journal Editors (ICMJE, <http://www.icmje.org/index.html#conflict>).

All authors must disclose any financial and personal relationships with other people or organisations that could inappropriately influence (bias) their work. It is the sole responsibility of authors to disclose any affiliation with any organisation with a financial interest, direct or indirect, in the subject matter or materials discussed in the manuscript (such as consultancies, employment, paid expert testimony, honoraria, speakers' bureaus, retainers, stock options or ownership, patents or patent applications or travel grants) that may affect the conduct or reporting of the work submitted. All sources of funding for research are to be explicitly stated. If uncertain as to what might be considered a potential conflict of interest, authors should err on the side of full disclosure.

All submissions to the journal must include full disclosure of all relationships that could be viewed as presenting a potential conflict of interest. If there are no conflicts of interest, authors should state that there are none. This must be stated **at the point of submission** (within the manuscript after the main text under a subheading "Declaration of interest" and, where available, within the appropriate field on the journal's Manuscript Central site). This may be made available to reviewers and will appear in the published article at the discretion of the Editors or Publisher.

If no conflict is declared, the following statement will be attached to all articles:

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

The intent of this policy is not to prevent authors with these relationships from publishing work, but rather to adopt transparency such that readers can make objective judgements on conclusions drawn.

Plagiarism

Informa has a strict policy against plagiarism. We define plagiarism as the use of extracts from another person's work that are not placed in quotation marks, without the permission of that person, and without acknowledgement to that person (using the appropriate reference style), with the result that your article presents these extracts as original to you. By submitting your work to an Informa Healthcare journal, you warrant that it is your original work, and that you have secured the necessary written permission from the appropriate copyright owner or authority for the reproduction of any text, illustration, or other material.

If any article submitted to an Informa Healthcare journal is found to have breached any of these conditions, Informa Healthcare reserves the right to reject that article and any others submitted by the same authors. Informa Healthcare may also contact the authors' affiliated institutions to inform them of its findings.

Clinical Trials Registry

Brain Injury requests, as a consideration of publication, that clinical trials are registered in a public repository at their inception and prior to patient enrolment.

The registry must be accessible to the public at no charge, be open to all prospective registrants and managed by a not-for-profit organization. For a list of registries that meet all of these requirements, please see the WHO International Clinical Trials Registry Platform (ICTRP) <http://www.who.int/ictrp/en/>. This is in accordance with the guidelines published by the International Committee of Medical Journal Editors (ICMJE). For more information, see ICMJE Uniform Requirements for Manuscripts Submitted to Biomedical Journals <http://www.icmje.org>

The registration of all clinical trials facilitates the dissemination of information among clinicians, researchers and patients, and enhances public confidence in the research enterprise.

Copyright permission

Contributors are required to secure permission for the reproduction of any figure, table, or extensive (more than 50 word) extract from the text, from a source which is copyrighted - or owned - by a party other than Informa Healthcare or the contributor.

This applies both to direct reproduction or 'derivative reproduction' - when the contributor has created a new figure or table which derives substantially from a copyrighted source.

The following form of words can be used in seeking permission:

Dear [COPYRIGHT HOLDER]

I/we are preparing for publication an article entitled

[STATE TITLE]

to be published by Informa Healthcare in *Brain Injury*.

I/we should be grateful if you would grant us permission to include the following materials:

[STATE FIGURE NUMBER AND ORIGINAL SOURCE]

We are requesting non-exclusive rights in this edition and in all forms. It is understood, of course, that full acknowledgement will be given to the source.

Please note that Informa Healthcare is a signatory of and respects the spirit of the STM Agreement regarding the free sharing and dissemination of scholarly information.

Your prompt consideration of this request would be greatly appreciated.

Yours faithfully

Code of experimental ethics and practice

Contributors are required to follow the procedures in force in their countries which govern the ethics of work done with human or animal subjects. The Code of Ethics of the World Medical Association (Declaration of Helsinki) represents a minimal requirement.

When experimental animals are used, state the species, strain, number used, and other pertinent descriptive characteristics.

For human subjects or patients, describe their characteristics.

For human participants in a research survey, secure the consent for data and other material - verbatim quotations from interviews, etc. - to be used.

