AN EXPLORATION OF SELF-DISCLOSURE AFTER TRAUMATIC BRAIN INJURY

by

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Abstract

Aims: To investigate the motivation for concealment and disclosure of issues related to acquired and traumatic brain injury, and the association of these motivations with a range of possible predictors and outcomes (specifically, self-esteem, social support, social avoidance, loneliness, life satisfaction and community integration).

Method: Three studies were carried out. The first (N=18) was a qualitative exploration of the reasons why people with acquired brain injury and their family carers chose to disclose or conceal information about the brain injury. In the second (N=55) two questionnaires were developed from the first study (the Non-Disclosure and Self-Disclosure questionnaires). These focused on the motivations of the person with the brain injury, one addressing motivations to conceal and the other motivations to disclose. Assessments of the reliability and validity of these measures were carried out. The third study (N=65) investigated the relationships between these motivations to conceal/disclose and some possible predictors and outcomes of these motivations.

Findings: In the first study, a range of motivations for disclosure (e.g. seeking social support) and for concealment (e.g. avoiding the negative reactions of others) emerged from the data. In the second study, the derived questionnaires showed good internal consistency (the Cronbach's alpha levels are N-DQ = .92 and S-DQ = .92) and the test-retest reliability (ICC= ranged from .38 to .805). Predicted significant correlations with Brief Fear of Negative Evaluation and N-DQ$_1$ (r=.418, n=55, p=.002) and with the Distress Disclosure Index and S-DQ$_2$ (r=.595, n=54, p=.001) provided evidence of their concurrent validity. In the third study, as hypothesized, higher motivations to conceal (i.e. high N-DQ scores) were significantly correlated with lower self esteem (r = -.357, n = 65, p = .003 with the Rosenberg Self-Esteem Inventory); higher social avoidance (r = .345, n = 64, p = .005 with the SAD); and greater loneliness (r = .380, n = 65, p = .002 with the University of California Los Angeles loneliness scale). The results of a mediation analysis were consistent with the hypothesis that higher motivations to conceal had an impact on general life satisfaction (as measured by the LiSat-11) via the mediation of social avoidance (SAD) and loneliness scale (UCLA). However, the hypothesis related to social support was not supported.

Conclusions and implications: Many people affected by a brain injury and their families are concerned about the negative and positive impact that disclosure of information about the brain injury may have. Concern about the negative impact may be associated with negative views of the self, and have a range of negative social consequences. However, disclosure in some circumstances does, in reality, have a negative impact. People with an acquired brain injury and their families may need support in learning to conceal and disclose information about their injury in a more effective way.

In loving memory of Mum and Dad

Hilda Florence Carr (nee Green) and Francis (Frank) Carr

(18.09.1928 to 14.02.2011 and 15.04.1927 to 11.09.2002)

We miss you – thank you for your love and care.
This is for you

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CHAPTER 1

SECTION ONE

1.1 Introduction

This research is about the information people affected by traumatic brain injury (TBI) decide to give others about their situation. In choosing what we do, or do not say to others and how we say it, we project a particular view of ourselves. In the field of Organizational Psychology, controlled self-presentation is often referred to as “impression management” (Leary & Kowalski, 1990). Use of impression management matters because how we manage disclosure influences the response we get from others, and in turn the amount of social support we receive (Dyer, Bell, McCann, & Rauch, 2006; Leary & Kowalski, 1990). Without social support many opportunities, for the emotional and physical rehabilitation and social reintegration of those affected by TBI, may be missed.

Impression management is seldom applied within the field of health psychology and is not usually combined with brain injury research, and more generally, there are few studies that merge the research from one field with another. Most tend to stay within the boundaries of one specialism; this means that many possibilities for alternative ways of interpreting observations are missed. Some of the studies, mainly from the area of mental health, that consider more than one field of research are discussed in the literature review.

To some extent, brain injury research can be quite negative in its outlook, seeing alternative ways of coping with major changes to an individual’s life as maladaptive or non-compliant. This is unfair to the person or family concerned. Alternatively a number of studies attempt to be overly positive in their outlook. This is also unfair to those who are struggling to deal with major personal and life changes as they are seen as dwelling upon their situation, unable to look upon the brighter side of life. Of course, it is acknowledged that some behaviour is unacceptable and at times antisocial. But there are other ways of looking at phenomena, supported by work from other fields of research, which offer a middle ground. Looking at the role of impression management in the day to day life of people with a brain injury gives this opportunity.

1.2 Statement of the problem

Traumatic brain injuries (TBI) are "acquired" after birth and have an external origin (Gan, Campbell, Gemeinhardt, & McFadden, 2006). Each day in the United Kingdom approximately 2,500 people sustain a traumatic head injury (HES, 2009); although this figure probably includes minor injuries with temporary effects. TBIs are sudden and unexpected events giving rise to temporary or permanent injury. They result for example, from motor vehicle collisions, falls, assaults, accidents at work, sports injuries, falls or attempted suicide (Gan, et al., 2006; Judd & Wilson, 1999). They can lead to cognitive, social and behavioural difficulties for the individuals themselves and changes also affect families, friends and associates.

These injuries may be obvious to others, as with visible impairment, but they may also be fully or partially hidden, for instance cognitive deficits (Cloute, Mitchell, & Yates, 2008). Cloute et al. analyzed the interviews of 6 adults and their significant others, following a severe TBI. They identified 4 main themes in relation to care and rehabilitation. While useful, these themes are joint constructions of the problems facing individuals after a brain injury; they may not necessarily represent the themes the service user would raise if interviewed on their own. Those affected may have a combination of difficulties which they have to overcome in their daily lives. The way individuals present themselves after a brain injury may not always be as it appears to be. Putting a brave face on things or over-emphasising difficulties in one area to cover up difficulties in another may cause problems for those supporting others with their rehabilitation and community reintegration. The fact that individuals may be withholding information needs to be recognised: this may not always be due to poor insight (lack of self-awareness), but to the individual controlling the impression they give about their situation to others.

1.3 Studies carried out

This research was devised to look at how individuals cope with life after a traumatic brain injury; specifically, what motivates the individual to conceal or disclose issues associated with their brain injury. It also aimed to see if this behaviour could be classified as impression management, and if so to assess the extent to which a broader representative group endorsed these strategies. The possible use of impression management is assessed in Chapter 6.

This research is composed of three studies each building upon the work of the previous one, and contributing to our investigation into how brain injury is managed by those most closely affected, that is persons with a traumatic brain injury (TBI) and their family carers. Is the best strategy disclosing this to others, or not? How does that decision relate to psychological and rehabilitation outcomes?

The goal of this research is to understand more about disclosure and concealment after brain injury and how this affects self-esteem, social support, loneliness, avoidance, participation in social activities and life satisfaction. These factors have an impact upon successful rehabilitation and social reintegration (Curran & Ponsford, 2000; Ponsford, Sloan, & Snow, 1995; Wilson, 2002).

Information collected in these studies will help shed further light on the processes involved in successful and unsuccessful cognitive rehabilitation, functional adaptation and social reintegration after TBI. The use of concealment and disclosure are seen as opposite ends of a continuum reflecting an individual's emotional willingness or ability to think about the difficulties their head injury has caused them and the impact this has made upon their life. According to O'Callaghan, Powell and Oyebode (2006), it has yet to be studied how much individuals share or obscure their experience of TBI with others.

1.4 Overview of Thesis Structure

1.4.1 Chapter 2

In Chapter Two a review of the literature is presented after the search strategy has been explained. The review includes literature from studies in the areas of concealment, disclosure, stigma, and stress, and impression management. The literature relating to our hypotheses, specifically social support, loneliness, self-esteem, avoidance, participation and life satisfaction is given in Chapter 5.

1.4.2 Chapter 3

This chapter covers our first qualitative study and consists of 4 sections. The introduction gives an overview of the issues of concern. Eighteen people (10 people with a TBI and 8 family carers) were interviewed with the aim of exploring their motivation for disclosing or concealing information about the TBI. Section three covers the analysis of these semi-structured interviews using Thematic Analysis. This revealed six main themes linked to the concealment and disclosure of issues related to brain injury. We were also able to identify some of the reasons behind the use of these strategies. In Section Four, there is a brief discussion of these findings and where appropriate, their possible implications are discussed.

1.4.3 Chapter 4

Chapter four is in four sections. The aim of the study was to develop and evaluate a questionnaire that covered the themes identified in the first study, discussed in Chapter 3. In Section Two – Methodology, the processes involved in the development of the Non-Disclosure Questionnaire (N-DQ) and Self-Disclosure Questionnaire (S-DQ) and their structure, completion and scoring, are fully described. Procedures for data collection and the specific methods for the evaluation and validation of the questionnaires (and reasons for this choice) are given. In Section Three, the results of the evaluation and analysis are provided. Validity and reliability, including test re-test reliability, are assessed. In Section Four, the results are briefly discussed.

1.4.4 Chapter 5

In Chapter 5, the literature relating to social avoidance, loneliness and social support are discussed and the hypotheses are stated in relation to each of these areas. A number of hypotheses were derived about factors that might influence decisions about disclosure (specifically, self-esteem); about the possible social consequences of these decisions (specifically, social avoidance, loneliness and accessing social support); and about the broader consequences of these social consequences in terms of community participation and life satisfaction.

1.4.5 Chapter 6

Chapter 6 covers the testing of the hypotheses, explained in Chapter 5. In Section Two – Methodology, the demographic details of participants are provided in Tables 6-1 to 6-3. Changes in the inclusion criteria are explained; otherwise the procedures followed are the same as those given in Chapter 4. The processes involved in data evaluation are also stated.

In Section Three – the results of our hypothesis testing are given. In Section Four these results are discussed in relation to the literature: this is covered further in Chapter 7.

1.4.6 Chapter 7

The introduction covers a brief overview of the earlier Chapters. In Section Two there is a discussion of the results from the three studies; these are summarized in Table 7-1 and 7-2. In Section Three, validity and reliability, limitations and strengths of the study are considered. Suggestions are made for future research and implications are discussed.

CHAPTER 2

LITERATURE REVIEW PART I

SECTION ONE

2.1 Introduction

This literature review provides the setting for three studies forming the thesis which is based upon three research questions and seven hypotheses (discussed in Chapters 5 and 6). It is essential to find existing work addressing the main areas of concern, or to ascertain the extent to which the issues raised within our research questions and hypotheses have been studied. We focus on the concealment and disclosure of issues around the effects of brain injury as potential impression management strategies. One possible reason for differences in the use of concealment and disclosure may be the individual's level of self-esteem. Concerns about disclosure and unwillingness to seek support are hypothesized to lead to social avoidance and loneliness (social consequences). And the broader consequences of the use of concealment and disclosure may affect the individual's level of community integration and life satisfaction. It is important to consider these areas as the information given to or withheld from others about one's relationship with brain injury may affect their behaviour and could impact upon their quality of life.

In this Chapter, the search strategy is explained and tables of these searches relating to seven key areas (concealment, disclosure, impression management, self-esteem, social avoidance, loneliness and social support) are given. Stress and coping, concealment, disclosure, stigma and impression management are then discussed. Over three and a half years, more than 700 studies were identified that relate in some way to our research. Tables

2-1 and 2-2 show that the decision to conceal or disclose information about one's brain injury has received inadequate attention from researchers. Tables 2-5 and 2-6 relate to the core areas of our study; showing where there are gaps in the available literature. Work from brain injury and non-brain injury studies was combined; collectively covering the seven core areas putting our research questions and hypotheses into context. The number of articles accessed for each of these areas is given. Two main questions were asked in relation to these studies: '*How does the study provide support to, or refute arguments in, our study?*', '*What have they done and how*?' Closely related papers are discussed in greater detail than more peripheral papers. Issues relating more closely to the hypotheses (self-esteem, social avoidance, loneliness and social support will be discussed later Chapter in 5.

SECTION TWO

2.2 Methodology

This is a conceptual literature review which attempts to provide a summary account of relevant research.

2.2.1 Inclusion/Exclusion Criteria

Published papers were initially selected for more detailed reading if they fulfilled the following criterion: they were studies on brain injury, they included two or more of the core areas; 'concealment' (withholding of information), 'disclosure', 'impression management' (controlled 'self-presentation' to others), 'stigmatization' or 'stigma' and associated areas 'denial', 'avoidance', 'self-esteem' and 'social support'.

By truncating some of these key words using ‘*’ or ‘$’ it was possible to capture wider use of the terms, so for example inju* captured injury and injured in a text. The addition of ‘OR’ with ‘AND’ also helped to widen the search. For example:

1. Brain; injur*; trauma; stroke
2. Carer OR care AND giver

Review papers from non-brain injury areas that addressed one or more of the key concepts were also obtained. Literature relating to only one of our search criteria was obtained on subsequent searches, when a better understanding of the range of the material available was developed. We did not include unpublished dissertations or manuscripts, papers not in English and articles where only the abstract was available. No specific restriction was placed upon the age of the participants in the studies. The initial search strategy was set for the years 2000 to 2007; this was extended to all dates available on each database (Table 2-4) in an effort to seek out other work related to brain injury. The literature selected for this study subsequently ranged from 1942 (the earliest empirical paper accessed, but not the earliest influence) to 2011. References for each paper were also searched for other potential papers.

2.2.2 Search Strategy

The initial search of the literature from 2007 is reproduced as Table 2-1:

Table 2-1: Literature search strategy for November 2007

Search strategy 1 - in title, abstract, full text and caption text							
No	Key Word	or	Found	combine	Manual Search	Abstract read	Kept
1	Disclosure		51293	1 to 6	0		
2	Stigma		13029	2 and 4	80	10	1
3	Concealment		3882	1 and 4	240	12	10
4	Traumatic brain injury	TBI	8858	4 and 5	14	14	8
5	Self-identity		1688	3 and 4	31	16	2
6	Revealed		145828	4 and 6	804	11	1

Database: Journals@Ovid Full Text: November 19th, 2007

A recent search to update Table 2-1 for this review showed that the number of articles referring to ‘stigma’ and ‘concealment’ had almost doubled and the overall increase in published studies in the areas of TBI had increased five fold in four years (Table 2-2). Tables 2-3 and 2-5 below, show that despite this increased availability of research there was still limited evidence of the application of ‘impression management’ and issues relating to ‘concealment’ in TBI research, certainly within articles available in the data bases for Health and Biomedical Sciences (H & BS) and Life and Environmental Sciences (L & ES), which includes the Web of Science (Table 2-4).

Table 2-2: Literature search strategy for April 2011

Search strategy 2 - in title, abstract, full text and caption text							
No	Key Word	or	Found	combined	Manual or electronic Search	Abstract read	Kept
1	Disclosure		46965	1 to 6	0		
2	Stigma		24675	2 and 4	91	29	0
3	Concealment		6684	1 and 4	96	29	4
4	Traumatic brain injury	TBI	44737	4 and 5	330	27	1
5	Self-identity		91348	3 and 4	36	30	1
6	Revealed		2029549	4 and 6	3646	30	0
				1, 3 and 4	6	6	1

Search: 20th April 2011 (Database as Table 2-4)

Table 2-3: Additional literature searches carried out – April 2011

Search strategy 3 - in title, abstract, full text and caption text							
No	Key Word	Specific Site	Found	combined	Manual or electronic Search	Abstract read	Kept
1	Traumatic brain injury						
2	Self-esteem	H & BS	82536	1 and 2	155		
		L & ES	26880	1 and 2	1		
		SSE	50483	1 and 2	51	51	6
				1, 2 and 3		2	0
		H & SB		1, 2 and 4	34		1
		L & ES		1, 2 and 4	0		
		SSE		1, 2 and 4	22	19	4
3	Impression management	H & BS	8080		211	38	4
		L & ES	3617		264	264	
		SSE	6638		200	200	1
		H & BS	37	1 and 3	37		1
		L & ES	0				
		SSE	5	1 and 3	5		1
		H & BS		1, 2, 3 and 4	28	25	4
		L & ES		1, 2, 3 and 4	0		
		SSE		1, 2, 3 and 4	22	19	4
4	Social Support	H & BS	379681	1 and 4	685		
		L & ES	131459	1 and 4	4		
		SSE	361349	1 and 4	685	96	4
		H & BS		1, 2 and 4	34	34	1
		L & ES		1, 2 and 4	0		
		SSE		1, 2 and 4	22	19	4

Databases 21st April 2011: Health and Biomedical Sciences = H & BS
Life and Environmental Sciences = L & ES
Social Sciences and Education = SSE

A full list of the data bases searched is given in Table 2-4.

Table 2-4: Data bases searched for literature for this study

Data Bases Searched for figures given in tables 2-1, 2-2 and 2-3	
H	Health and Biomedical Sciences
L	Life and Environmental Sciences
S	Social Sciences and Education
-	ABI/INFORM Global - ProQuest (new interface)
S	ASSIA (CSA)
L	Biological Sciences - ProQuest (new interface)
L	BIOSIS Previews (ISI)
S	Business Source Premier (EBSCO)
L	CAB Abstracts (Ovid)
H	CINAHL (EBSCO)
H	Cochrane Library (Wiley)
H S	ebrary
L	Ecology Abstracts (CSA)
S	EconLit (EBSCO)
H	EMBASE: Excerpta Medica (Ovid)
L	Environmental Sciences and Pollution Management (CSA)
-	ERIC
L	GEOBASE
-	Google Scholar
L	Intute
H S	MEDLINE (Ovid)
S	Periodicals Index Online (Proquest)
H	PsycINFO (Ovid)
-	Psyclit – e-journals
S	Social Services Abstracts (CSA
S	Sociological Abstracts (CSA)
H	Sport Discus (Abstracts)
H	Toxicology Abstracts (CSA)
-	University of Birmingham Library Catalogue
H L S	Web of Science (ISI)

To show how these issues relate to our research, Table 2-5 shows the brain injury literature accessed in the main areas and Table 2-6 the non-TBI/ABI research. Researchers have tended to concentrate upon issues relating to self-esteem, support, denial and avoidance. In addition to these sources, when we asked authors for permission to use their questionnaires, two authors sent us electronic copies of their original papers, one in relation to rehabilitation and the other concealment; these papers were not readily available.

Table 2-5: Literature relating to the main areas of concern in this research: gaps show where there are areas needing further study in relation to TBI.

Examples of TBI research papers and articles										
Number of articles / papers obtained for this thesis that relate to this category				6	11	3	14	18	41	D =32 A=26
First author	Year	Type of study	Number of participants with TBI	Concealment	Disclosure	Impression Management	Stigma	Self Esteem	Support	Denial (D) Avoidance (A)
Crisp	1993	Qualitative - interviews	10	3			2	2	4	A1
Karlovits	1999	Qualitative - interviews	11	1	6		2		5	A23
Kendall	2009	Longitudinal study - questionnaires	90					35	28	D1 A1
Leathem	1998	Self completed questionnaires	53		2			1		
Livneh	2005	Review - adaptation to disability	-				7	3	3	D7 A1
Man	2002	Qualitative - interviews	50				1		3	D1
Man	2003	Interviews and questionnaires	120				1	5	3	A1
Nochi	1997	Qualitative - interviews	4					8		D2 A2
O'Callaghan	2006	Qualitative - interviews	10				1			D34 A4
Olney	2003	Qualitative interviews on disability	25	3	4		7			D3 A3
Shorland	2010	Qualitative – grounded theory	2		4				5	
Shotton	2007	Qualitative - interviews	9					1	2	D1 A5
Simpson	2000	Qualitative - interviews	39	1	2		16			A3
Tomberg	2007	Longitudinal study – interviews and questionnaires	31						40	D1 A17
Velikonja	2009	Quantitative – from medical records	432			22				
Yeates	2007	Qualitative - interviews	3	1					2	D5

Figures relate to the number of times the word was mentioned in the ABI/TBI document excluding page headings and references

Table 2-6: Non-TBI/ABI Literature relating to the main areas of concern in this research

Examples of other research papers and articles										
Number of articles / papers obtained for this thesis that relate to this category				11	50	35	44	17	83	D=45 A=82
First author	Year	Type of study	Number of participants	Concealment	Disclosure	Impression Management	Stigma	Self Esteem	Support	Denial (D) Avoidance (A)
Afifi	2010	Questionnaire study family secrets	520	63	19		1	5	3	A8
Akintola	2008	Ethnographic: in depth interviews	20	2	6		17		19	D5
Baumeister	1982	Review – self presentation Impression management research	-	1		15		9	22	D5 A2
Bouman	2003	Social experiments	32 and 56	46	5					A16
Chaudoir	2010	Theoretical model building: review	-	82	631		90	4	80	A76
Endler	2002	Social experiments	371, 356 and 79	17	169	9		1	9	A4
Garssen	2007	Review	-	19	1	11		3		D21 A20
Kahn	2001	Questionnaire Development	557, 331 and 90	97	189			13	21	
Kahn	2002	Questionnaire study	69	45	47			1		D15 A1
Kawamura	2004	Questionnaire study	116	63	21			1	2	A3
Kelly	1996	Review of the literature	-	26	27	3	2	2	5	D1 A9
Leary	1990	Review	-		2	86		19		D1 A4
Leary	1992	Review	-	1		2		3		D2 A7
Pachankis	2007	Review	-	240	81	10	401	18	4	D1 A30
Petronio	2000	Review: family relationships	-	2	15				1	
Ritz	1996	Questionnaire study	224	11	2			2		A4

Figures relate to the number of times the word was mentioned in the non-ABI/TBI document excluding page headings and references

SECTION THREE

2.3 Theoretical Influences

Authors of many of the papers reviewed, particularly those relating to brain injury, have been influenced by the work and theoretical framework of Lazarus and Folkman (Figure 2-1). The stress-appraisal-coping model looks at coping with stress; key concepts from this model are explained in Table 2-7. A later revision of this model by Folkman (1997) is reproduced as Figure 2-2. The third model discussed is relatively new and looks at disclosure (Chaudoir & Fisher, 2010) which is central to our research and is reproduced as Figure 2-3. Existing research has been retrospectively fitted to the concepts relating to this model in Table 2-8.

2.3.1 Stress and coping

The original stress-coping-appraisal model considered the concepts of appraisal, coping behaviour, coping style, external resources, internal resources, physical consequences, social consequences and psychological consequences; these are briefly explained in Table 2-7. The basic model was revised further in 1997 by Folkman; she built upon her earlier work with Lazarus. Working on a longitudinal study of carers for individuals who had AIDS, she added positive psychological states to the previously studied negative ones, revising the literature on the coping process.

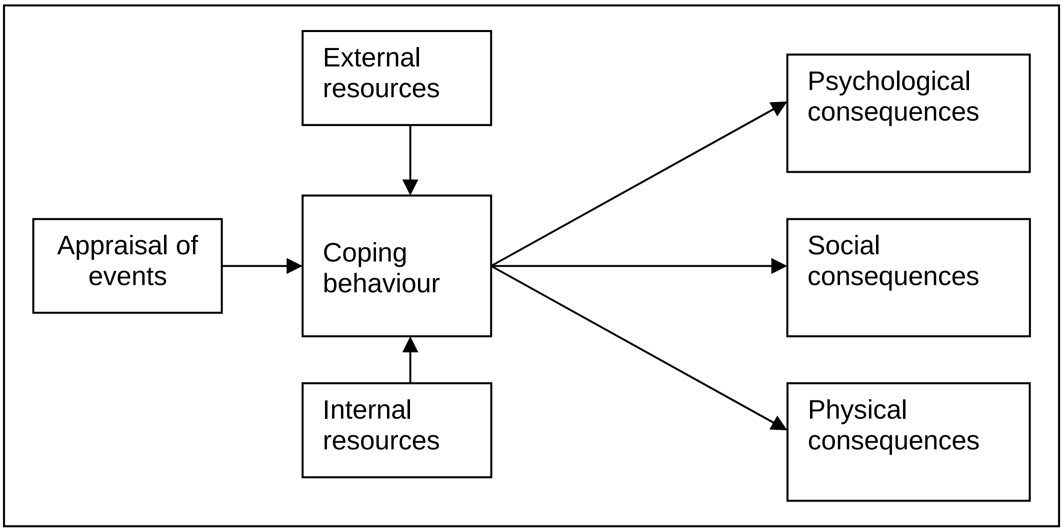
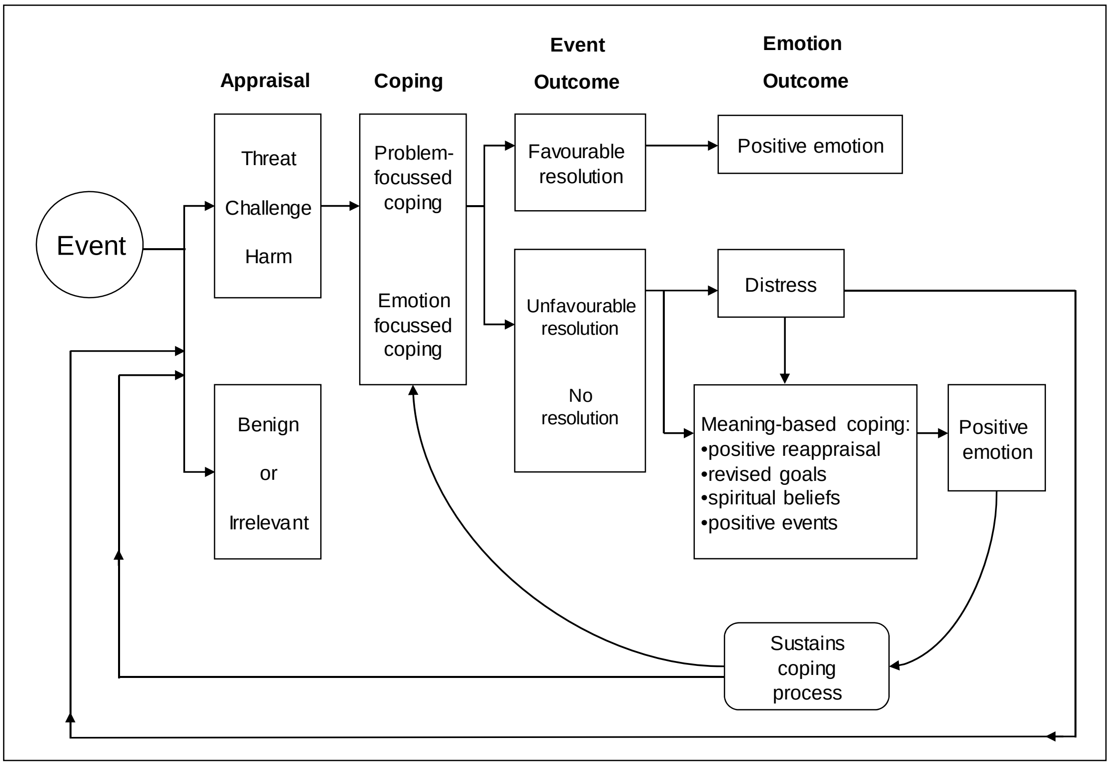


Figure 2-1: Stress-Appraisal, and Coping Model (Lazarus & Folkman, 1984)



Modified theoretical model of the coping process: Folkman (1997)

Figure 2-2: Coping Process Model, Folkman (1997)

Table 2-7: Coping concepts – for the Folkman and Lazarus Model

Concept	Covers	Example Authors (year)
Appraisal of events (See Fig. 2-1)	**Primary** – Evaluative judgement about the demands of the situation or event, psychological threat to self. **Secondary** – Appraisal of whether coping resources are adequate to deal with the threat	Benn & McColl (2004) Chronister & Chan (2006) Folkman *et al.*(1986) Godfrey *et al.* (1996) Knight *et al.* (1998) Ownsworth *et al.* (2006) Riley *et al.* (2004) Sander *et al.* (1997) Serio *et al.* (1995) Shotton *et al.* (2007) Strom& Kosciulek (2007)
Coping behaviour	Relationships linked to coping behaviour. Protective mechanism. Studies link internal and external resources to coping behaviour.	Pearlin & Schooler (1978) Serio *et al.* (1995) Shotton *et al* (2007) Watts& Perlesz (1999)
Coping Style Deemed to be maladaptive if they lead to poor health outcomes (physical and mental)	Coping style is a mixture of strategies – **Emotion-focussed:** regulate emotions └── **Avoidant** – **Problem-focussed:** deal with the problem └── **Adaptive** – (approach)	Benn & McColl (2004) Carver *et al.* (1989) Chronister& Chan (2006) Folkman & Lazarus (1980) Godfrey *et al* (1996) Lazarus (1993) Riley *et al.* (2004) Sander *et al.* (1997) Serio *et al.* (1995)
External resources	Information seeking - facilitates coping behaviour. Poverty affects coping behaviour, reduces availability and access to external resources. Social support – usually leads to better emotional adjustment.	Benn & McColl (2004) Godfrey *et al.* (1996) Minnes *et al.* (2000) Sander *et al* (2003) Serio *et al.* (1995) Wade *et al.* (2001) Watts & Perlesz (1999)
Internal resources	Cognitive/psychological aspects of coping.	Nadell (1991) Riley *et al.* (2004) Shotton *et al.* (2007)
Physical consequences	Outcome of behavioural aspects of coping.	Blais & Boisvert (2007) Knight *et al.* (1998) Minnes *et al.* (2000) Nadell (1991) Serio *et al.* (1995)
Social consequences	Outcome of behavioural and psychological processes; links with internal and external resources. Social support has been positively and negatively linked to coping behaviour.	Chronister & Chan (2006) Godfrey *et al.* (1996) Minnes *et al.* (2000) Nadell (1991) Ownsworth *et al* (2006) Riley *et al.* (2004) Sander *et al.* (1997) Schwarzer & Knoll (2007) Strom& Kosciulek (2007) Verhaeghe, Defloor, & Grypdonck (2005)
Psychological consequences	Outcome of cognitive/psychological process.	Blais& Boisvert (2007) Folkman *et al.* (1986) Minnes *et al.* (2000) Nadell (1991) Riley *et al.* (2004) Sander *et al* (2003) Serio *et al.* (1995) Shotton *et al.* (2007) Strom & Kosciulek (2007) Wade *et al.* (2001)

Source: compiled from extant Literature

2.3.2 Disclosure Process Model

The Disclosure Model by Chaudoir and Fisher (2010) shows how the concepts involved in the disclosure of information are related.

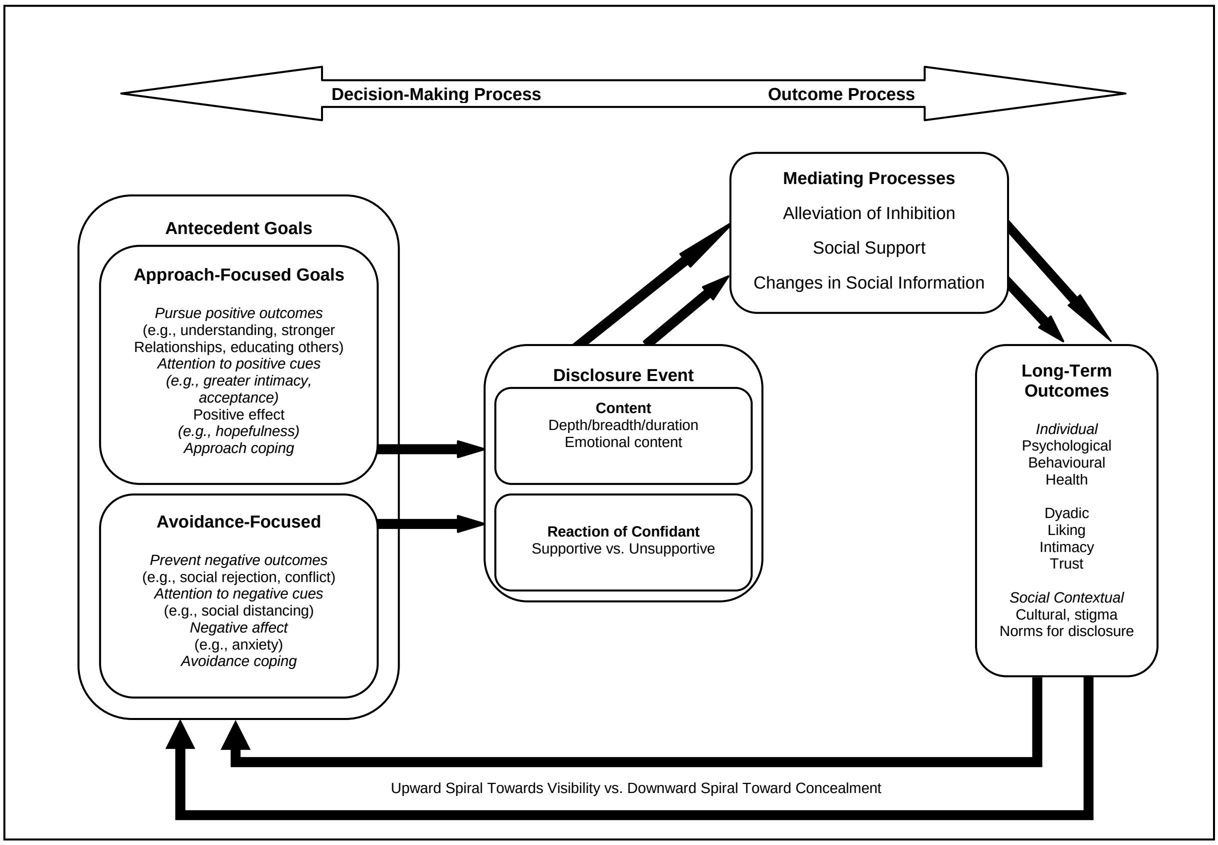


Figure 2-3: Disclosure process model – Chaudoir and Fisher (2010)

Table 2-8: Disclosure Process Model by Chaudoir and Fisher (2010)

When and why disclosure may be of benefit		
Concept	Covers	Retrospective Example Authors (year)
Antecedent Goals Moderate disclosure (See Fig. 2-3)	Approach-focussed goals Pursue positive outcomes Avoidance-focussed goals Prevent negative outcomes	Afifi and Steuber (2010) Burgener & Berger (2008) Carver, *et al.* (1989) Kittikorn, Street, & Blackford (2006) Livneh & Antonak (2005) Major & O'Brien (2005) Pachankis (2007)
Mediating Process	Internal or external resources **Alleviation of Inhibition** Benefits from disclosure – getting things off one's chest. Opportunity to express/externalize thoughts and emotions External resources: **Social Support** **Social Information**	Corrigan & Watson (2002) Francis & Penn (2001) Helgeson (2003) Kittikorn, Street, & Blackford (2006) Mak *et al.* (2007) Pyne *et al* (2004) Schwarzer & Knoll (2007) Turner, Catania, & Gagnon (1994)
Disclosure Event Reaffirm or re-build self-image and self-esteem	**Content** – what and how it was said **Reaction of Confidant** – negative, positive or neutral reaction **Feedback Loop**	Cozby (1973) Darley & Fazio (1980) Dindia & Allen (1992) Grytten & Måseide (2006) Helgeson (2003) Jourard & Lasakow (1957) Kelly & McKillop (1996) Major & O'Brien (2005) Olney & Brockelman (2003) Olney & Kim (2001) Pinel (2001)
Long-Term Outcomes Effects of disclosure moderated by antecedent goals	**Individual** Psychological Behavioural Somatic/Health **Dyadic** Liking Intimacy Trust **Social/Contextual** Cultural Stigmatization - disclosure Norms of reference	Afifi and Steuber (2010) Corrigan, (2000) Corrigan *et al.* (2000) Corrigan, Markowitz, Watson, Rowan, & Kubiak(2003) Corrigan & Watson (2002) Crocker & Major (1989) Garcıa-Lopez, Olivares, Hidalgo, Beidel, & Turner (2001) Greenberg, Wortman, & Stone (1996) Helgeson (2003) Jourard & Lasakow (1957) Major & O'Brien (2005) Pachankis (2007)

Source: compiled from extant Literature

2.3.3 How the concepts relate to the coping and disclosure models

The basic stress-appraisal-coping model (Figure 2-1) put forward by Lazarus and Folkman (1984) is explained in Table 2-7, because some of these subordinate concepts are used throughout this review. Revised versions have been used in many fields of research

(Aldwin & Revenson, 1987; Ising, 2006; Strom & Kosciulek, 2007). Essentially, coping strategies fall into two major categories, either emotion-focussed or problem-focussed coping, and within which there are a number of subordinate strategies. These are artificial distinctions as many strategies may fit both functions (Verhaeghe, et al., 2005): problem-focussed strategies are used to deal with a problem; and emotion-focussed strategies are applied to ease the emotional burden behind the problem but do not actually deal with the issue directly. Emotion-focussed and avoidance strategies are often used when the situation is recognised as too challenging to fight. There is a distinction between positive emotion-focussed strategies (e.g. a cognitive re-appraisal of a situation that makes it seem less threatening) and avoidant strategies (escaping or avoiding the threat by behavioural and/or cognitive means – so one doesn't have to face it either physically or mentally). Use of strategies such as denial and avoidance are mostly viewed negatively in the literature; they are referred to as maladaptive because problems may intensify if they are ignored (Wade, et al., 2001); their longer-term use has been linked to poorer outcomes and reduced well-being (Shotton, et al., 2007), such as depression and anxiety (Curran & Ponsford, 2000).

Following the appraisal of a situation, subsequent coping behaviour (Figure 2-1) is influenced by the availability of external and internal resources. Coping behaviour influences the psychological, social and physical consequences for the individual.

Mixtures of strategies are applied in difficult situations, reflecting the individuals coping style. Strategies are often considered in combination with an external resource, for example 'social support', as such help is thought to buffer (moderate) the effects of difficult situations (Hopwood & Treloar, 2008). Buffering protects the individual from stressful events, which is why social support is said to have a beneficial effect on well-being (Cohen & Wills, 1985).

Adaptive strategies include the search for meaning or understanding (i.e. an emotion-focussed but non-avoidant strategy), and gaining a sense of mastery or control over daily life which in turn will have an effect upon self-esteem (Duhachek & Iacobucci, 2005). Adaptive (positive) coping behaviour is linked to social support and can impact upon the health of the individual (House, Umberson, & Landis, 1988): cognitive appraisal links potential social stressors to health outcomes (Sutherland & Cooper, 2000) and social relationships and support moderate these appraisals, affecting coping behaviour (for example another person encourages or discourages the individual), and hence coping behaviour links to social consequences.