When describing surgical procedures on animals, identify the pre anaesthetic and anaesthetic agents used and state the amount of concentration and the route and frequency of administration for each. The use of paralytic agents, such as curare or succinylcholine, is not an acceptable substitute for anaesthetics. For other invasive procedures on animals, report the analgesic or tranquilizing drugs used; if none were used, provide justification for such exclusion.

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

Specific permission for facial photographs of patients is required. A letter of consent must accompany the photographs of patients in which a possibility of identification

exists. It is not sufficient to cover the eyes to mask identity.

Mathematics

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

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

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

$$\frac{6l + 5h + q}{3n + 3yz^2}$$

But: $\frac{a}{b} + \frac{c}{d} + \frac{a}{d}$

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

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

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

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

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

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

Notes on style

All authors are asked to take account of the diverse audience of *Brain Injury*. Clearly

explain or avoid the use of terms that might be meaningful only to a local or national audience.

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

1. *Brain Injury* prefers US to 'American', USA to 'United States', and UK to 'United Kingdom'.

2. *Brain Injury* uses conservative British, not US, spelling, i.e. colour not color; behaviour (behavioural) not behavior; [school] programme not program; [he] practises not practices; centre not center; organization not organisation; analyse not analyze, etc.

3. Single 'quotes' are used for quotations rather than double "quotes", unless the 'quote is "within" another quote'.

4. Punctuation should follow the British style, e.g. 'quotes precede punctuation'.

5. Punctuation of common abbreviations should follow the following conventions: e.g. i.e. cf. Note that such abbreviations are not followed by a comma or a (double) point/period.

6. Dashes (M-dash) should be clearly indicated in manuscripts by way of either a clear dash (-) or a double hyphen (- -).

7. *Brain Injury* is sparing in its use of the upper case in headings and references, e.g. only the first word in paper titles and all subheads is in upper case; titles of papers from journals in the references and other places are not in upper case.

8. Apostrophes should be used sparingly. Thus, decades should be referred to as follows: 'The 1980s [not the 1980's] saw ...'. Possessives associated with acronyms (e.g. APU), should be written as follows: 'The APU's findings that ...', but, NB, the plural is APUs.

9. All acronyms for national agencies, examinations, etc., should be spelled out the first time they are introduced in text or references. Thereafter the acronym can be used if appropriate, e.g. 'The work of the Assessment of Performance Unit (APU) in the early 1980s ...'. Subsequently, 'The APU studies of achievement ...', in a reference ... (Department of Education and Science [DES] 1989a).

10. Brief biographical details of significant national figures should be outlined in the text unless it is quite clear that the person concerned would be known internationally.

Some suggested editorial emendations to a typical text are indicated in the following with square brackets: 'From the time of H. E. Armstrong [in the 19th century] to the curriculum development work associated with the Nuffield Foundation [in the 1960s], there has been a shift from heurism to constructivism in the design of [British] science courses'.

11. The preferred local (national) usage for ethnic and other minorities should be used in all papers. For the USA, African-American, Hispanic, and Native American are used, e.g. 'The African American presidential candidate, Jesse Jackson...' For the UK, African-Caribbean (not 'West Indian'), etc.

12. Material to be emphasized (italicized in the printed version) should be underlined in the typescript rather than italicized. Please use such emphasis sparingly.

13. n (not N), % (not per cent) should be used in typescripts.

14. Numbers in text should take the following forms: 300, 3000, 30 000. Spell out numbers under 10 unless used with a unit of measure, e.g. nine pupils but 9 mm (do not introduce periods with measure). For decimals, use the form 0.05 (not .05).

Notes on tables and figures

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

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

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

Insert table 2 about here

3. Each table and/or figure must have a title that explains its purpose without reference to the text.

4. Figures and tables must not be embedded in the text.

Thus tables and figures must be referred to in the text and numbered in order of appearance. Each table should have a descriptive title and each column an appropriate heading.

Citations in text

References should be cited using the numerical system (e.g. [3], [5-9]). They should be

listed separately at the end of the paper in the order in which they appear in the text. 'Ibid.' (and the like) are not used when repeating citations.

Acknowledgements

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

Book reviews

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

Student Engagement and Achievement in the American Secondary School.