In the second model (Figure 2-2), primary appraisal of an event falls into three categories. Firstly, where the issue may be minor with no implications for well-being and little effort is required to resolve it (benign). Secondly where appraisal is associated with a positive outcome, well-being is protected or enhanced (irrelevant). Thirdly, anxiety may arise with the thought that there may be a cost (‘harm/loss’, ‘threat’ and ‘challenge’) to pay for some benefit. Harmful situations include circumstances that can lead to the potential damage of one’s self-esteem. Threat covers anticipated or potential harm, and is linked to negative emotions such as fear, anxiety and anger; where the individual may question their ability to cope. But challenge requires substantial effort, offering delayed benefits such as confidence and positive emotion (also seen as benefit or mastery which has health benefits). Individuals evaluate their options during secondary appraisal, the feedback loop accommodates the opportunity to re-evaluate one’s options, and the outcome will depend upon the choices made (Folkman, 1997).

Avoidance is escaping or avoiding a threat by behavioural means or avoiding thinking about it. Emotion-focussed strategies may include avoidant responses (dealing with the emotion by escape, not thinking about it etc); but more usually it refers to positive efforts to regulate one's emotions that don't involve avoidance (that is by cognitively re-appraising the situation so that it is perceived as less of a threat). Emotion-focussed coping in the latter sense is not seen as maladaptive. In some circumstances it may be an effective way of solving a problematic situation (for example, to prevent ridicule). In the context of the Chaudoir and Fisher model (Figure 2-3) the avoidance/approach split is somewhat different, they are referring to the pursuit of positive, or the avoidance of negative outcomes, and include the opportunity for feedback to alter subsequent behaviour. A problem-focussed strategy within the Lazarus and Folkman model could be an avoidance strategy within the Chaudoir and Fisher model – individuals can take problem-focussed action to avoid a negative outcome.

SECTION FOUR

2.4 Literature Review

2.4.1 Clarification

Denial and minimization are said to be used because of a lack of awareness or lack of insight (Fleming, Strong, & Ashton, 1996). Use of these strategies may be due to reduced self-awareness and the loss of, or restricted ability to recognise or acknowledge personal problems and disabilities. Depending upon the cause, this is referred to as anosognosia or neurogenic (organic) unawareness, which is lack of awareness due to cognitive deficits. Psychogenic unawareness (psychological lack of awareness) or denial relate to the emotionally-related mechanisms of denial, suppression and repression (Fleming, et al., 1996; O'Callaghan, et al., 2006; Prigatano, 1992). Suppression and repression are difficult to distinguish from denial, they relate to issues of which the individual is unaware or only partially aware and they deliberately avoid thinking about. Denial can mean denial to others or denial to oneself and refers to a psychogenic process only. Failure to understand, or underestimating the difficulties that have occurred since the brain injury, are problems frequently associated with moderate and severe trauma (O'Callaghan, 2004; O'Callaghan, et al., 2006). This thesis is about the deliberate concealment of information of which the person is aware – not about lack of insight and understanding, and not about repression or suppression. These issues are outside the scope of this study. Impression management relates to information that the person is aware of, but chooses not to disclose.

In this study, denial is considered as a coping strategy, which may be knowingly used, and so may not always be an unconscious defence mechanism. Use of elusion or avoidance is not seen here as a dichotomy, but as a continuum, reflecting an individual's willingness (or ability) to think about the difficulties TBI has caused them and the impact this has made upon their life (Walker & Winter, 2007).

2.4.2 Concealment

Concealment can be seen as a strategy for helping to project a specific self-image (Rusbult & Van Lange, 2003), where individuals suppress aspects about themselves which they feel could otherwise result in discrimination, stigma or other negative reactions from others (Argyle, 1967; Chaudoir & Fisher, 2010). Concealment can also be used by individuals after a brain injury to cover up the loss of their self-identity (Karlovits & McColl, 1999). However, research from social psychology has shown that failure or lack of opportunity to discuss worries or concerns with others can increase stress levels, especially if the individual actively hides information (Kelly & McKillop, 1996; Pachankis, 2007). Social psychologists have also linked the longer term use of concealment to depression and reduced well-being (Matheson & Cole, 2004).

The decision to conceal information about one's brain injury or being a carer for a family member or friend with a TBI has received little direct attention, apart from Simpson, Mohr and Redman's (2000) Australian based multicultural study. They investigated most of the core issues of our study, concealment, disclosure, stigma, support, avoidance and loneliness, focussing upon stigmatization, using semi-structured interviews. Participants with a TBI and family representatives (N=39 with 6 participants and 6 carers from each group, sometimes more than one) were from three cultural backgrounds, Italian, Lebanese and Vietnamese, with different religions and mixed ages. Bespoke interview schedules were prepared for family members. Two focus groups were held to ensure the interview schedules were suitable, one was held with health professionals and the other with health interpreters (translators who work with patients and doctors when translation is required). The interpreters carried out the interviews and submitted reports on them. They looked at each family's circumstances and history; their understanding of symptoms in relation to the brain injury; culturally related differences in coping with disability; the differing roles of family members in relation to cultural norms; personal and family goals; and understanding of the treatment and rehabilitation goals of the health care providers. They asked about service providers, communication barriers, and cultural issues. Reports were analysed using inductive thematic analysis.

Simpson et al. (2000) found that cultural reactions to disability, and the social stigma attached, led carers and those with brain injuries to conceal information from family, influential friends and health care professionals. Because Vietnamese families function as a unit, interviewees explained that brain injury linked to assault was viewed as shameful for the whole family. In these circumstances the individual affected would be seen as culpable for mixing with the wrong crowd. The consequence of this was that the individuals concerned withdrew socially to avoid friends and sometimes relatives who asked potentially revealing questions. Several interviewees said they had lied to their friends about the cause of their injury because of the shame attached to brain injury. For Lebanese and Italian families brain injury was found to lead to the breakdown of family life. This loss of relationship with one's family has also been discussed by Man, Tam, and Li, (2003) they found it led to unhappiness and a reduced quality of life, in Hong Kong Chinese families. Lebanese families in particular withheld information from each other to protect the family; an example was given relating to compensation payments which caused family strife and breakdown: retaining the money was seen to conflict with religious beliefs as it was expected to be shared with the extended family, when it was needed to pay for long-term care. Other interviewees explained they had withdrawn from their social networks to minimize their feelings of stigma and shame because TBI is linked to madness, especially in Arabic cultures. Despite strong cultural traditions of caring for family members, conflicts and distance led to the loss of or lack of social support networks. Personality and behavioural changes and the stigma attached to brain injury contributed to the loss of friends and social isolation. For many families, their cultural background meant they relied on each other rather than external social support, which was seen as intrusive. Man, Lam, and Bard (2003) also found that different cultural traditions needed to be accommodated in the provision of support for families.

Another study of importance to our research is that by Yeates, Henwood, Gracey and Evans, (2007). They investigated family disagreement and misunderstanding over the effects and impacts of brain injury, between carers and individuals with a brain injury. Poor awareness of these issues was associated with negative outcomes for the carer, such as social isolation, as Simpson et al. (2000) also found. Yeates et al. carried out semi-structured interviews with three family carers and three individuals who were 2 years post-injury; asking open ended questions. Purposive sampling techniques were used to recruit participants (Denzin & Lincoln, 1998, 2000). Their aim was to understand issues from the participants perspective. They identified the need for information and services, and found that families continually contrasted pre- and post-injury lives in an effort to build new identities (yet appeared to be still mourning the loss of their past selves – similar to complicated grief discussed by Chamberlain, 2006). Another theme related to family interactions and the need to educate others, was also found by Karlovits and McColl (1999). Yeates et al. explained that social influences (such as support, information and social interactions with others) mediated awareness directly and indirectly. And the burden of care and a lack of awareness were mediated (changed) by social support from others. Following a brain injury individuals and their families have to rebuild their personal and social identities within a social context, and a relationship with others helps to support these revised identities (Bowen, Yeates, & Palmer, 2010). However, in his cross-cultural study, Simpson et al. (2000) found that some families avoided other family members and friends as brain injury was seen as a stigma bringing shame to the whole family. Physical changes after a brain injury were seen as easier to identify and understand than hidden cognitive changes. Yeates et al. cited a study by Hutchinson, Leger-Krall, and Skodol Wilson (1997) who explained that family doctors, the person with dementia and the carer all controlled their level of disclosure, actively concealing information from each other, but this behaviour could well be described as impression management. They also found that family accounts of the disability were at times incompatible with professional accounts. This is explained as shared denial and is seen as influential in the sharing of information regarding disability within the family. In explaining events after a brain injury, understanding of the clinical information that is given may be understood and acknowledged differently by different family members and this may impact upon rehabilitation (Yeates, Gracey, & Collicutt McGrath, 2008). Some families kept difficulties secret or played down (minimized) the effects of the disability; this was also found in a quantitative study by Velikonja et al. (2009). This study was relevant to our work as it linked concealment to social support and denial, relating to our core concerns.

Picking up Yeates et al. theme of hidden cognitive changes, researchers looking at mental illness say that the distinction between an individual who has hidden disabilities (concealable) and one whose injuries are visible to another person needs to be taken into consideration (Corrigan & Watson, 2002). Social and health psychologists have found that individuals tend to react to overt (obvious) disabilities and distinctive features before they communicate directly to the individual, so hidden (concealed) disabilities provide a window of opportunity within which the person can project themselves as they were pre-injury, or as they wish to be seen (Livneh & Antonak, 2005; Olney & Brockelman, 2003; Olney & Kim, 2001; Yang, et al., 2007). This brings into play concerns about stigma and discrimination and may result in the individual with a brain injury dealing with these issues in somewhat different ways to those whose TBI injuries are not immediately obvious.

Living with an obvious disability restricts the degree to which difficulties can be hidden from others and affects the way that a person can present themselves in a social situation (Olney & Brockelman, 2003). Yang et al. (2007, p. 1532) cites denial of a disability as “assuming a protective cloak of competence”: in other words, a means of concealing the effects of one’s disability in an attempt to present oneself, as ‘undamaged’ (Nelsen, 2005). Health psychologists have found that living with a secret can lead to a preoccupation with it (Pachankis, 2007), even after disclosure (Wenzlaff & Wegner, 2000). Jambor & Elliott

(2005, p. 67) found the same when looking at self-esteem within the deaf community; covering up undesired attributes increased individuals stress because they "live with the fear of being disclosed". And, Kelly and McKillop (1996) found evidence that concealment can lead to increased shame and reduced self-worth because the individual feels guilty about their hidden identity: which is a similar finding to that of Simpson et al. The literature search revealed two studies that considered the issue of concealment after brain injury (Table 2-5). They both looked at concealment for reasons of avoiding shame and stigma. It is possible that there are other negative outcomes that the person wishes to avoid through concealment. So there is a need for further research that explores the reasons for concealment following a TBI. Raising the question for our first study:

Q_1: What motivates individuals (carer or person with a TBI) to conceal their situation?

2.4.3 Disclosure

Disclosure has been defined as the verbal or written expression of personal information, thoughts, emotions and experiences (Chaudoir & Fisher, 2010). The sharing of personal concerns with others has been called 'distress disclosure' (Kahn & Hessling, 2001) and in relation to health 'protective disclosure' (Burgener & Berger, 2008). There are potential advantages and disadvantages to disclosure. One advantage, found by social psychologists and psychophysiologists in the sharing of selected information was the reduction of stigma and discrimination through the education of others, and another was the recruitment of support from empathetic others who are trusted not to reject or stigmatize the person if they share sensitive information with them (Argyle, 1967; Taylor, et al., 2000; Tops, Van Peer, Korf, Wijers, & Tucker, 2007).

Social psychologists Chaudoir and Fisher (2010) looked at hidden disabilities and illness where disclosure could lead to stigmatization. They put forward the disclosure process model (DPM) - a protocol for supporting a decision to disclose information to others. Negative reactions are not the desired outcome with disclosure, but it is possible (and potentially beneficial) to prepare oneself for disclosure, because the way information is presented can affect the response. Disclosure is said to be mediated by openness, social support and information. Individuals who are motivated to achieve their goals are more likely to obtain positive feedback, which encourages further disclosure but changes the nature of the relationship: it can open avenues and help individuals to gain social support (Chaudoir & Fisher, 2010). In brain injury research Karlovits and McColl (1999) found participants disclosed to educate others about their brain injury, to make friends and deal with discrimination. Social psychologists say disclosure can have both positive and negative outcomes depending upon the way the information is received and the response (if any) is given (Chaudoir & Fisher, 2010). Speculating about the outcome of disclosure, if consciously considered, may prove to be more difficult for some individuals than others. Behavioural researchers see disclosure as cathartic, (Bouman, 2003), that is the opportunity to express buried emotions, thoughts or problems (Reber, 1985), while social psychologists see that this is not always the case (Kelly & McKillop, 1996).

From the perspective of brain injury research, Leathem et al. (1998) discussed the motivation to express oneself honestly but in doing so explained that participants in their study did not disclose due to concern about upsetting others. Similarly, Shorland and Douglas (2010) in their study explained that friends were distressed by the disclosure of a TBI, leading to feelings of shame for the discloser. Social and health psychologists have found that disclosure, which involves trust on behalf of the person disclosing, may place the individual in a difficult situation, if what they reveal puts them at risk from negative stereotyping arising from discrimination, stigma, rejection and exploitation (Argyle, 1967; Major & O'Brien, 2005; Rusbult & Van Lange, 2003) and increased fear (Kahn & Hessling, 2001). In addition health researchers have shown that fear of discrimination following disclosure in carers, can lead to isolation and loss of social support, which increases stress and affects well-being (Akintola, 2008). When studying mental illness, health psychologists Francis and Penn (2001, p. 827) said that "one would expect that in a potentially stigmatizing situation, individuals would not self-disclose or would be less inclined to do so", a view later supported by Major and O'Brien (2005). The need for disclosure to be controlled and to the right people is related to impression management. For example, researchers from health and social psychology looking at the reasons behind disclosure found that individuals who believed the person they were talking to disliked them disclosed less, they disclosed more if they thought the person liked them (Pinel, 2001). Motivation to impression manage increases in these circumstances because of expected benefits, and rejection is felt more strongly (Leary & Kowalski, 1990).

In their article Chaudoir and Fisher (2010) looked at the potential disadvantages of disclosure for those who have hidden disabilities and illness where disclosure could lead to stigmatization, and regret (Kelly & McKillop, 1996). In support of this, social psychologists have shown that some individuals especially those with hidden disabilities, are sensitive to the negative and stigmatizing cues around them, because of this increased sensitivity their health may be affected (Pachankis, 2007). Whereas individuals who tend to disclose, may be more receptive to positive cues (Leary & Kowalski, 1990) and gain more from their interactions, with better outcomes and positive effects on their well-being (Chaudoir & Fisher, 2010).

Chaudoir and Fisher (2010) called for a better understanding of how disclosure impacts upon well-being. Together these studies led to the question:

Q_2: What motivates individuals (carer or person with TBI) to disclose their situation?

2.4.4 Stigma and Outcome

Weiner, Perry and Magnusson (1988) explained the origin of the term 'stigma' and its relationship to being marked out as deviant (slaves were branded when escaping their Greek captors), and were seen as different from the majority or in possession of an undesirable quality. According to Manzo (2004) stigma is a poorly defined and overused concept. It relates to conditions that need to be managed, especially if they are unknown by others or hidden, and where exposure would be seen as negative or detrimental to the individual concerned. Manzo says that brain injuries, specifically stroke, are not stigmatizing and that any view that they are should come from those affected and not be imposed by others. Attention should be paid to the way individuals manage their conditions; they are not victims. Some researchers would agree with these comments (Crisp, 1993), others found that stigma was a very real threat to individuals after TBI (Simpson, et al., 2000). Being defined by disability is seen by many as stigmatizing and can lead to concealment.

Mental health researchers found that stigma can lead to physiological responses that can impact upon one's subsequent behaviour and judgement (Major et al., 2005). It is not always necessary for an individual to be aware of the effects others have upon them for their behaviour to be altered. Language, gestures, meanings, feelings and cultural images, are all ways that stigma can be conveyed from social values to one's inner emotions (Gauntlett, 2002; Lysaker, Tsai, Yanos, & Roe, 2008; Major & O'Brien, 2005; Nochi, 2000; Yang, et al., 2007). Business researchers looking at impression management identified very similar issues to those arising within brain injury research, specifically Nelsen (2005). That the public presentation of oneself may be damaged if others react to distinctive features (overt disabilities) before they communicate directly to the individual: As stigmatization occurs when others take note of an individual's condition, which they see as threatening, unpleasant or culpable (Nelsen, 2005 ; Simpson, et al., 2000). Brain injury, mental health, and counselling researchers have found that the quality of relationships with others can affect how an individual copes with their disability (Blais & Boisvert, 2007; Godfrey, et al., 1996; Judd & Wilson, 1999; Robson, 1988; Sander, et al., 2003). Because over time stressful negative evaluations may have an impact upon self-esteem and lead to social isolation and withdrawal from community activities and rehabilitation (Livneh & Antonak, 2005).

Crisp (1993, 1994) carried out a series of in-depth interviews with ten individuals recovering from a brain injury. To analyse his data Crisp used thematic analysis. His rationale for the study was that the process of recovery was usually presented from a medical perspective, where psychometric testing and assessments were supplemented by the views of others; and commented further that these did not meet the social and everyday needs of the individuals affected anyway. Crisp wanted the interviewee's point of view (Engberg & Teasdale, 2004). He found that the extant literature did not reflect the personal perspective, or the process of change individuals go through after a brain injury. He reported how these individuals who shared sheltered accommodation (and with whom he worked for twelve months) were aware of, but did not talk about unwanted social comment about their disabilities. Themes emerging from the data collected by Crisp related to well-being, and feelings of discrimination, isolation and concealment of disabilities. He mentions the different views held by those whose disabilities are visible, and those whose disabilities are hidden and comments that social rejection by others was not seen to decrease self-esteem or self-worth in the longer term. He found that memberships of groups frequented by those without disabilities were preferred; and further that disability related issues were not shared with family members or friends. The reason suggested for this was a response to their relatives desire not to hear difficulties and to be positive: the adoption of concealment was therefore a necessary strategy. Crisp (1993) expressed the group's desire for personal companionship and for a wider network of friends, which was not achieved. The participants in Crisp's study were said to be living together in sheltered accommodation. So how representative were they of the wider population with ABI? Would we expect that because they did not disclose to their family members, that this would also be the case for others with ABI who live with their families? And why did these individuals appear to put less value on socializing, outside of their home, with others with disabilities? Crisp's study is relevant to our work as he linked concealment, stigma, self-esteem, avoidance and social support, all issues of concern in our study.

2.4.5 Impression Management

In this study the use of concealment and disclosure will be investigated as tools of impression management. But what is impression management? Impression management is an example of modifying and controlling behaviour to create a specific image (Garssen, 2007; Leary & Kowalski, 1990; Peebles & Moore, 1998) and a favourable impression (Barrick & Mount, 1996). Impression management involves all of these aspects and above all requires control of the information given to other people (Garssen, 2007; Shotton, et al., 2007). Individuals need to have some level of insight into their own behaviour to adjust the way they present themselves to others, and the degree to which they can alter their self-identity will depend upon observable disabilities and their behaviour (Francis & Penn, 2001; Livneh & Antonak, 2005; McNamara, Durso, & Brown, 2003; Nochi, 2000; Paterson & Scott-Findlay, 2002). According to Garssen (2007) an extreme form of impression management would be for an individual to project a positive image to others, while being aware of their own negative thoughts and feelings.

Traumatic brain injury affects all aspects of personal and social life and may damage the socially desired image an individual wishes to present to others; because of this some individuals and their carers may feel the need to re-create their identity and revise their coping strategies (Judd & Wilson, 1999). But this isn't to say they engage in impression management. Individuals face the dual tasks of needing to create a new life and at the same time learn to accommodate their disabilities (Karlovits & McColl, 1999). Developing a new social-identity that accommodates these changes post-injury, takes time, a great deal of effort and can be exhausting (Vohs, Baumeister, & Ciarocco, 2005). Support from family, close friends and more distant friends, acquaintances and other members of the public is important in this process (Abbey, 1985; Jones, et al., 2011).

Velikonja, Warrinera and Bruma (2009) used quantitative methods to assess individuals with acquired brain injuries. The aim of their study was to look at the diverse range of symptoms that have been categorised after a brain injury. They used the medical records of 440 patients who attended a brain injury programme between 1994 and 2007 in Canada. Participants (N=275 males and N=157 females, age range 15 to 69 yrs) were selected for inclusion on the basis of past psychometric evaluations. The symptoms they categorised were clinical depression, anxiety, confused thinking, pain, substance abuse, risk taking, and antisocial behaviour. Velikonja et al. indicated that marital status may be a buffer, mediating or reducing more severe symptoms and emotional distress. This study explicitly mentions impression management (Table 2-5), but this was discussed only briefly in relation to behaviours that were taken as indicators of IM; which included the tendency to minimize (play down) concerns and a reluctance to admit to personal faults. These characteristics were identified in older, married, professional and managerial participants. IM was measured using questionnaires but this was the only mention of those results, and no other details were provided. What was their definition of impression management in relation to those who have a brain injury? How exactly did they measure it? Velikonja et al. said it was important to study these issues as affective disorders can increase in intensity over time and individuals could, as a consequence, remain unemployed, have poor community integration and be unable to function in a domestic role; possibly leading to economic hardship and personal loss. Measures of psychosocial well-being were said to be good predictors for a return to work. Their results showed high rates of psychological difficulties after a brain injury. Functional status was said to be affected by the individual's emotional response to their injury. This was a very technical paper, and disappointing in that it was the only paper, using quantitative methods, that was identified under impression management and brain injury, but failed to discuss the issue in any depth.

Mental health researchers have found that individuals who have insight into their mental illness make use of impression management strategies: which include selective self-disclosure, downplaying the effects of the disability (using denial and destigmatization), highlighting positive attributes (compensation), and avoiding any mention of their disability (exclusion and concealment). These strategies are used to reduce the risk of becoming anxious in social situations where the individual might face discrimination (Francis & Penn, 2001; Major & O'Brien, 2005). Yet some of these strategies have been identified following a brain injury, for example minimization (Velikonja, et al., 2009). There is a slight difference in the terminology for some of these strategies, for example under-reporting personal difficulties is termed 'defensive denial', and using destigmatization is referred to as 'minimization' (Dyer, et al., 2006; Fleming, et al., 1996; Hillier & Metzer, 1997; Livneh &

Antonak, 2005). The main difference is that they are rarely called impression management strategies when discussed in the TBI literature. Researchers from behavioural psychology and brain injury have found that coping strategies were used to reduce anxiety in situations where the individual might face discrimination, fear a negative response from others, or fear failure (Garssen, 2007; Shotton, et al., 2007). Health and social behavioural researchers identified the use of these strategies as protection against emotions such as shame, fear and embarrassment; describing them as mediators between behaviour and thought (Pearlin & Schooler, 1978).

Changes in personality, behaviour and socializing that occur in an individual after an ABI, impact upon the whole family, friends and associates (Simpson, et al., 2000). Some of these behaviour changes may be deliberate, for example for self-protection (Gracey & Ownsworth, 2008; Yeates, et al., 2008), such as the use of impression management. Alternatively, the behaviour changes may be due to other social factors such as the loss of social status for example, rather than to neurophysiological changes alone (Haslam, et al., 2008).

After an ABI some individuals may lose memories or their recall may be disorganized, and with this a sense of their personal history is lost. So when they are talking about themselves, as a result of their impairment they may be prone to magnify (or deny) personal characteristics, getting them out of proportion; they are not deliberately misleading others: this behaviour has been negatively labelled ‘confabulation’ (Fotopoulou, 2008). However, some of this behaviour may be due to the conscious use of impression management. According to Schlenker, Britt and Pennington (1996 - cited in Murphy, 2007), impression management is used daily to maintain one’s position in respect to others and to demonstrate intelligence and personal competence. Social psychologists have found that the difference between those successful in the use of impression management and those who are not, is related to the level of monitoring (sensitivity to interpersonal cues) the individual is able to do (Turnley & Bolino, 2001). Interactions between individuals may be affected if tactical impression management is being used. This takes effort and individuals who spend time monitoring their own behaviour will have fewer cognitive resources available to interpret the other person's intentions (Hoff-Macan & Hayes, 1995).

Within a social constructivist perspective, meaning is formed from experiences; it is the availability of information and social interactions which help with the re-building of one's self-identity after an ABI (Draper & Ponsford, 2008). Identity is partly reflected from the behaviour and actions of others towards us (Gracey, et al., 2008; Massimi, et al., 2008). The biopsychosocial perspective is that all these aspects (biological, psychological and social) need to be considered in order to understand changes to self and identity after a brain injury: however inadequate emphasis is placed upon the social context in which rehabilitation occurs (Yeates, et al., 2008). Developing a revised self-identity after a brain injury takes place with others (for example family, friends, health professionals and group members), within a particular socio-cultural context and this can give rise to both positive and negative social and practical experiences (Gracey, et al., 2008; Haslam, et al., 2008; Massimi, et al., 2008).

The support of individuals, while a revised self-identity is being established following a brain injury, is seen as important to rehabilitation interventions (Coetzer, 2008). As part of the rehabilitation process, managing the impression (perceptions) that others form is critical to the development of a new identity (Cloute, et al., 2008; Olney & Brockelman, 2003; Olney & Kim, 2001). The desire, or not, to achieve personal goals (such as those for rehabilitation) is in part due to those around us (Ylvisaker, McPherson, Kayes, & Pellett, 2008). Outcomes can be measured in terms of the achievement of rehabilitation goals (Cloute, et al., 2008), but where there is little support, these goals may be difficult to achieve, and lead to social isolation and loneliness impacting upon well-being.

Francis and Penn (2001) found that individuals diagnosed with a mental illness reported using selective disclosure as one way of dealing with potentially stigmatizing situations. Each participant's behaviour may influence the other in an interaction and so self-fulfilling prophecies can easily occur: either party may form an impression of the other that may not reflect their true ability (Darley & Fazio, 1980). Impression management may be used in an attempt to re-create or protect one’s personal image and self-esteem by directing attention away from internal issues (disability) and onto the situation (Burkley & Blanton, 2007). There has been little research into the use of impression management in natural (non-clinical/uncontrolled) settings (Francis & Penn, 2001) and it is now needed. These studies led to the question:

> Q_3: Do individuals recovering from traumatic brain injury, and carers, use impression management?

2.4.6 Summary

Disclosure and concealment have been associated in other areas of psychology with important social and mental health outcomes; but, within ABI research, there are very few studies that have directly addressed the issues of disclosure and concealment as significant parts of their study. Further study of these issues in ABI is indicated.

CHAPTER 3

QUALITATIVE STUDY

SECTION ONE

3.1 Introduction

How do individuals with traumatic brain injury (TBI), and their carers, feel they are viewed by society and does this influence their decision to disclose information regarding the brain injury to others? Do they use concealment or disclosure coping strategies to manage selectively the impression they wish to portray to others? We investigated why information about disability or role as a carer is concealed or disclosed, and if so, to what extent and to whom (for example family, friends or acquaintances). These issues were considered from a person-centred perspective with the collection and analysis of actual experiences. Before the methodology and results are discussed, examples of concealment, disclosure and impression management are revisited here as they are closely connected to issues related to this study (see also Tables 2-5 and 2-6).

3.1.1 Brief overview of concealment and disclosure

Argyle (1967) and Jourard and Lasakow (1957) referred to concealment and disclosure as strategies for projecting a specific self-image, where individuals hide aspects of themselves which they feel may lead to disapproval from others.

An example of concealment comes from research psychologists Kawamura and Frost (2004) who asked 116 female undergraduates, in a questionnaire study, about the concealment of their difficulties. They found higher levels of distress in those who were perfectionists (individuals who believed they would lose respect from others if they admitted to making mistakes). Perfectionism was linked to low self-esteem and failure to seek social support, which, they found, increased stress and affected psychological well-being. Maladapted perfectionists were found to avoid negative evaluation from others by using concealment. Active concealment (including monitoring and inhibiting disclosure) can give rise to higher levels of distress, especially in those who are self-critical, and may prevent the use of more adaptive coping strategies (Kawamura & Frost, 2004).

Emotion-focussed strategies are used to reduce emotional reactions such as stress and distress (Tomberg, Toomela, Ennok, & Tikk, 2007); and are seen as adaptive if they are used for short time periods (Hopwood & Treloar, 2008). Concealment has also been called a maladaptive strategy: strategies have been linked to poorer health outcomes (as with other emotion-focussed strategies used longer term) which may require therapeutic intervention, such as confronting the need to hide personal inadequacies (Crisp, 1994; Francis & Penn, 2001; Karlovits & McColl, 1999; Kawamura & Frost, 2004; Livneh & Antonak, 2005; Tomberg, et al., 2007; Wade, et al., 2001).

Reporting in the Journal of Advanced Nursing, Akintola (2008) described in-depth interviews carried out with twenty volunteers in South Africa, who were caring for people with AIDS. They found that, after appraisal, volunteers used emotion-focussed and then problem-focussed coping strategies to deal with the difficult circumstances they faced daily, showing that coping is a flexible process (linking Tables 2-7 and 2-8). Family caregivers used more emotion-focussed coping strategies such as anger, concealment, denial, impatience, distancing and seeking social support. Using emotion-focussed strategies puts the users personal well-being at risk as it avoids dealing directly with the stresses experienced. Fear of stigmatization encourages concealment of personal information, which in turn restricts access to support. Feelings of threat, associated with the disclosure of sensitive information to others, is referred to as trait self-disclosure anxiety (Endler, Flett, Macrodimitris, Corace, & Kocovski, 2002).

The effect on health arising from emotion-focussed coping is revealed in a study by Akintola (2008), about trust. Trust, built up between the volunteer and the individual being cared for, enabled the disclosure of health status to the volunteer. This disclosure then placed a burden upon the volunteer to maintain the secret. Caregivers were subsequently found to have poor health outcomes related to their high burden of stress. Earlier findings by Matheson and Cole (2004) support this further, they found that individuals who extensively used emotion-focussed coping strategies, were sensitized to emotion-relevant cues in their environment. And research on social motivation indicates that individuals who are primed (sensitized) are more aware of discrimination and stigma (Brody, 1980). They found that hidden knowledge (concealment of personal issues) can lead to an increase in one’s awareness of stigma and discrimination around them, and in turn this can intensify the impact upon the individual using emotion-focussed coping strategies, impacting upon their physical and psychological health and well-being.

As explained in Chapter 2, coping is part of a process (following appraisal and guided by coping style, strategies are applied to stressful situations) mediating outcomes such as anxiety, depression, distress, health and well-being (Endler & Parker, 1990; Folkman, Lazarus, Dunkel-Schetter, et al., 1986). This was shown in a social psychology study by Endler and Parker (1990) who asked (N=559, N=130 and N=275), undergraduates about the strategies they used to enable them to deal with challenging or stressful situations. They found that the use of emotion-focussed coping was related to depression; and increased anxiety was associated with negative thoughts, and physiological changes such as sweating, nausea and palpitations. These results are typical of those found by other researchers, for example Sutherland and Cooper (2000).

These examples indicate that concealment can be classed as an emotion-focussed coping strategy (Akintola, 2008). Our first question was:

What motivates individuals (carer or person with a TBI) to conceal their situation?

Personal reflection, following the disclosure of a traumatic experience, was clinically tested by social psychologists Lutgendorf, Antoni, Kumar, and Schneiderman (1994 - cited in Greenberg, et al., 1996): three groups of college students were given semantically matched writing tasks, the trauma group wrote about personal reactions to real events, the imaginary-trauma group wrote about their reactions to scenarios given to them, and a control group wrote about non-emotional events. Post-test analysis showed that disclosure in the real trauma group was associated with an enhanced immune system, with the ability to overcome viral infections, indicating that disclosure can lead to improvements in health and well-being.

In a series of three studies (N=371 undergraduates, N=356 museum visitors and N=155 new parents), Endler, Flett, Macrodimitris, Corace, and Kocovski (2002) found that social and disclosure anxiety were related to most situations where individuals disclosed information to others, including to family and friends. They found that social anxiety encompassed social evaluation, separation anxiety (in adults as well as children) and self-disclosure. The anxiety was related to situations where individuals were evaluated privately or publicly. According to Argyle (1967), in some circumstances disclosure can lead to disapproval (negative stereotyping) from others: a finding supported in later research (for example Major & O’Brien, 2005; McCausland & Pakenham, 2003; Ramirez, Adington-Hall, & Richards, 1998).

So, is disclosure always adaptive and is concealment maladaptive in all circumstances or are they used as a form of impression management, as indicated by Argyle (1967) and Jourard and Lasakow (1957), to overcome stigma and discrimination? The decision to conceal or disclose information about one's brain injury; or for a family carer to discuss their role in the care and rehabilitation of a family member or friend has received little direct attention. Our second question was:

What motivates individuals (carer or person with TBI) to disclose their situation?

Individuals are, at times, motivated to present themselves to others in particular ways; this is known as impression management (Leary, 1992; Leary, Tchividjian, & Kraxberger, 1994). They manage this by adjusting their behaviour to portray their desired self-image, concealing undesired personal characteristics as far as possible. Impression management is a concept first put forward by Jourard and Lasakow (1957) and then by Goffman (1959) and is linked closely to the work of Giddens (1988); they linked activities in one's social environment to individuals' lives (both cited in Gauntlett, 2002). Whilst our focus is on brain injury, any disability is interpreted within a particular cultural and social situation and this has an impact on those who have disabilities and how others, who stand in judgement of their abilities, relate to them (Gauntlett, 2002; Robson, 1988; Yang, et al., 2007). Our third question was:

Do individuals recovering from traumatic brain injury, and carers, use impression management?

3.1.2 About this study

We wanted to identify factors involved in the disclosure and concealment of traumatic brain injury, so we interviewed those directly affected. We used in-depth, one-to-one, semi-structured interviews to investigate these issues and to provide the foundation for a broader, quantitative exploration (Eisenhardt, 1989). Interview recruitment and procedures are explained in section 2. In section 3, extracts from the interviews are given in relation to concealment, disclosure, impression management and the themes we identified during the analysis. These themes form the basis of our questionnaires used in the next two studies. In section 4 our findings are discussed in relation to the extant literature.

SECTION TWO

3.2 Methodology

3.2.1 Recruitment

Recruitment for this study began following ethical approval from the University of Birmingham ethics committee in June 2008 (Appendix A-1). Twenty individuals, ten with traumatic brain injury and ten family carers associated with traumatic brain injury were required. Potential participants were approached by a member of staff at a Headway (UK) (a brain injury charitable trust) Day Centre and invited to take part. They were provided with an information leaflet which explained the aims and objectives of the study and included contact details for use by those who were interested in participating. This document could be taken away for the individual to read. There were three information sheets, one for those whose disabilities were obvious, one for those whose disabilities are hidden and one for carers (Appendix A-2 is a copy of the sheet relating to participants whose injuries are not obvious to others). No direct contact was made by the researcher to potential participants and no follow up was made if those individuals approached by staff did not contact the researcher. For those who did get in touch an initial meeting took place at their nearest Day Centre to explain the study, and a day and time for the interview was arranged. Everyone involved in the interviews received direct or indirect support from Headway. They all gave their time, without remuneration, to support this study. Interviews took place between July 2008 and December 2008.

3.2.2 Inclusion/exclusion Criteria

For this study, we required individuals recovering from a traumatic brain injury who could express their thoughts and were able to communicate them. For some people with TBI, this is not easily achieved. An individual's ability to provide informed consent was also one of the inclusion criteria. This was demonstrated by participants who in the opinion of the staff were capable of giving their consent and by the individual reading (or having read to them) the information sheet prior to deciding whether or not to take part. The researcher assessed if participants were able to understand their role within the study, while taking participants through the information sheet, before the consent form was signed. Participants between 19 and 70 years of age were invited to take part.

3.2.3 Procedure

At the beginning of each interview, participants were asked to sign a consent form (Appendix A-3) and were given a photocopy of the form (as stated in the ethics application). During this time the format of the interview was explained again, and any questions answered. To increase inclusion and for those who required support, the information sheet was read to them. All interviews were taped with the full consent of the interviewee. At the end of each interview participants were asked if they were comfortable with the information they had provided; they were each reminded that they may withdraw their participation and consent at any time. Interviews with individuals with a brain injury were shorter in duration than those of carers (between 25 minutes and one hour, compared to, between one and three hours). This was due, in part, to individuals becoming easily tired and needing to put a great deal of effort into organising their thoughts and expressing their opinions, in response to the questions they were asked. Support systems were put into place before the interviews to deal with issues that might arise. Pseudonyms are used for all participants in this study.

3.2.4 Interviews

Eighteen participants were recruited; semi-structured questions were asked during one to one interviews. Guided by a list of topics (Table 3-1), we asked how they decided to discuss (or not) their experience of TBI with others, in relation to different social circumstances (work-place, family, neighbours etc.). To gain a broader perspective and to start the interview, each participant was asked about their TBI experience.

3.2.4.1 Interview Topics

Information was sought in relation to an individual's decision to discuss their experience of TBI with others or not. Interview topics are given in Table 3-1:

Table 3-1: Interview Topics for the first qualitative study

Potential risks are the emotional, social and cognitive consequences for the individual of disclosing or concealing this information.
• Is it possible for an individual to describe when they feel comfortable enough to share personal information and when they do not feel comfortable?
• To reflect on whether they have chosen to avoid thinking too closely about their problems.
• Experience of any costs and benefits of concealment on occasions when they have hidden their circumstances, and their perceptions of the potential risks of concealment; explored in relation to different social circumstances (work-place, family, neighbours etc.).
• Experience of any costs and benefits of disclosure on occasions when they have discussed their circumstances, and their perceptions of the potential risks of disclosure; explored in relation to different social circumstances (work-place, family, neighbours etc.).
• What factors (in terms of emotions, cognitive appraisals, social and environmental aspects) influence a person's decision to conceal from, or disclose to, others information about the injury and its consequences?
• Does gender play a part in concealment and disclosure, whether the individual themselves or the person to whom they are speaking?