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

2. Page references within reviews should be given as follows: (p. 337) or (pp. 36-37).

References

References should follow the Council of Biology Editors (CBE) Citation & Sequence format. Only works actually cited in the text should be included in the references. Indicate in the text with Arabic numbers inside square brackets. Spelling in the reference list should follow the original. References should then be listed in numerical order at the end of the article. Examples are provided as follows:

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

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

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

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

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

Webpage: [6] *British Medical Journal* [Internet]. Stanford, CA: Stanford Univ; 2004

July 10 - [cited 2004 Aug 12]; Available from: <http://bmj.bmjournals.com>

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

Further examples and information can be found in the CBE style manual *Scientific Style and Format*, sixth edition.

Offprints and Reprints

Offprints and reprints of articles published in this journal can be purchased once the article has been published online. Corresponding authors will receive free online access to their article through our website (www.informaworld.com). Reprints of articles published in this journal can be purchased through the Publisher when proofs are received. Copies of the Journal can be purchased separately at the author's preferential rate of 15.00/US\$25.00 per copy.

Colour figures

a. Any figure submitted as a colour original will appear in colour in the journal's online edition free of charge and can be downloaded.

b. Paper copy colour reproduction will only be considered on condition that authors contribute to the associated costs. Charges are: £500/US\$1030 for the first colour page and £250/US\$515 for each colour page after per article. (Colour costs will be waived for invited Review Articles.)

NIH Public Access Policy

In consideration of the National Institutes of Health (NIH) Public Access Policy, Informa Healthcare acknowledges that the broad and open dissemination of NIH-funded-research results may benefit future scientific and medical research. Because we value the current and future contributions our journals make to the scientific body of knowledge, we have made certain that our policies accommodate those authors who wish to submit to PubMed Central.

Informa Healthcare's position with respect to public access to NIH-funded work published in Informa Healthcare journals is as follows:

- Informa Healthcare authors may voluntarily submit their funded work to PubMed Central after a 12-month embargo period;
- "funded work" shall be defined as the final, peer-reviewed manuscript that is accepted by the Editor in Chief of the journal. This manuscript must not be altered by Publisher's copyediting and typesetting services; and
- this embargo period begins the day the work is published online at www.informaworld.com.

Appendix 3
Ethical Approval and Research Governance documentation

Appendix 3.1 LREC documentation

Appendix 3.2 Research Governance approval

These have been removed as part of the process of anonymising the thesis.

Appendix 4
Supplementary materials for Systematic Literature Review

Appendix 4.1 Quality control checklist
Appendix 4.2 Data Extraction Form

Quality Control Checklist- adapted from Foukes & Foulton (1991)

Ratings: 2= No problem, 1= minor problem, 0=major problem, NA= not applicable
 (Note: this system of rating is reversed from Foukes & Foulton's system (1991) who used 0 as a rating of 'no problem' and 2 as 'major problem'. A higher quality rating for a better quality paper seemed more intuitive to the researcher and so this was changed to avoid confusion).

<u>Abstract</u> Does the abstract include: Objectives Design ó does it state whether case report, cross-sectional, case series, cohort, case control etc. Method Important results Conclusions	
<u>Objectives</u> Do the authors explicitly state what they are trying to measure? Concepts clearly defined?	
<u>Study design appropriate to objectives?</u>	
<u>Study sample representative?</u> Source of sample Sampling method Sample size ó has this been justified? Entry/exclusion criteria Non-respondents	
<u>Control Group acceptable?</u> Definition of controls Source of controls Matching/randomisation Comparable characteristics	
<u>Quality of measurements and outcomes?</u> Validity Reliability Quality Control	
<u>Completeness?</u> Compliance Drop outs Deaths Missing Data	
<u>Are statistical analyses methods stated?</u>	
<u>Are the main findings stated?</u> Is enough detail given that interpretations can be seen to be drawn from the results?	
<u>Are conclusions stated?</u> Is there a clear link between data, interpretation and conclusions?	