These topics were structured, but sufficiently open to allow flexibility in response. The specific questions asked were dependent upon the needs of the interviewee and their circumstances. This format was used to encourage a response and guide the conversation (Pons, 1992), but the nature of semi-structured questioning enables follow-up questions to be asked related to comments arising within the interview, giving a broader and more personal perspective of the issue from the participant's perspective (Chwalisz, Shah, & Hand, 2008). Sufficient structure was maintained to enable the interviews to be analyzed by comparing and contrasting the responses in order to identify themes and categories.

3.2.5 Conducting qualitative research with participants who have a TBI

Paterson and Scott-Findlay (2002) provide guidelines for researchers conducting interviews with individuals' post-TBI. They refer to a number of pertinent issues for prospective interviewers to consider; their suggestions are discussed along with examples from this study. During the research presented here, the researcher was careful with probing questions, although interviewees were encouraged to provide autobiographical memories as recommended by Paterson and Scott-Findlay. The researcher was also careful with questions that might trigger painful or negative memories. Arrangements were made for those who may be distressed following their interview to be able to contact a member of staff at any time should they feel the need to do so. Interviewees were provided with these contact details as well as the general Headway contact e-mail address and researcher contact details (in the participants information sheet discussed in section 3.2.1), as recommended by Ramos (1989 - cited in Paterson & Scott-Findlay, 2002).

Paterson and Scott-Findlay recommend a pre-interview or even an initial group interview to pilot questions and check their suitability. Paterson and Scott-Findlay's suggestion of an advisory group regarding the formulation of the questions (Worth & Tierney, 1993 cited in Paterson and Scott-Findlay, 2002) was not appropriate for this first study as the study was designed to obtain interviewees perspectives on their use of concealment and disclosure. In addition, the semi-structured interview questions were developed and sent for ethical approval prior to any data collection.

The first approach to all participants was made by staff at Headway (section 3.2.1). Potential participants with a brain injury were subsequently taken through the participation sheet by the researcher to ensure they understood the procedure, were happy to take part and to organize a time for their interview (Paterson & Bramadat, 1992 cited in Paterson &Scott-Findlay, 2002). This process assisted in evaluating the potential participant's ability to respond to questions. Headway staff helped with the initial selection process for participants because they knew all the participants well. Participants who would be unable to deal with an interview, or because of additional problems would not be able to focus on the process, were not invited by staff to take part (see also 3.2.2 and 4.2.5.3). Interviews were all carried out by the researcher, which was important for identifying signs of fatigue, to enable additional questions to be asked when required and because several of the interviewees had communication difficulties that may have been difficult to overcome in a telephone or group interview. Interviews were all done one-to-one, overcoming the problems found by Paterson and Scott-Findlay of family carers contradicting the responses of the interviewee.

Interviews carried out by Paterson and Scott-Findlay were approximately an hour long, with the most important questions being asked first. In this research, the interviews lasted between half an hour and one hour (see section 3.2.3 for further discussion). However, this was managed by noting and responding appropriately, to changes such as additional stammering, shorter responses, and change of subject, additional slurring or slowing of speech, yawning and loss of energy. Participants were asked if they wished to stop or to have a break when signs of tiredness were observed, rather than asking the interviewee to use a pre-determined signal to show they were tired or needed to rest (suggested by Hibbard, Uysal, Sliwinski, & Gordon 1998 cited by Paterson & Scott-Findlay, 2002). No follow-up telephone calls were made after the interviews had been transcribed, although these were recommended by Hertz (1995) for clarification (cited in Paterson & Scott-Findlay, 2002).

Paterson and Scott-Findlay warn interviewers about the use of ‘impression (image) management’, where interviewees present themselves in a favourable light, playing down personal problems to appear more able that they are; managing the disclosure of their personal experiences. The nature of our research was, in part, to identify these strategies. Participants who attended Headway had met the researcher on several occasions, as a volunteer, before their interview took place. So the participant’s self-presentation was more likely to be authentic, unlike the situation suggested by Paterson and Scott-Findlay where the interviewer was seen as another health care professional.

3.2.6 Demographic Information

Basic demographic details of participant are provided in Table 3-2.

Table 3-2: Demographic statistics for the qualitative study

Table of demographic statistics for first study

Demographic	N	Percentage or SD
Demographics of individual with TBI		
Male	9	90
Female	1	10
Age (item 4.2)	48 yrs	SD 11.02
Demographics of carers		
Male	1	12.5
Female	7	87.5
Age	49 yrs	SD 13
Carers relationship to person with TBI		
Daughter	1	12.5
Father	1	12.5
Sister	3	37.5
Wife	3	37.5
Accident type		
Assault	1	8
Fall	2	15
Motorcycle accident	3	23
Motor vehicle accident	5	39
Other	2	15

These accidents leading to the brain injury occurred when the individual was between thirty months and thirty nine years of age. For carers, their ages at the time of the accident ranged from fifteen years of age to their mid fifties. The most recent accident occurred two years ago and the earliest accident more than thirty years ago. There were differences in the way that individuals responded to the interview and the issues they discussed, which appeared to be related to their age at the time of their accident.

3.2.7 Thematic Analysis of Qualitative Data

Thematic analysis was chosen because we sought information about a specific issue; namely, what individuals' motivations were for disclosure and concealment. Basic thematic analysis is an appropriate qualitative method when researchers are interested in answering specific questions and their investigations and interviews are structured around those questions, especially when they require a straightforward non-interpretative and non-theoretical representation of what participants say (Braun & Clarke, 2006). When researchers are interested in broader issues and there is less expectation about what might emerge, other qualitative methods that allow a more open analysis (for example Interpretative Phenomenological Analysis - IPA) would be more appropriate. Similarly, other approaches are more appropriate when there is an intention to interpret or theorise about the information gained (for example, IPA and grounded theory).

3.2.8 Thematic Analysis

Procedures for conducting thematic analysis, described by Braun and Clarke (2006) and Aronson (1994) were followed. With the consent of all those who took part, each interview was recorded onto a small digital tape recorder. These recordings were put into electronic files and stored until they were transcribed and the tape erased. This approach was combined with Nvivo 7 software for storing data and assisting in the coding. The transcripts were read many times and extracts were selected, coded (named) and placed into headed files (tree nodes) each relating to a specific topic. Extracts were then merged under theme headings. A detailed account of this procedure is given in Appendix A-4.

Thematic analysis avoids interpretation and minimizes subjectivity. Quotations supported the descriptions of what was said by participants. The emergent themes were discussed in supervision, and with staff, volunteers and a number of clients at the Headway

Centres visited. A poster of these themes, with supporting extracts was also made available (as stated in the Ethics application). To enable wider consultation, this poster was read by and received endorsement from those who attended a second Headway Day Centre; all those who read the poster recognised and identified with the themes that we had identified.

Many themes were identified (see Appendix Table A-4) because we conducted semi-structured interviews, but concealment, disclosure and impression management were the focus for this study and only themes relating to these processes are described here.

SECTION THREE

3.3 Findings

This section considers reasons given (motivation) in the interviews for disclosure and concealment. Thematic analysis enabled us to focus on specific aspects of the participants' experiences. The interviews showed that individuals managed the amount of information disclosed about traumatic brain injury to others and how it was disclosed. Themes arising from the analysis of the 18 interviews are given in figure 3-1.

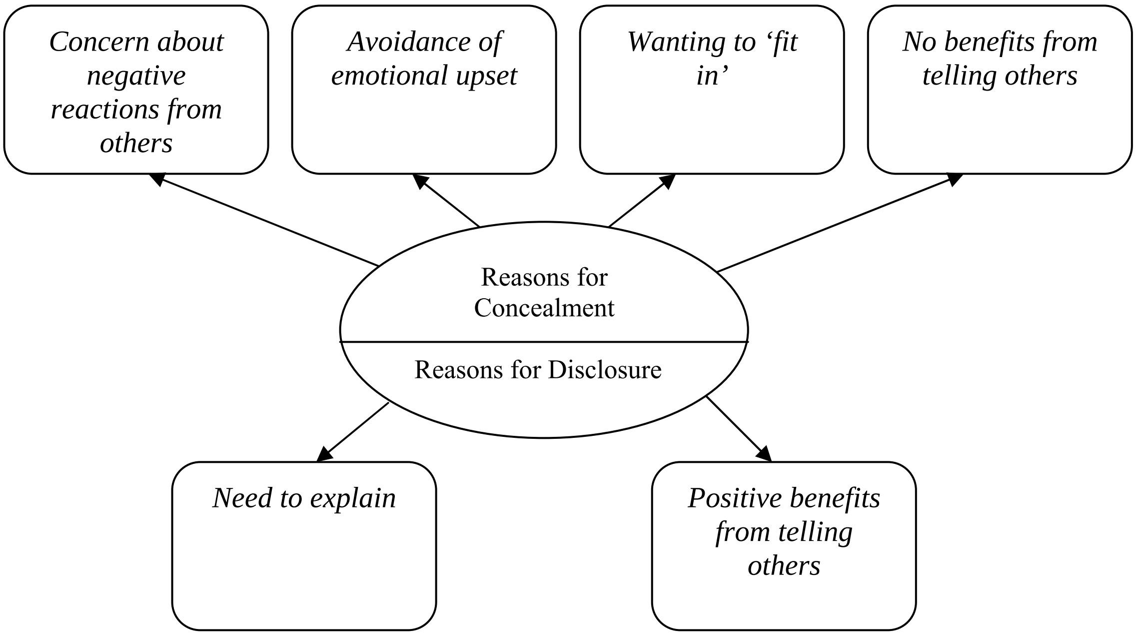


Figure 3-1: Illustration of the six themes identified in the first 'qualitative' study.

Reasons and factors involved in concealment, or disclosing a limited amount of information

The six main themes relating to concealment and disclosure are shown in Figure 3-1 above. The overall findings are given in Tables 3-2 and 3-3. The tables are followed by quotations from the interviews; quotations from carers are all indicated, otherwise quotes are from an individual who has had a brain injury. Our results begin with themes relating to concealment and the reasons for the use of this strategy.

Table 3-3: Overview of qualitative findings-part 1

ACTIVE MANAGEMENT OF DISCLOSURE

Nearly all the carers and the people with the TBI actively managed the amount of, and the way in which, information about the TBI was disclosed to others and were able to articulate the reasons for doing so (impression management). For example, one participant said they would not hold back in what they said to others –
"*If someone asks I'll tell them. It doesn't bother me at all.*"

REASONS AND FACTORS INVOLVED IN NOT DISCLOSING OR DISCLOSING A LIMITED AMOUNT OF INFORMATION

Reasons for not disclosing/limiting disclosure

1. Protecting others from worry and distress;
    - Particularly children, also partner, wider family and others
    - Not wanting to impose burden on others outside the immediate family because they have their own lives to lead
2. Protecting self:
    - From ridicule
    - From violence and exploitation
    - From stigma and social rejection – people edging away if anything is revealed about the TBI
    - From getting distressed or feeling uncomfortable. Examples from both carers and people with TBI of disclosing little or disclosing in a fixed automatic way to avoid getting distressed or feeling uncomfortable in front of others. Also thinking about what's happened can be upsetting – so try to avoid doing so, and this includes not talking to others about it.
    - From the sympathy of others – being patronised?
    - Being different? Set apart from the rest of society by the TBI?
3. To avoid losses that may occur from disclosure:
    - Benefits in the case of carers
    - Employment
4. Resentment at having to justify self (see reasons for disclosure): "*Why should we have to keep explaining ourselves to other people?*"
5. Perception that many people do not really want to know – even if they ask, don't really want to know the whole story
6. Concern about confidentiality – not wanting to tell people outside of immediate family because it would become a topic of gossip round the neighbourhood

Other factors

1. Not disclosing / not seeking help is part of who they are – "*I keep myself to myself*"
2. Not conceiving of self in terms of the TBI, TBI not part of self-identity – life has moved on, not important any more, not living in the past
3. Social isolation – not having anyone that they know well enough to make significant disclosures to.

Table 3-4: Overview of qualitative findings – part 2

REASONS AND FACTORS INVOLVED IN DISCLOSURE

Reasons

1. Need to explain and justify changes and difficulties. Particularly relevant where problems are hidden and people assume that because s/he looks okay, they are okay and assume that they are ready to go back to work etc; and because there is nothing obviously wrong, misinterpret difficulties as being rude, stupid etc.
2. Disclosure and seeking support is very much part of their self-identity – "*We're very open as a family. We tell each other everything.*"
3. Practical benefits – health and safety at work because of seizures; boss helping out at work because she knows about the memory difficulties
4. A few references to benefits from social support. There was one reference by implication from a female carer who went to see a counsellor. Social support that was discussed came mostly from friends and nine interviewees made reference to support from their family.
5. Need to prepare others, especially children, for the shock (only relevant to those in the early stages and this study is confined to the later stages).

Other Factors

1. Need to feel that the other person is genuinely interested. Disclosure can be hard and it needs to be someone who would appreciate knowing.
2. Some people are more accepting than others. No need to justify or explain to new friends and acquaintances in Headway, or people that they didn't know before the TBI. More pressure to explain and justify to those who knew him/her before the TBI.
3. Sometimes easier to disclose the closer the person is, but not for everyone.

HOW TO DISCLOSE

Given what people are trying to protect themselves against, and other factors related to reasons for not disclosing, when they do disclose, these disclosures can have certain characteristics that can be understood against this background.

1. Having a set way of dealing with questions that can be automatically reeled off so that you don't need to start thinking about what's happened – otherwise it can be difficult
2. Using humour?
3. Minimizing: "*I've had a little injury*"

Concealment

We identified four overriding reasons for concealment. The first theme covers 'negative reactions from others' and how the individual feels they are treated by others (section 3.3.1). The second theme is the 'avoidance of emotional upset' which looks at self-protection and reaction to challenging situations (section 3.3.2). The third theme 'wanting to fit in', looks at being part of society without having to explain personal difficulties (section 3.3.3). The fourth theme covers 'no benefits from telling others' about one's TBI (section 3.3.4).

3.3.1 Concern about negative reactions from others

These quotes all have '*concern about the negative reactions from other*s' in common. Reasons for concealment relate to self protection, protection from gossip, prejudice and stigmatisation, both for one's self and family.

Negative interpersonal reactions

The extract from Rose is a typical example of the reasons given for not discussing personal concerns about the impact of the accident. Information cannot be controlled or taken back, once it is in the public domain, so restricting what is said helps to control what others can discuss, or gossip about.

- being the target of gossip:

> I mean if you sort of tells one; then they tells the other one; then they tells you. And I, I don't want it round the street. I keep me-self to me-self. You can't be going in other people's houses and start to talk about things, personal I think, you know. I think it's personal (Rose, 2008 - Carer).

- being treated as an idiot:

Andy's gives his view of negative comments from others:

> They treat you as an idiot. They look down on ya', if you know what I mean. As if you're second class (Andy, 2008).

- being teased and ridiculed:

Difficulties can arise in the workplace as well as at home from unsympathetic work colleagues. Harry explains what happened when he took on a new job, and shortly afterwards other new staff arrived:

> I found some of the chaps were taking the Mickey, and you know; insulting [me] in a sexual way. So it really got on my nerves. I'm there to work not listen to that…. I was getting teased, and X wouldn't do anything about it (Harry, 2008).

He tried to tell his manager what was happening:

> I try to explain to them, I can't express me-self properly to word wise. So I got a bit of a temper on me, 'cos I don't know what to do to get the information across. So I get a bit irritated. I don't mean to but you know (Harry, 2008).

And Frank explained what happened to him:

> Sometimes I has to remind myself, and I talk to myself. I had these posh guys behind me….They says 'he ain't normal'. 'He's one of those something-or-others, nut' (Frank, 2008).

Because of such attitudes Frank says:

> Well I, sometimes I just keeps that to me-self. And I think to me-self 'well, why should I tell other people about like err things what I can't do' so they can laugh at me (Frank, 2008).

When asked why he wanted to keep things from others Frank replied 'I get a bit embarrassed'. Some of Frank's daily coping strategies are misconstrued by others and he is ridiculed as a result. Concern about getting angry or annoyed because the individual cannot communicate clearly to others what's going on leads them to avoid telling people and to avoid people as well.

The second reason identified is protection from violence and exploitation, Ian discussed his pre-injury life when he was involved with groups who exploited others:

> The way I was, or used to be, half the people I know they'd be killing me…. they'd blow your head off….they are violent (Ian, 2008).

Using humour to reframe difficult situations

> I can just turn myself off….when someone's talking about ya'. Just switch yourself off: keeps you out of trouble. Very true. If you don't hear it, don't matter. And it's easy now 'cos I'm deaf in one ear (ha ha) (Don, 2008).

Other negative consequences / losses

In addition to the personal issues, concerns were raised regarding the losses that may be felt if others were to be informed about the individual's involvement with TBI. These comments were made in relation to benefits and employment; one of the examples we were given was from Pat, she explains:

> I go over for three to four hours a day; but apart from that she doesn't need seven hours a day. You know what social's like, if they took it off they'd take it off Mum. They'd give it to me and then they'd take it off me with me rent. So I wouldn't be any better off. And then they'd say 'well you're not available for work'. It's easier not to tell 'em (Pat, 2008 - Carer).

The sentiments behind this were echoed by several carers in relation to benefits. They also know that claiming for the time they provided care, if they were eligible, would affect them in other ways financially. The reaction to this is to conceal their care role from others. When they did decide to share this, they became frustrated, as Louise explains:

> I sent for a carers' pack, that came and it said about 'How many hours do you care?' and 'How many days?' and 'How much time do you get off and things?' And I didn't feel that I really qualified, because X doesn't live with me. And there was nobody. You can never talk to anyone when you 'phone up….and you press this button if you need this question and you press that button if you need that question, and there never seems to be a, a person that you can talk to (Louise, 2008 - Carer).

3.3.2 Avoidance of emotional upset

These quotes have in common the '*avoidance of emotional upset*'. Forward planning of interactions that may prove to be difficult or distressing helps the individual to portray a controlled self-image to others. Other reasons for concealment include protection from the unwanted sympathy of others, and the feeling of being patronised. An important part of this theme is the idea that some people don't want to disclose because they feel ashamed of their TBI. Concern was raised about being distressed and feeling uncomfortable in front of others. This led to less disclosure over time or disclosure in a prepared and almost automatic way.

Not disclosing because you don't want to get upset yourself (protecting oneself):

> I just would end up in tears and not be able to speak until it happened a few times and then you have a sort of speech prepared don't you, and even if they ask you questions you are sort of on auto-pilot, so that you don't associate your words with the feelings. And that's how I think you get through in public, by preparing for what you say and disassociating from what it actually means and then get upset when you get home, when nobody's around (Nicola, 2008 - Carer).

Many individuals try to avoid thinking about what has happened as this can be upsetting, bringing back intrusive memories. This includes not talking to others about the accident or controlling what they say, Nicola continued:

> You don't really want them comforting you….I prefer to get upset when I was on my own and not with people, associates, and if you're with me embarrassing to get upset in public…. It's very difficult to put it into words I find, because you go through all these feelings but actually telling somebody how you felt, I find quite hard (Nicola, 2008 - Carer).

- People don't always listen, so why bother

> You know when you're talking, to someone. They don't understand because they're talking to you….And they change the subject….I say 'stop changing the subjects,

> keep it on one; I've had a head injury'…. An' I get a bit annoyed then and I said 'forget it, don't talk to you anyway'. Because it makes ya' feel s'just don't want to talk to ya' (Don, 2008).

Not disclosing because you don't want to upset others (protecting others):

The protection of others from the burden of knowing about the TBI was a concern. This can be seen in the quote from Louise:

> A lot I keep to myself, I share it obviously with my husband who's in the same frame of mind as me really. We've got no one to share it with. We've got no family really. I've got no uncles or aunties left really to speak to about it. And obviously they would be older than me anyway. So they wouldn't be able to. The kids I don't like to talk to about it. I don't want them to [deep sigh] to be responsible. Because I know they would say that they would be. My son and daughter don't want all that worry, they've got enough with their own little families and that you know. I don't want them to have to give up their life I suppose. You know, I feel sometimes that I've given up my life (Louise, 2008 - Carer).

This concern to protect the family is sometimes balanced by other considerations, such as their right to know, as Mary said:

> I suppose with my two I've always tried to be as open as I can with them both really, because I think you have to. But with me son I think I can tell him more and explain more about what happened with his Dad. But me daughter was that bit younger. Well he was a bit older and he could probably understand it more, but you still can't overload them (Mary, 2008 - Carer).

Like Louise, Mary does not have support from her extended family, only her young children. Information is given to them, but is controlled to protect them; disclosed at a level she feels is appropriate to their age and level of understanding. She manages with the emotional support of a few close friends with whom she can confide. However, the support Louise is offered from her children is kept at arms length as she worries that they will lose their independence, if they become carers, as she has.

Carers also expressed their desire to keep issues hidden from the person with the brain injury. Betty said what a number of carers expressed.

> There's some things that I've said to you that I wouldn't like to say in front of him, because I wouldn't want to hurt him or make him, you know, feel upset (Betty, 2008 - Carer).

The relatives we interviewed who care for a member of their family with TBI were deeply affected by the life changes they have made to accommodate their relative.

Not disclosing due to embarrassment and shame.

> My attitude is 'ooh, yeah I'll have a go at that'. And then if and when I find it more difficult, I will then explain why I found it more difficult. But I think it's often afterwards rather than before. I guess in a way I'm almost sort of embarrassed about having a head injury (John, 2008).

- *Needing help from others can lead to discomfort:*

> Inwardly I felt ashamed that I had to rely on other people (Graham, 2008).

> I went to the club; ask people to read me letters…And some of ‘em was private. So ‘blow this I aint doing that’ (Frank, 2008).

Asking for help was difficult and the response for Frank was to walk away.

3.3.3 Wanting to ‘fit in’

Individuals don’t want to talk about their injury to others because they want to be the same as others and be able to ‘fit in’: not be marked out or labelled as being any different. Many of these examples are strategies used within impression management put forward by social psychologists Jones and Pittman (1982 - cited in Turnley & Bolino, 2001) such as “ingratiation” involving flattery and opinion conformity; “exemplification” go beyond expectations to achieve one’s goal; “self-promotion” involving playing down of inadequacies and building on one’s competence; and “supplication” playing on inadequacies to achieve sympathy or support. However, sometimes they find they have to talk about their injury because people don’t understand. Some people were motivated to conceal (or not). Not wishing to be labelled or singled out as having a head injury leads some individuals to adjust what they say to fit the circumstances they are in.

> I used the fact that something that was affecting her was similar to something that affects me. I effectively said that I had to stop work. I actually said for the same reason [tiredness]; which is not entirely true, but it sort of. I used something that she had said as an opening to tell her about me…. I think she was quite pleased to talk to somebody who wasn’t judging her (John, 2008).

- not wanting to be marked out as the person with a head injury:

> It's a sort of, almost like a kind of black mark….certainly not something I'd want to show off about (John, 2008).

John was in a position where he was asked to do something:

> I was pleased that I was asked, but I felt a little bit sort of segregated. And it's a, it's a positive separation, but I don't want to seem different (John, 2008).

When asked why, he replied:

> Maybe it's because I'm not quite confident of who I am (John, 2008).

- need to be with others:

> Actually I need these people more than they need me (Graham, 2008).

- not wanting to have to explain things yet again:

> It aint so bad coming 'ere, because I know everybody now. But if I go into a strange place where I've never been before, I feel as if everybody's looking at me (Andy, 2008).

> Again I suppose people don't understand, because they don't know do they you don't really want to be there all the time having to explain (Mary, 2008 - Carer).

3.3.4 No benefits from telling others

The reasons we were given for concealment include protection of the family, lack of interest from others and standing up for oneself. Social rejection and fear of stigma, leading to avoidance of situations were identified in this study, and increased vulnerability, which was discussed by Kelly and McKillop (1996). Other examples are given in Table 4-2.

- other people aren't that interested in what's happened to me:

> Normally people ask me [why I use crutches] and they're trying to walk away then. When I start reeling off a story….they'll start edging away from me (Collin, 2008).

There is an understanding that many people do not really want to know the whole story about someone's injuries even if they have asked, as reflected in Collin's comment. This has the effect of preventing the individual from sharing other issues they have, as the negative feedback is demeaning from the curtailment of a conversation even when instigated by the other person. There has to be some element of reciprocal empathy in such conversations.

- not much good ever comes from me telling other people about it:

> I would say, errm, 'He has a brain injury and….he's lost his memory'. And, and they're like 'oh'. But, you know, they'll carry on talking to him as if they was talking to the person that they have always spoke to….Even though I, you can see in his face he's struggling, because he doesn't know, he knows he knows him, but he doesn't know where from, or how (Betty, 2008 - Carer).

- talking about it doesn't help me:

> We felt that we got no help, no help at all, social services didn't want to know he was being looked after in a sense….in the end I went down to the social services and I said I wanted some help and I said 'I'm not leaving this waiting room until somebody comes to talk to me and sort out some help (Louise, 2008 - Carer).

Disclosure

We identified two overriding reasons for disclosure. The first theme includes the need to educate others, to explain what has occurred and to justify personal changes (section 3.3.5). The second theme relates to the positive benefits that may arise from disclosure such as the recruitment of social support (section 3.3.6).

3.3.5 Need to justify or explain

Ian tells others of his accident in the hope that he may prevent others, especially bike riders, from the same fate. In controlled settings, Ian explains about his previous life and the risks they are taking by being part of gang culture. Social psychologists Jones and Pittman (1982 - cited in Turnley & Bolino, 2001) explain this type of concealment and disclosure under 'intimidation', one of five strategies they described that are used by those employing impression management tactics.

- it makes me feel better if they know why I am like this:

> It's good for them to know….and it stops them doing silly things (Ian, 2008).

So depending on the context Ian discloses (to educate others) or conceals (for self-protection) specific aspects about his life.

The need to explain and justify changes and difficulties is of particular importance. When the problems are hidden, others assume that because the person looks okay, that they are okay and ready to return to their previous occupation. Because there are no obvious disabilities, this can be misinterpreted as rudeness, stupidity or laziness.

Disclosing information to others can be hard and it needs to be to someone who would appreciate knowing about what has happened, as John explains:

> I don’t find it easy talking to people about my, effectively my medical situation, because it’s not. I’m not always comfortable doing it and it, I feel it has to be worth it….I have to feel that they will appreciate knowing. Such as the lady at the voluntary work who uses it to her advantage and also mine. That’s, it was worth going through the effort and saying something. But other people, it’s not as simple as ‘why bother’ it’s, but it’s ‘is it worth going through the hardship’ in a way of telling somebody what the situation is (John, 2008).

Mary says that having a husband with a brain injury has made her and her husband think about the behaviour of others, whereas before they would have thought badly of them.

> I just think you get a bit frustrated sometimes because obviously people look and think ‘oh don’t that lazy sod go to work’, type of thing. And I think well then I’ve probably said that I suppose before all this. Even [my husband] would say ‘lazy bugger’. Because he always worked he was in the army, but you know he had been in the army eleven years and even he’d say ‘oh weren’t that so and so a lazy sod’….. until you’re in that position you, you know. If like you could see somebody on the street homeless

> you might think that; but you don't know that person's circumstances or whether they've got mental problems or whatever. So I guess, but you don't kind of judge people…I think I've learned that bit from it (Mary, 2008 - Carer)

Other interviewees also said that they needed to feel that the person they were sharing their experiences with was genuinely interested in their story.

For some, there is a need to explain and justify changes and difficulties that they have post-injury. Sue explained:

> I don't know how much understanding they've got when somebody's had a brain injury of what, you know, the impact can be. You know the long term impact. Errm it's a hidden, it's a hidden injury so people don't seem to think [about it, or be] that bothered…. It's not always apparent, it's quite often not apparent. You know if somebody's had their legs amputated you can see it so you know. But you know with, with particularly when you look at X you can't tell straight off that there's anything wrong with him. He walks with a little bit of a gait but, but nothing major you know (Sue, 2008 - Carer).

This same concern is raised by Kevin, who said:

> If somebody breaks a leg, they limp, you can see it. If they can't express themselves you either think they're being rude or they're thick or something like that. That's why perhaps, why I go to lengths to, and I think I do go to some lengths to, to let; X doesn't like it when I say he's got, had an, a acquired brain injury so I don't. He doesn't like me saying it but I prefer to let people, let people know because it explains

> things which otherwise you would think you were, ‘why does he behave like this’ and ‘why doesn’t he respond to me’ etcetera, etcetera. Because you can’t tell looking at him….I think it’s important to do it, for understanding. I don’t see the stigma if any. I can understand X being upset about it. Because he now cannot behave in a way he used to behave, and he wants to be where he was before (Kevin, 2008 - Carer).

Some impairments need time and understanding from others, for example where the individual with a TBI takes longer to process information (Hoofien, Gilboa, Vakil, & Donovick, 2001). Kevin explains in the quote above, that physical disabilities are accommodated (adaptations to meet physical needs are available), but not the hidden ones (Olney & Brockelman, 2003; Olney & Kim, 2001).

Resentment at feeling the need to explain

Some interviewees expressed their resentment at having to justify personal changes in their behaviour (reason for disclosure) and two carers reported problems in the way other people speak to their relatives. There is pressure on both carers and those affected to explain and justify specific actions and behaviours to those who were known before the TBI. This is resented by some because not disclosing and not seeking help is part of the person’s sense of self and who they are.

- I just feel I've got to explain myself to them:

John explained why he used to feel the need to justify how he behaved in public:

> I felt I needed to explain myself, because I was, well I felt I was quite different and I needed to justify why I couldn’t remember things and why I wasn’t particularly good at time keeping. Now, before my head injury I was. I need to sort of justify why there

> had been the change. So at that point I did try to explain things quite a lot (John, 2008).

Mary said that when she is out with her husband people talk to him either as if he is a child or as if nothing has happened as she explains:

> It happens and everything whether we have to go to the bank or something or you have to explain something, and you know obviously they're busy and…. they haven't always got the time have they. So they don't always understand you know. And they think you're just being, you're just wasting their time really. And it's actually taking a bit longer to think….You don't really want to be there all the time having to explain….Why should we have to keep explaining ourselves to other people (Mary, 2008 - Carer).

Hidden injuries can lead to unwarranted comment from others in social situations. Mary was not the only one to express concerns about the lack of public support. She, like several other interviewees, attempted to consider the situation from the other person's perspective, at the same time justifying her reactions to the situation. Having to explain isn't something that they are satisfied with – either because they resent having to do it (in Mary's case) or because they now want to move on from the past (in John's case).

> But now, other than a few people who show an interest, I don't really explain very much at all. Yes I, I think that the sort of head injury has become less important to me because it's sort of 'I've been there and done that'. And I'm trying to move on rather than think about the past I suppose….I don't want to be sort of judged and questioned.

> 'Why the hell didn't you remember that?' Which is what I think to myself (John, 2008).

3.3.6 Positive benefits from telling others

There are known benefits from telling others. Such as educating people about the effects of a brain injury to protect against prejudice and stigma and to recruit social support (Karlovits & McColl, 1999). The potential benefits of telling others were understood by some participants, as the quotes from Harry and Rebecca reveal:

> I've got a friend who lives next door….He does the Samaritans. And I've been chatting to him and he's been, been quite helpful with me (Harry, 2008).

> I could look round the shops before, ever such a lot. But not now, I can't do it now. I'm really tired. So she does the shopping for me, which is nice. Because I know when I'm running out of something, I'll just tell her and it'll be her to go. She's very good (Rebecca, 2008).

Social Support and disclosure

Some interviewees found comfort by talking about their accident, gaining the support of their family or friends, supporting Argyle's (1965) perspective. Others disclosed certain concerns to friends rather than family, reflecting Endler et al. (2002). For example:

> We're very open as a family. We tell each other everything (Nicola, 2008 - Carer).

> We all used to help each other there and it was really nice (Rebecca, 2008).

> In fact [the accident] probably in some respects brought them a bit closer [family] all of them, it makes you realise doesn't it (Pat, 2008 - Carer).

Social support was discussed in relation to those relatives and close friends who assisted the family through the difficult times. Social support was not always provided by family members. Sue raises her concerns for those individuals who do not have such support:

> I had the support of my family I mean, and he, he had the support from his family if you like. I just, the one thing I would say is I think if somebody who doesn't really have a lot of family support and they've got a brain injury or anything like that I think it's really, really hard for them to get the services that they need because they're reliant on the system (Sue, 2008 - Carer).

Sue is emphasising the importance of having family and friends in obtaining the services needed for a better quality of life and an improved rehabilitative outcome. For most carers, we found there were one or two close friends who supported them. Betty found the increased attention and presence from her in-laws very difficult to deal with after her husband's accident. She turned to her mother on occasions, but most of all to her neighbour for support, saying:

> She's been a rock, an absolute rock to me, she has. And she's been there you know, through everything with him. When he's had a fit she's been there. She's the first person I call (Betty, 2008 - Carer).

There were differences in the levels of self disclosure, the amount and sensitivity of the information given, how the information was received by others and to whom the individual was talking. We found we had to ask the right question to elicit a response from interviewees, and they found they had to ask the right question from professionals. This view was confirmed by a number of interviewees. Two examples from carers show this:

> If you don't ask him right he will tell you, and he thinks and he's telling you the truth as far as he's concerned. And he will, and he will tell people what he thought they wanted to hear (Kevin, 2008 - Carer).

> You have to ask the right questions all the time, which I find infuriating. Because there are so many people that don't have what they are entitled to or don't know about things that could help them. The information isn't readily available (Nicola, 2008 - Carer).

Impression Management

We have related the extant literature on impression management to the use of concealment and disclosure. Regarding concealment, the three themes that appear to be most closely related to impression management are 'concern about negative evaluation', 'avoidance of emotional upset' and 'wanting to fit in'. Regarding disclosure, the theme most closely related to impression management would be the 'need to explain and justify'.

3.3.7 Impression Management

Individuals are at times motivated to present themselves to others in particular ways; this is known as impression management (Leary, 1992; Leary, et al., 1994). Argyle (1967) and Jourard and Lasakow (1957) referred to concealment and disclosure as strategies for projecting a specific self-image; where individuals hide or compensate for undesired aspects of themselves (Turnley & Bolino, 2001) which they feel may lead to disapproval from others, as found in other studies (for example Major & O'Brien, 2005; McCausland & Pakenham, 2003; Ramirez, et al., 1998). Associated with this, health researchers have found that the extent to which individuals can adjust their self-presentation will depend upon their circumstances and this may be restricted by their personal and social image; role constraints; degree of disability, their behaviour and level of self-awareness (McNamara, et al., 2003) and the perceived values of those they are with (Draper & Ponsford, 2008; Tomberg, et al., 2007). Jones and Pittman (1982 - cited in Turnley & Bolino, 2001) put forward five tactics of impression management; these are ingratiation (i.e. flatter to achieve goals), self-promotion (i.e. play down, minimize and self-handicap or build-up and compensate), exemplification (go beyond expectations to achieve a goal), supplication (play on inadequacies to achieve sympathy and support) and intimidation (play-up threats, intimidation, dangerous activities and anger). Turnley and Bolino (2001) say that use of minimization, specifically through the application of supplication and intimidation tactics may lead to lower self-esteem.

Impression management involves a combination of strategies which include modifying behaviour to portray a specific image and controlling the level of disclosure to others to deal with potentially stigmatizing situations (Garssen, 2007; Shotton, et al., 2007): this is particularly relevant to the control of gossip. Other strategies may involve downplaying or minimizing the effects of one's disability (Velikonja, et al., 2009) and compensating by emphasising one's good qualities and destigmatization etc. Examples of these strategies have already been given in the quotes above which suggest that individuals with a TBI engage in deliberate impression management, as well as the carer. Impression management is considered further in the discussion (section 3.4).

Many of our participants seemed to actively choose to conceal or disclose, depending on their circumstances. Disclosure is quite stressful, and therefore has to be worth it before they will consider it. Examples are given from individuals showing how they under-reported or concealed their loss of skills, and compensated for these. Argyle (1967) found that in some circumstances disclosure could lead to disapproval or negative stereotyping, we were given many examples of this in our study, relating to carers, but especially to those with a TBI.

Frank explained the concern he lived with when employed:

> I used to like keep it under me hat, and used to say like about like going for jobs and that. I didn't [know] how to work tills, err I didn't how to work err sort money wise, and things like that. And used to like, umm I didn't know how to like err what change I should, shouldn't hand back. And I would then hand it back and be praying all the time (Frank, 2008).

As a result of Frank's concealment he lost his job, because his employers said he should have told them.

Talking about computer games played on-line with others Collin says:

> The games I used to play, but I can't, still can't remem'ember 'em. But any new games that come out that we get, I'm at the same advantage as them. So it's new for me and it's new for them. So I try and get the new games that are coming out (Collin, 2008).

Asked how he managed Collin said:

> I can get by. But it's not as good as I used to be….We used to play as a team against other teams. I can't, can't do it now. Can't do it, thumbs are too slow; they don't do as they are told (both laughing) (Collin, 2008).

Collin acknowledges his injuries saying "I just wish I hadn't, hadn't 've hurt me head, my body I can cope with. It's just this thing" (banging gently on his head).

Examples from individuals who said they would not hold back in what they would say to others – yet managed their disclosures:

> Oh if somebody asks, I tell 'em. I don't, it don't bother me. Don't bother me at all (Collin, 2008).

However, Collin also minimizes his disabilities saying 'You just, you get used to the pain' and 'I'm alright. I'm alright. Fine, just want to get on'.

> I would tell anybody anything if they asked me (Eric, 2008).

> I'm a very chatty person. Err I like talking, do you know I like conversation. Err it makes me feel better (Graham, 2008).