Individual study data extraction form

Main aims	
Participants	
Method	
Method quality	
IVs and measures	
DVs and measures	
Analysis	
Main findings	
Conclusions	
Clinical Implications	

Appendix 5
Supplementary materials for empirical paper

Appendix 5.1- Post Traumatic Growth Inventory

Appendix 5.2 ó The Brief Illness Perception Questionnaire

Appendix 5.3 ó Impact of Event ScaleóRevised

Appendix 5.4 ó Perceived Social Support from Family and Friends Scale-
Revised

Appendix 5.5 ó Hospital Anxiety and Depression Scale

Appendix 5.6 ó Mayo-Portland Adaptability Inventory-4

Appendix 5.7 ó DEX Questionnaire from the Behavioural Assessment of
the Dysexecutive Syndrome (Self Rating, and Independent Rater forms)

These have been removed for copyright reasons.

Appendix 6
Participant Information Sheet and Consent Form

Appendix 6.1 ó Participant Information Sheet
Appendix 6.2 ó Consent Form

Department of Clinical Psychology
Hertford Building
University of Hull
Hull
HU6 7RX

Participant Information Sheet

Post-traumatic growth, illness perceptions, social support and social functioning after brain injury

You are being invited to take part in a research study. However, before you decide whether you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.

- Part 1 describes the purpose of this study and what taking part will involve.
- Part 2 provides further detail on issues such as confidentiality agreements and complaints procedures.

Please ask the researcher any questions you may have about the information provided or if there is anything else you would like to know about the study.

Part 1

What is the purpose of the study?

Many people will experience a type of brain injury in their lives. It is important that professionals who work with these patients conduct research in order to try to understand how to help patients to adjust after such a life-changing event. Previous research has shown that people experience both positive and negative changes in their lives after a brain injury such as a stroke or traumatic brain injury.

This study will help us to understand the positive changes that people may experience in their lives as a result of the struggle with a brain injury. These positive changes can be called *post-traumatic growth*. We also want to explore the beliefs that people have about illness (which can be called *illness perceptions*) and the social support they have from family and friends. We will determine whether these are related to the amount of post-traumatic growth experienced by people who have had a stroke or traumatic brain injury.

We also want to find out whether the positive changes people experience after a brain injury can have an effect upon the way they function socially.

This study is being conducted by a Trainee Clinical Psychologist as part of their training.

Why have I been chosen?

You have been chosen because you have had a brain injury at least three years ago.

We are aiming to recruit a total of 50 participants.

Do I have to take part?

No. It is up to you to decide whether or not to take part. Following reading this information sheet, if you decide to take part you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. In this instance, your data will be destroyed and not used in the research. If you decide not to take part, or to withdraw during the study it will not affect the standard of care that you receive.

What will I have to do if I choose to take part?

- The study will take a maximum of 60-90 minutes.
- You will be asked to fill out some questionnaires. .
- Once you have finished the questionnaires, you will not be required to complete any further tasks for this research project. There will be no follow-up.

Expenses and payments

Unfortunately we are not able to offer any payments or reimburse any expenses for taking part in this research.

What are the possible disadvantages of taking part?

There are no foreseen risks involved in taking part in this study.

What are the possible benefits of taking part?

There is no intended clinical benefit to participants taking part in this study. However, the research being conducted may help us to understand more about post-traumatic growth after brain injury which could help improve treatment for people who have experienced a brain injury.

Part 2

Confidentiality

- All information about your participation in this study will be kept confidential.
- Only the chief investigator will have access to identifiable data.
- Data will be held for 5 years in a secure place before it is disposed of securely.

- The procedures for handling, storage and destruction of data are compliant with the Data Protection Act 1998.
- Confidentiality will only be broken if there are concerns that you or another person is at risk of harm. This will be discussed with you first.

Complaint Procedure

If you have any concerns about this study, you should contact the chief investigator who will try to answer your questions (telephone: 01482 303966). If you wish to make a formal complaint, you can do this through the NHS Complaints Procedure (Telephone: 01482 303966).

Harm

In the event that you are harmed and this is due to someone's negligence then you may have grounds for a legal action for compensation against Humber Mental Health Teaching NHS Trust but you may have to pay your legal costs.

What will happen to the results of this study?

Once information has been collected from participants, it is intended that the results of the study will be published in a peer-reviewed journal. You will not be identified in any report/publication. You will be asked if you wish to be informed of the results of the study when it is completed.

If you have any questions that are not answered in the Information Sheet please don't hesitate to ask me or contact me by post, telephone or email.

Contact details:

Julia Loomes
 Trainee Clinical Psychologist
 Department of Clinical Psychology
 Hertford Building
 University of Hull
 Hull
 HU6 7RX

Telephone: 01482 303966

Email: j.loomes@hull.ac.uk

Thank you for considering taking part in this study and taking the time to read this information sheet.

Department of Clinical Psychology
 Hertford Building
 University of Hull
 Hull
 HU6 7RX

Participation Identification Number:

Consent Form

Post-traumatic growth, illness perceptions, social support and social functioning after brain injury.

Researcher: Julia Loomes, Trainee Clinical Psychologist.

Please initial
 box

1. I confirm that I have read and understand the information sheet dated 28.6.2008 (Version 1) for the above study. I have had the opportunity to consider the information, ask questions and have 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 medical care or legal rights being affected.
3. I agree to take part in the above study.

 Name of
 Participant

 Date

 Signature

 Name of person
 taking consent

 Date

 Signature

Appendix 7
Summary of Statistical Analyses

Regression analysis table for overall growth (illness perceptions and social support)**Coefficients^a**

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	12.764	17.428		.732	.469
	personalcontrol	1.117	1.254	.143	.891	.379
	concern	2.190	1.104	.320	1.983	.055
	understanding	1.322	1.172	.181	1.128	.267
	overallss	.363	.456	.128	.796	.432

a. Dependent Variable: overallptg

Regression analysis table for social functioning predicted by PTG, controlling for level of disability**Coefficients^a**

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	1.385	1.595		.868	.391
	Mpaiabilities	.940	.172	.663	5.461	.000
2	(Constant)	2.872	2.279		1.260	.215
	Mpaiabilities	.965	.175	.681	5.526	.000
	Overallptg	-.037	.040	-.113	-.916	.366

a. Dependent Variable: mpaiparticipation

Regression analysis table for overall growth predicted by level of distress and disability.**Coefficients^a**

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.
		B	Std. Error	Beta		
1	(Constant)	39.401	8.442		4.667	.000
	mpaiabilities	.224	.890	.052	.252	.803
	IESR	-.816	2.478	-.080	-.329	.744
	anxiety	-.536	1.521	-.094	-.352	.727
	depression	2.256	2.292	.317	.984	.332

a. Dependent Variable: overallptg

MANOVA for effect of cause on overall PTG and PTG components**Multivariate Tests^b**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.852	31.637 ^a	6.000	33.000	.000
	Wilks' Lambda	.148	31.637 ^a	6.000	33.000	.000
	Hotelling's Trace	5.752	31.637 ^a	6.000	33.000	.000
	Roy's Largest Root	5.752	31.637 ^a	6.000	33.000	.000
intermalexternal	Pillai's Trace	.420	3.978 ^a	6.000	33.000	.004
	Wilks' Lambda	.580	3.978 ^a	6.000	33.000	.004
	Hotelling's Trace	.723	3.978 ^a	6.000	33.000	.004
	Roy's Largest Root	.723	3.978 ^a	6.000	33.000	.004

a. Exact statistic

b. Design: Intercept + intermalexternal

MANOVA for effect of previous trauma on overall PTG and PTG components**Multivariate Tests^b**

Effect		Value	F	Hypothesis df	Error df	Sig.
Intercept	Pillai's Trace	.698	12.688 ^a	6.000	33.000	.000
	Wilks' Lambda	.302	12.688 ^a	6.000	33.000	.000
	Hotelling's Trace	2.307	12.688 ^a	6.000	33.000	.000
	Roy's Largest Root	2.307	12.688 ^a	6.000	33.000	.000
scid	Pillai's Trace	.052	.303 ^a	6.000	33.000	.931
	Wilks' Lambda	.948	.303 ^a	6.000	33.000	.931
	Hotelling's Trace	.055	.303 ^a	6.000	33.000	.931
	Roy's Largest Root	.055	.303 ^a	6.000	33.000	.931

a. Exact statistic

b. Design: Intercept + scid