> My memory is totally different now and there are certain things that I find very difficult to remember. Umm names is the classic one I….don't always ask people for their names because I know I won't remember and I find it very embarrassing when I should know somebody's name but don't (John, 2008).

When asked how he dealt with this John said:

> I've always got some little cards in my wallet and if there's something I need to remember such as a time or date I will write it down. I include with that, with things like names and for example I wrote, I wrote down the fact that I was seeing you today. Just as a memory jogger (John, 2008).

The way that disclosure and seeking support are handled may relate closely to the individual's self-identity or family identity.

These examples show that individuals with a brain injury can and do make decisions to conceal or disclose relating to their circumstances; they put into place ways of coping with their loss of skill. As found by Tyerman and Humphrey (1984 - cited in Draper & Ponsford, 2008) individuals with a TBI do show more insight than some researchers have previously stated.

SECTION FOUR

3.4 Discussion

Tables 3-3 and 3-4 give a summary of results from the thematic analysis. There is considerable overlap between the findings from our study and the existing literature, both from a brain injury perspective and other areas of research, but predominantly from social psychology and mental health research. Extracts from the interviews are provided to highlight some of these connections. We identified six closely linked themes and many examples are a combination of these themes.

Gathering together some of the signs discussed in the literature review that indicate the potential use of impression management, shows that impression management is embedded within the themes we have identified in this qualitative study. These signs include the control of gossip, under reporting of personal difficulties (defensive denial, downplaying or minimizing the effects of the disability and destigmatization); emphasizing one's good qualities (compensation) and the reluctance to admit personal problems and avoiding mentioning disabilities and difficulties (exclusion and concealment and selective self-disclosure). Personal image and self-esteem are protected by directing attention away from personal issues onto other issues or the situation. These signs show how behaviour is modified and controlled to create a specific image.

Disclosure was related to educating others and helping with the recruitment of social support. Some of the motivations behind disclosure were identified and these highlight the importance of asking the right questions and not just with significant others (professionals) as reported by Draper and Ponsford (2008). Disclosure to others raises issues in relation to the need to avoid negative outcomes (for example, gossip, stigma and discrimination) and the use of concealment as an adaptive coping strategy. Gender differences were found in carers regarding the disclosure of information relating to TBI, but not for those with a brain injury. The potential benefits of disclosure in obtaining support linked into the use of impression management, a strategy used by both carers and those with a TBI.

Looking at the cycle of concealment within families and close friends, disclosures are usually made to trusted individuals who are similar to themselves (Afifi & Steuber, 2010). As discussed earlier, disclosure has been found to improve health and well-being (Lutgendorf, Antoni, Kumar, & Schneiderman, 1994 - cited in Greenberg, et al., 1996). But, Chaudoir and Fisher (2010) found that disclosure was not always the best option. We found support for these seemingly contradictory perspectives in this study, for example:

> People who I know quite well I tend to try and tell them quite a lot…people who I don’t know very well, I tell them a lot less (John, 2008).

John’s comment directly reflects the findings of Pinel (2001) about disclosing to those whom the individual knows. This is contrasted with:

> I would tell anybody anything if they asked me (Eric, 2008).

Carers also identified the issue of disclosure, particularly in relation to dealing with professionals:

> You have to ask the right questions all the time, which I find infuriating (Nicola, 2008 - Carer).
>
> If you don't ask him right he will tell you, and he thinks, and he's telling you the truth as far as he's concerned (Kevin, 2008 - Carer).

So individuals need to actually be asked about their TBI before they will talk about it. Whereas Kevin said:

> Actually I think it's important to do it [talk about it], for understanding. I don't see the stigma if any. I can understand X being upset about it (Kevin, 2008 - carer).

But Rose expressed the view of most carers:

> I mean he used to tell, umm, other people about the [accident]. Well, if (laughs) as far as he could (Rose, 2008 - Carer).

Disclosure of brain injury, to educate or inform others, can help some individuals to build up their social support networks (Bowen, et al., 2010; Karlovits & McColl, 1999), which was seen in Kevin's case (and others quoted earlier). And in some circumstances, avoidance has also been described as adaptive if, as Karlovits and McColl (1999) found, it was a means of preventing worse outcomes, such as the loss of control over personal information, as with Rose. Disclosing information about the brain injury raises concerns about gossip:

> I don't want it round the street; you know (Rose, 2008 – Carer)
>
> If you tell somebody you say 'don't say it' and before you know it they've told everybody else (Mary, 2008 - Carer).

These examples contrast the difference between our male and female carers in relation to control of information in the public domain. Female carers applied more control (as far as possible) over the release of information to others, compared to Kevin who disclosed to justify and explain his son's behaviour. Social psychologists Goodwin and Russell (1977) (cited by Endler, et al., 2002), have shown that both male and female participants disclosed more to female friends than to other relatives. In this study we found there was typically one special friend, who was usually, but not necessarily female or family, for example:

> I probably had more help from friends and things than probably family. (Mary, 2008 Carer).

Having associated with others who took advantage of him, Frank says:

> I've walked away from these other people now. I'm err with new friends now and they're looking after me. And showed me things what I can't do (Frank, 2008).

Adaptive coping has been associated with the development of skills and mastery in carers of those with a brain injury (Chronister & Chan, 2006); they used the stress-appraisal-coping theory (model shown as Figure 3-1) to consider how the psychosocial resources available to carers impacted upon outcomes. We looked at disclosure as an adaptive coping strategy, because it has been linked to more successful outcomes; specifically the acknowledgment of feedback and support from others (as in Model 3-3), which is related to better psychological health (Kawamura & Frost, 2004). Mary was the only carer, who received professional support, saying:

> I just completely had no confidence what so ever, and I went for counselling. I mean X doesn't even know because I didn't tell him. I used to just go, because my daughter was there and I'd just go one evening….I spoke to my GP and he gave me some antidepressants….I'm not one to take tablets, but I had to do something because it was

> as if there was; I suppose I was looking for a way to help myself really because I didn’t really have a lot of people around me to give me the support (Mary, 2008 - Carer).

Mary went on to say “I went for some counselling….it was only for a few weeks so I just went for one evening a week” after which she received additional help for a few weeks longer. In explaining this, Mary gave us an example of impression management, as discussed in 3.3.7 and her reason for using it, namely lack of social support.

As we said earlier, some people react to overt disabilities and distinctive features before they communicate directly to the individual (Livneh & Antonak, 2005). Comments from two carers gave support to this:

> If somebody breaks a leg, they limp, you can see it. If they can’t express themselves you either think they’re being rude or they’re thick’ (Kevin, 2008 - Carer).
>
> It’s a hidden injury so people don’t seem to think [about it or be] that bothered…. It’s not always apparent….particularly when you look at X you can’t tell straight off that there’s anything wrong with him (Sue, 2008 - Carer).

Don (2008) who has a brain injury said:

> ‘If you take a longer view when I’m walking you can tell, because my limp’ and ‘if I have my hair cut short you can tell I’ve got so many scars all over me head from, m, the staples’.

Managing the impression given to others can be seen in our examples, for instance in Harry’s comment, where he attempts to minimize the effects of his brain injury when talking to others:

> I’ve had a little injury (Harry, 2008).

He acknowledges that something has happened, but plays down the extent to which the TBI has affected his life.

In relation to physical concealment Rebecca (2008) explained:

> I used to wear make-up and do my hair every day. And it annoys me and upsets me that I can't wear make-up now. And I can't do my hair. So I don't wear make up…. I always felt if, I, my eye make-up looked good that I could give my best, the rest of me. And I used to sometimes wear a lip gloss, but now I don't wear any. But my make-up was put on in the morning because I'd be visiting people…. And now I don't wear any colouring at all. I can't do eye make-up because the eye looking strange. I know people can fear. I don't want it make-up' (Rebecca, 2008).

Rebecca was aware of her physical appearance, and was practicing impression management by removing the focus of attention away from her eye. She later said "I know it is a brain injury, but I don't feel like it is to other people".

Discrimination and stigma has been faced by every interviewee with a TBI in this study. Our next example is from John who explains what happened when he went for an employment interview at a local hospital:

> It's not the same as a mental illness. And I have on a number of occasions, and that I think that's one of them, come across people who don't separate not so much as being mad, but being sort of mentally deficient, and having a brain injury….made me feel less able than I was before I had the head injury. It made me think that it was a bit of a hill to climb….I think it sort of reminded me that dealing with a head injury isn't always easy (John, 2008).

Taking up the discussion from 'impression management' in the findings section - Harry explaining his brain injury is a good example of impression management when the controlled disclosure minimizes the effect of the injuries, distracts from the other impacts of the TBI and emphasizes his good qualities (Francis & Penn, 2001). Just as those from Rebecca do in relation to her management of her additional overt disabilities. She does not use make-up which was once part her self-image in relation to work, and she now minimizes the injury, and attempts to direct attention away from it. All these quotations relate to interviewees redirecting attention away from the problems related to their ABI, or problems for the person they care for, onto other situations as Burkley and Blanton identified in their study (2007).

Endler, Flett, Macrodimitris, Corace, and Kocovski (2002) found that social anxiety and social evaluation were related to situations where individuals were evaluated privately or publicly. This is supported in this study by the examples from carers and those with a TBI, that also related to impression management; namely concealment of the need for counselling by Mary, and the need to control gossip, and minimization of physical injury by Rebecca and Harry. Participants needed to ‘fit in’ and not be seen as different from others because of their relationship with TBI. These findings link closely to the work of Simpson et al. (2000) regarding the need to conceal brain injury from other members of one’s family and associates: and the use of controlled concealment and disclosure and the impact that feedback has upon the individual (to disclose further or to conceal more) as discussed by Chaudoir and Fisher (2010). In Chapter 7, we suggest that some of these areas may be useful for future research.

3.4.1 Managing disclosure

We looked at how individuals dealt with their lives post TBI. We found that disclosure and concealment are used as strategies by those with a brain injury and their carers: within the family to protect each other, outside the family to protect themselves against perceived and actual stigma and discrimination, as Chaudoir and Fisher (2010) and Simpson et al. (2000) found, and for portraying a particular self-image as, for example, less disabled than they really are. In addition, people regulate the amount of information they disclose in different circumstances, including those who have had severe brain injuries. We were also able to identify some of the motivations for the use of concealment and disclosure strategies, given within the quotations and compiled in Tables 3-3 and 3-4.

Group affiliation helps boost self-esteem and through social support and companionship eases loneliness (Haslam, et al., 2008; Leander, Chartrand, & Wood, 2011; Minnes, Graffi, Nolte, Carlson, & Harrick, 2000; Ryan & Deci, 2000); interviewees said they could be themselves when associating with others who have a brain injury; for example:

> Comin' here [Headway], sounds stupid to some people. Comin' here I feel back to normal, I look normal but….inside there's always that twinge of err, the way I feel, and coming here you can see it for yourself. There's worse off people and I, I know no one stares at me inside and I, I just feel sorry for them, they don't. I feel anyone feelin' sorry for me and I don't like it. Ooh, because 'I a ma'n', a, as this old bloke use to say…. I'm a hundred and ten percent men (Don, 2008).

> I can't read a book because of my eyesight and I don't really wanna chat to women, but not that much. And at least they 'oh hello' and 'how are you' and all that, and once that's said there's nothing to say. So playing dominoes passes the time. And it keeps your mind a little bit busy as well (Rebecca, 2008).

This has been related to situations where the individual does not feel so self-conscious (Walker & Winter, 2007) and this fits with Rebecca's motivation for joining the group.

Each interviewee has some level of awareness of the effects the accident has had upon themselves and those around them, especially their children. Several carers and those post-injury have said they disclose to educate others (Karlovits & McColl, 1999). Most individuals managed the information they gave out to others, they actively engaged in impression management. Rather than as references to understated comments, which are used to minimize difficulties as Dyer et al. (2006) and others suggest (Green, 2006; Vohs, et al., 2005) or be the result of self-deception (Ownsworth, McFarland, & Young, 2002): participants appear to be deliberately choosing to disclose or conceal. Others may be using impression management less actively, or they may not consciously engage in it the way many participants in our study did, protecting themselves from negative reactions, emotional upset and to ‘fit in’. Impression management is practiced in many situations and sometimes, as Simpson et al. (2000) found, with rehabilitation professionals; we were given examples of this too, but this is outside the scope of our study.

It seems very likely that how others respond to the disability, and then to the person with the disability, is in turn dependent on how the person deals with the issue of disclosure, as identified by Leary and Kowalski (1990). Throughout this chapter, examples were given from all of our participants that in a small or more significant way reflect the use of impression management. Someone who does not disclose to others that they are emotionally distressed, is unlikely to receive emotional support from others to overcome their despair, as seen in some of the examples. There is a degree of impression management in disclosure; comments can be controlled, pre-prepared and distracting. They may help the person protect themselves, or to put across a particular image of themselves to others.

3.4.2 From the themes identified to the items on the questionnaires

Following thematic analysis, the main issues raised were grouped into one of six themes (shown in Figure 3-1). Extracts from service user interviews are given at the beginning of the next chapter in Tables 4-1 and 4-2 showing how the issues were used to develop items in the questionnaire: the focus on individuals with brain injury is reflected in the leader to each question. In some instances these issues also reflect concerns raised by carers. Provision of ‘carer only’ themes would not necessarily represent the perspectives of service users whose neuropsychological problems would pose particular threats to their identity or give rise to stigma. Threats perceived by carers may well be different, and so data collected only from carers was not included in the questionnaires. After the first study, we decided to concentrate on individuals with a TBI. This decision, also addressed some of the issues raised by Cloute, Mitchell, and Yates (2008) who were concerned that service users perspectives were not adequately represented.

Evidence for this concern comes from several studies. For example Draper and Ponsford (2008) compared the personal perspectives (subjective reports) of 54 individuals with a TBI and their carer/significant other, with the results from a series of psychometric and clinical tests, because differences in self-awareness and mood (such as anxiety and depression) are known to affect responses. Carers/significant others are sometimes seen to hold different concerns to those of the service user with a TBI and they may offer a different perspective, down-playing (minimizing) or over-reporting the severity of the service users difficulties; although most reports are said to be an accurate representation of ability (Bogod, Mateer,& MacDonald, 2003 cited in Draper & Ponsford, 2008). And Dyer et al. (2006) see the under reporting of aggression as a coping response related to socially desirable responding. These studies show that the effects of a TBI are influenced by the experience of the person reporting them, their understanding (knowledge), the social context including cultural factors and relationship (as found by Simpson et al., 2000 and Chaudoir and Fisher, 2010), as well as their level of self-awareness and emotional adjustment to the injuries (acceptance). Service users who describe motor problems, physical problems such as balance and mobility issues, who fail to discuss symptoms, may be described as lacking awareness (Koskinen, 1998 cited in Draper & Ponsford, 2008). Differences have been found between the level of disability an individual has and self-reports of difficulty, specifically regarding cognitive changes, communication, memory and attention deficits, compared to reports from others. In the Draper and Ponsford (2008) study, 88% of the carers/significant others agreed with the response of service users that emotional and behaviour issues, such as aggression, cause problems, a finding also supported by Hart T, White J, Polansky M, et al. (2003 - cited in Dyer, et al., 2006). While there may be differences in the reported abilities of the individual with a TBI and carer/significant other, there are also many shared issues.

3.4.3 Strengths and limitations of this study

The main limitation of our study was the small number of participants who were interviewed. Basing the foundation of our study on ten interviews with those who have a TBI and eight carers may not be seen as representative. However, we did find that the same issues were raised many times by participants. One of the strengths of this study was that participants appreciated the time to talk about concerns that many had kept to themselves since the accident occurred. So, the questionnaires that we developed from these results were based upon real issues of concern for those facing life with a TBI; as recommended by Draper and Ponsford (2008). A major criticism with the use of thematic analysis was raised by Goldfinger (2001), who said that theme selection, by the researcher, influences the data, which they observed in work by Nochi (1997, 2000). This is a natural outcome when the study is designed from the start. We asked others if they endorsed each of the themes identified, and to what extent, in our next two quantitative studies. This should counter some of the concerns that the data reflects researcher bias rather than accurately representing participants' lives.

CHAPTER 4

EVALUATION OF THE QUESTIONNAIRES

SECTION ONE

4.1 Introduction

This second study covers the development and evaluation of two questionnaires: the *Non-Disclosure Questionnaire* (N-DQ) and the *Self-Disclosure Questionnaire* (S-DQ). These questionnaires were designed to measure participants' motivations for concealment or disclosure of issues regarding their TBI.

Potential items for the questionnaires were generated from qualitative data collected during our first study (Chapter 3). The initial questionnaires had 53 items selected from interview extracts from carers (N=8) and individuals receiving rehabilitation care (N=10). The preliminary questionnaires were reviewed by two groups of people with a brain injury, and changes to the items and format were made in accordance with their feedback. The revised questionnaires were then administered to a sample of people with a TBI (N=55), between January and April 2010, and their internal consistency, test re-test reliability and concurrent validity were evaluated.

Several forms of analysis were used in this study, including item analysis which was used to remove unsatisfactory items. Concurrent validity was assessed by examining how two selected sub-scales correlate with two established measures. Reliability was assessed by examination of the internal consistency of the measure, and through an examination of test-retest reliability (temporal reliability) with a sub-sample of participants (N=20).

SECTION TWO

4.2 Methodology

4.2.1 Generation of item pool

The first step in this process was to develop the questionnaire items. Initially 73 items were selected from eighteen interview transcripts, described in the previous chapter. In this selection, the aim was to represent each of the main themes identified. These were reduced to 43 items with the removal of data extracts that were not directly related to the person's willingness or unwillingness to disclose information to others. Ten further items were then developed to ensure there were sufficient numbers of items within each sub-scale. Thus the initial pool consisted of 53 items, encompassing the six themes shown in Figure 4-1 below:

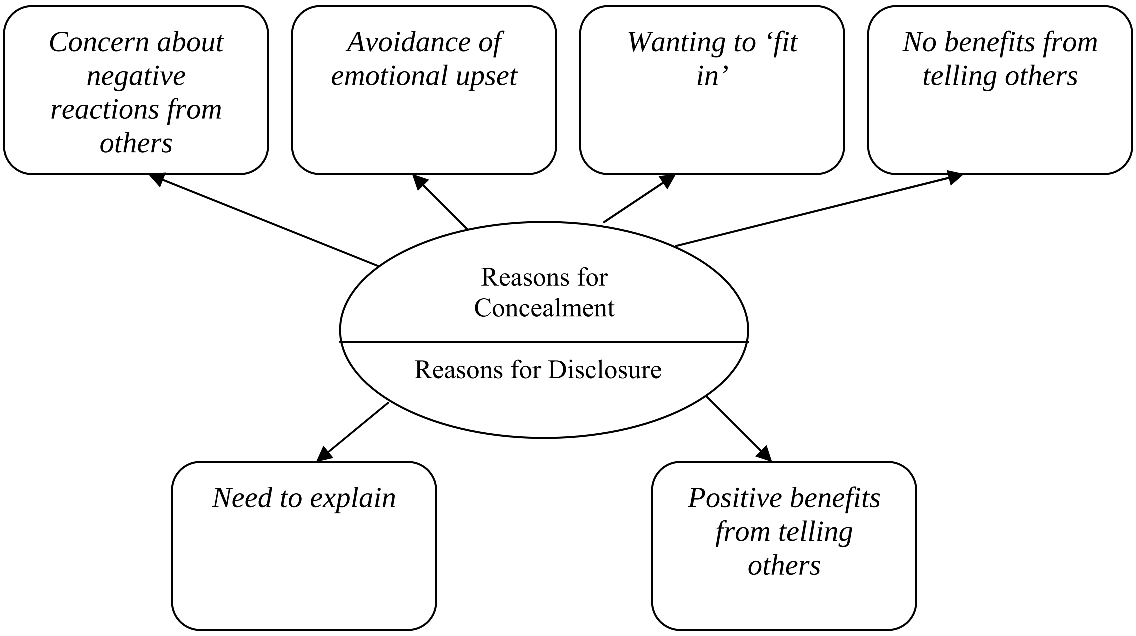


Figure 4-1: Illustration of the six themes identified in the first 'qualitative' study

4.2.2 Review Groups

Individuals attending a Headway day-care rehabilitation centre were invited to take part in an informal discussion about the development of the questionnaire. The questionnaires were given to two groups, on two different occasions to review the format, wording and overall impact. They were asked to attempt some, or all of the questions and to comment on any problems they found. Participants who helped with these evaluations had acquired brain injuries (for example strokes) or traumatic brain injuries that were outside of our inclusion criteria for this second study.

On the first occasion, six female participants took part. The mean age of this group was 61 years (SD 6.4) with an average of 11 years (SD 7.2) since their ABI or TBI event. The second group, who reviewed the questionnaires on a different day, consisted of eight male participants. The mean age of this second group was 45 years (SD 13.3) with an average of 9 years (SD 4.6) since their ABI or TBI event. Their feedback was used to improve items.

Several changes were suggested regarding the wording and length of the item ‘leaders’ and that the format of the items should be changed. Items were originally positively and negatively worded as recommended by Kline (2000). However negatively worded items were revised as reviewers found these items ambiguous and difficult to answer. Following these informal reviews negatively worded leaders for items 1.30 to 1.33 were changed: the associated reverse scoring was also removed so that all questions were scored in the same way. The introductions were felt to be too long. These were subsequently changed from ‘*I don’t say too much about my injury (or the problems it causes me)*’ to ‘*there are times when I keep quiet about my injury*’ for all items in the N-DQ. The leading words to the S-DQ ‘*there have been times when I have explained to other people about my injury (and the problems it causes me)*’ were all changed to ‘*there are times I talk to other people about my injury*’.

Changes were made without altering the intended meaning of the questions. The response scales were originally scored as often = 5, sometimes = 4, not sure = 3, rarely = 2 and never = 1 (Appendix B4). Items 1.30 to 1.33 were worded differently and reverse scored, the rest were presented in a similar format within sections one and two of the S-DQ. Interviewees had explained that they could not swap quickly between topics (for instance Don, 2008 and Collin, 2008), so this was taken into consideration in the design of the layout.

Both review groups were later invited to choose from two revised versions of the questionnaire; each version having different formats. One format was favoured and this was selected, this is shown as Figure 4-2. The benefits of these adjustments were shown in a reduction in the time taken to complete the questionnaires which went from an hour to less than thirty minutes (ranging from 15 minutes to 25 minutes). Feedback from reviewers and other professionals (one academic, one Director of Headway, one Manager of Headway, two Headway trustees and members of staff, carers and volunteers) also helped to improve the questionnaires.

4.2.3 Non-Disclosure and Self-Disclosure sub-scales

The individual questions were grouped into the six themes, or sub-scales, illustrated in Figure 4.1. Each item in the N-DQ and S-DQ questionnaires is supported by an auditable trail from the interview extracts to the questionnaire (Clarke & Watson, 1995). Examples of how the interview extracts and subsequent questionnaire items relate to the 6 sub-scales are given in Tables 4-1 and 4-2. These extracts are all from individuals with a TBI, although many of the issues were also raised by carers. Further information on these sub-scales is given after the tables.

Table 4-1: Example of extracts forming sub-scales 1 to 3 for the Non-Disclosure Questionnaire (N-DQ)

Extract example	N-DQ Sub-Scales 1 to 3	Ref.
Concern about negative reactions from others		**N-DQ$_1$**
People who don't separate not so much as being mad but being sort of mentally deficient and having a brain injury	1.2/ss1: other people might think I was mad or dangerous	11-J
X gets most of it. I'm always moaning about something…. She gets mad at me	1.6/ss1: the other person might get annoyed if I talk about it	5-C
They look down on ya', if you know what I mean. As if you're second class.	1.8/ss1: the other person might start to talk down to me or patronize me	3-A
They treat you as an idiot.	1.9/ss1: the other person might think badly of me	3-A
Does annoy me sometimes because….she won't even let me get down one step.	1.11/ss1: people might start to watch closely what I do and say	2-D
When someone's talking about ya', just switch yourself off.	1.13/ss1: the other person might gossip about me to others	2-D
I was getting teased, and X wouldn't do anything about it. They was taking the Mickey, you know what I mean?	1.15/ss1: I might be made fun of	10-H
I was mixing with the wrong people and err and they wanted other things like that. And when I didn't have no money they just ran off. They didn't want to know me.	1.17/ss1: the people I am with might take advantage of me	7-F
[I appear] stupid sometimes. If I get into a situation where I'm, especially with things like names	1.19/ss1: the other person might think I was stupid	11-J
That's banned in our house, don't, I can't say that.	1.20/ss1: the other person might be fed up of hearing about it	5-C
Avoidance of emotional upset		**N-DQ$_2$**
Like they could've ended up in a wheelchair and they've had a motorbike accident and you don't know it…..and you tell 'em what's happened to you it, and it upsets 'em, even more and makes 'em remember what happened to them	1.1/ss2: talking about it reminds me of all the bad things that have happened	1-I
Inwardly I felt ashamed that I had to rely on other people	1.4/ss2: I would feel ashamed if I told them	8-G
(Telling others about the accident) It upsets you, yourself a bit	1.10/ss2: I would get upset if I started to talk about it	1-I
I don't find it easy talking to people about my, effectively my medical situation. Because it's not, I'm not always comfortable doing it and it, I feel it has to be worth it.	1.18/ss2: I know talking about it would make me feel worse	11-J
I get a bit embarrassed	1.21/ss2: I would get embarrassed if I told them	7-F
Wanting to 'fit in'		**N-DQ$_3$**
I don't want to be sort of judged and questioned. 'Why the hell didn't you remember that?' Which is what I think to myself?	1.3/ss3: I don't want to be asked all kinds of questions about it	11-J
Because when I explain the effects that the head injury has had. It tends to be explaining things that are not as good now as they used to be.	1.5/ss3: I don't want to be marked out as 'the person with the head injury'	11-J
….well I think it sounds quite bad, she has to keep an eye on what I eat, blah, blah, blah.	1.7/ss3: I think they might make a fuss about it	6-E
No, I don't talk about it immediately.	1.12/ss3: I don't like the attention I get when I do tell someone	11-J
This bloke up at the bar turned around and said, 'Are you coming to put us off our drinks you spastic'. I just turned around and walked out	1.16/ss3: I don't want to have to explain things yet again	1-I

Ref: Interview number and interviewees initial (pseudonym) all from individuals with a TBI

Table 4-2: Example of extracts forming subscale 4 of N-DQ and two sub scales for the Self-Disclosure Questionnaire (S-DQ)

Extract example	N-DQ$_4$ and S-DQ Sub-Scales	Ref.
No benefits from telling others		**N-DQ$_4$**
….they don't seem to care if I'm on crutches or not. I had one woman nearly knock me over with a trolley…. I think I shouted at her….I just walked away in the end	1.14/ss4: other people don't understand what I've been through	5-C
I start reeling off a story and they'll start edging away from me	1.22/ss4: other people aren't that interested in what's happened to me	5-C
I was still having a problem and I keeps telling her, and kept telling her.	1.23/ss4: not much good ever comes from me telling other people about it	10-H
Sometimes I feel 'what's the point of explaining how I feel'. 'Sod it like'	1.24/ss4: I can't see that there's much point talking about it	8-G
Everybody I go and see 'Oh, it'll take time'. I know it's gonna take time. That's all they ever say. 'Oh, it's gonna take time'.	1.25/ss4: talking about it doesn't help me	5-C
Need to explain		**S-DQ$_1$**
It's good for them to know…….and it stops them doing silly things.	2.11/ss1: It makes me feel better if they know why I am like this	1-I
Because when I explain the effects that the head injury has had, it tends to be explaining things that are not as good now as they used to be.	2.12/ss1: If I don't explain then they might think I'm stupid	11-J
Where I worked, I try to explain to them 'cos I can't express me-self properly to word wise.	2.13/ss1: I don't want them thinking I'm strange or odd	10-H
I felt I needed to explain myself, because I was, well I felt I was quite different and I needed to justify why I couldn't remember things and why I wasn't particularly good at time keeping.	2.14/ss1: I just feel I've got to explain myself to them	11-J
They didn't seem to be comfortable with the fact that there could be something wrong with my brain.	2.15/ss1: I don't want them getting the wrong idea about me	11-J
Positive benefits from telling others		**S-DQ$_2$**
We all used to help each other there and it was really nice.	2.1/ss2: I want emotional support	12-R
My brother said 'cos I was always upset, and then he said 'But the main thing is to get better, show people that you can do it, an' an you can be home'	2.2/ss2: they help me keep going when I feel like giving up	2-D
I like talking, do you know I like conversation. Err it makes me feel better.	2.3/ss2: I don't want to bottle up my feelings	8-G
And he says like 'Well done, you're learning', and err 'We're gonna teach you if you're willing to l, learn'. And I said 'Ohh yeah'. I wanted to better me-self	2.4/ss2: talking to others helps me understand my difficulties better	7-F
Well if it wasn't for having carers who helped me and day centres I'd be a right mess.	2.5/ss2: I feel like I'm not facing my problems alone	1-I
They deal with brain damages and err people who has breakdowns. And they err said like, 'We will all get together and we'll all like talk….about the same problems what we had'.	2.6/ss2: I wanted more information about my problem	7-F
I've been chatting to him and he's been, been quite helpful with me.	2.7/ss2: once they understand, people are generally helpful	10-H
Thank God I've got people that I can talk to	2.8/ss2: I am feeling low and need some emotional support	2-D
But you know you've got good brothers and who'll sort you out.	2.9/ss2: they help me sort my problems out	2-D
If I can find somebody to talk to I'm fine then after.	2.10/ss2: I feel better for getting things off my chest	10-H

Ref: Interview number and interviewees initial (pseudonym) all from individual with a TBI

4.2.3.1 Non-Disclosure sub-scales

N-DQ$_1$: Concern about negative reactions from others. Individuals may not want to reveal personal information because of worries about how others may react. There were 12 items in this sub-scale; for example '*the other person might get annoyed if I talk about it*'.

N-DQ$_2$: Avoidance of emotional upset. Individuals may not want to reveal personal information because they do not want to be upset. There were 6 items in this sub-scale; for example '*I would feel ashamed if I told them'.*

N-DQ$_3$: Wanting to 'fit in'. Individuals may not want to reveal personal information because they want to fit in and not be marked out as someone with a head injury. There were 7 items in this sub-scale; for example '*I don't want to have to explain things yet again'.*

N-DQ$_4$: No benefits from telling others. Individuals may not want to reveal personal information because they can see no benefits from telling others about their head injury. There were 8 items in this sub-scale; for example '*I can't see there's much point talking about it'.*

Together these 33 items in 4 sub-scales form the Non-Disclosure Questionnaire (N-DQ).

4.2.3.2 Self-Disclosure sub-scales

S-DQ$_1$: Need to explain. Individuals may want to reveal personal information because they want to explain about their head injury, or to educate others. There were 7 items in this sub-scale; for example '*I don't want them getting the wrong idea about me'.*

S-DQ$_2$: Positive benefits from telling others. Individuals may want to reveal personal information because they perceive there are benefits to telling others about their head injury.

There were 13 items in this sub-scale; for example '*they help me keep going when I feel like giving up*'.

Together these 20 items in 2 sub-scales form the Self-Disclosure Questionnaire (S-DQ).

4.2.4 Social support questions

Social support items were included in the questionnaire to measure the utilisation of support, as existing measures were considered to be unsatisfactory. Information on social support is required later in the consideration of one of our hypotheses (that those who conceal information access less social support). Ten questions relating to social support were asked. These were in four groups '*Do you have people you can talk to?*' (questions 1 and 2); '*How much do you disclose?*' (questions 5, 6 and 7); '*How often do you get support?*' (questions 8 and 9) and '*How supported do you feel?*' (questions 3, 4 and 10). These questions formed Section 3 of the questionnaire. Correlations are given in Appendix Tables B-1 and B-2.

4.2.5 Organization and completion of the questionnaire

The questionnaire was referred to as the 'Self-Disclosure Questionnaire' (S-DQ) for the first study. The S-DQ included fifty three statements related to different reasons why a person may conceal or disclose information regarding their experiences of traumatic brain injury. Instructions for completion were given on the first page of the questionnaire and were also given verbally to each participant. Appendix B4 shows the original version of the questionnaire before the response scale wording was altered. The format selected can be seen as Figure 4-2 and Appendix C1.

Section 1
Reasons you may have for not sharing information with others

1.3	There are times when I keep quiet about my injury because: **talking about it reminds me of all the bad things that have happened**				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

Figure 4-2: Example of an item in the questionnaire

Each item states the main theme (of disclosure or concealment) as a leader, for example '*I keep quiet about*' followed by the specific question. There are four sections: section one (known subsequently as the Non-Disclosure Questionnaire) had 33 items relating to concealment, section two had twenty items asking about possible motivation to disclose (known subsequently as the Self-Disclosure Questionnaire), section 3 asked about social support and section four asked for demographic information.

4.2.5.1 Completion and scoring of the questionnaires

Participants were asked to select a response for each item from a 5 point Likert type scale (an example is given in Figure 4-2). According to Tate (2010) 'ordinal' data collected from Likert Scales is not really the equivalent of 'interval' measurement. To help to overcome this as far as possible, wording on the scale responses was carefully arranged so that they were opposites, for example '*probably true'* and '*probably false'*.

Responses were scored as 5 = '*Definitely True'*, 4= '*Probably True'*, 3 = '*Not Sure'*, 2 = '*Probably False'* and 1 = '*Definitely False'*; only the text was given on the response option. High scores mean higher levels of concealment / disclosure. The social support questions (SSQ) were recorded on 5 point Likert scales, but with variously worded response options (the social support questions and different responses are given in Appendix B4 Section 3).

4.2.5.2 Procedure

Following the granting of ethical approval from the University of Birmingham (Appendix B1), participants were recruited from two Headway Day Centres (Headway is a charitable trust for people with acquired brain injuries and each centre is run independently).

Staff at each Day Centre approached participants who they considered were able to consent to take part in this study. Three further participants were unable to take part because of communication problems that could not be overcome. A further three did not participate because staff felt they would not co-operate due to alcohol or substance abuse in addition to their disabilities. Each potential participant was given an information sheet by the staff member (Appendix B2). Those who were interested then made direct contact with the researcher and were given the opportunity to ask further questions about the study. The procedure was clarified with each participant and they were given time to decide if they wished to participate.

Appointments were arranged with participants, and data collected, at their day centre during opening hours. Each participant was asked to sign a consent form (Appendix B3) before completing the six questionnaires. These were presented in different sequences (counterbalanced) to reduce possible order effects. Most participants read and completed the questionnaires themselves with occasional support. Some participants required their questionnaires to be read to them and where necessary their responses were recorded for them; supporting these needs helped to increase inclusion.

The questionnaires were trialled on participants who were asked to complete as many questions as possible. They could do this over more than one session if required. Sixty questionnaire packs were prepared and in total 55 were completed, giving an overall response rate of 91%. All participants were asked to help with the re-test, so we could check for temporal reliability. All consent forms and questionnaires were assigned an identity number, to enable follow up questionnaires for the reliability analysis to be matched to the participant and enable removal should anyone wish to withdraw from the study. The same researcher collected most of the data with three exceptions when support was given by Day Centre staff. No postal questionnaires were sent out and all data were collected in person.

A separate debriefing for participants was not required: details were included in the Information Sheet (Appendix B2) which was read to some participants. Details of available support, in case of distress or concern, were included. Participants were reminded that they could withdraw from the study if they wished to do so (before or after data collection) and their data removed.

A summary of the results, in the form of a poster (with few technical and no personal details) will be made available to participants at the end of the study. The poster will be shown by the researcher, during a visit to the Day Centres. This will give those who wish to discuss the study an opportunity to ask questions.

4.2.5.3 Inclusion and Exclusion Criteria

One change was made to this protocol arising from the first study and that was to ensure participants were adults when they had their brain injury. The study was open to male or female participants who:

- Have had a traumatic brain injury
- Are over twelve months post-injury
- Are over the age of nineteen and up to 70 years of age
- Were adults when their TBI happened
- Have been left with mental and/or physical disability as a result of their TBI.

- Have a level of English and level of cognitive ability that are adequate for them to read the questionnaires; or to listen to and understand the questions.

4.2.6 Demographic characteristics of participants

Demographic details were requested from 9 items in section 4 of the questionnaire. This is summarised in Table 4-3 below.

Table 4-3: Demographic characteristics of individuals with TBI (N = 55)

Characteristics of individual with TBI	N = 55	percentage
Gender – item 4.1		
Male	42	76
Female	13	24
Age (item 4.2)	47 yrs (SD 12.6)	Range 27 to 70 yrs
Marital Status – item 4.3		
Single	22	40
Separated/divorced	12	22
Widowed	2	4
Married/have a partner	19	34
How TBI occurred – item 4.4		
Vehicle driver/passenger	20	36
Pedestrian	6	11
Motorcycle	7	13
Bicycle	3	5.5
Fall	5	9
Industrial Accident	3	5.5
Assault	6	11
Sports Injury	1	2
Other	4	7
Disability – item 4.5		
Obvious to others	9	16
Both hidden and obvious	24	44
All hidden	22	40
Education – item 4.6		
Secondary School	32	58
Higher Education	23	42
Current Occupation – item 4.8		
Not working	47	85
Part-time voluntary	6	11
Working -time paid	2	4
Time since accident (item 4.9)	13.13 yrs (SD 12)	Range 2 to 35 yrs

Pre-injury employment coding from item 4.7 is given in Table 4-4 below

Table 4-4: Item 4.7 pre-injury employment coding for N=55 people with TBI

Employment Code		Frequency	Group	Percentage
Managers and senior officials	11	1	1	18
	12	2		
Professional occupations	21	4		
	23	1		
	24	1		
Associate prof. and technical occupations	32	1		
Administrative and secretarial occupations	41	1	2	40
Skilled trades occupations	51	2		
	52	3		
	53	4		
	54	4		
Personal service occupations	61	3		
	62	1		
Sales and customer service occupations	71	1	3	38
Process, plant and machine operatives	81	3		
	82	4		
Elementary occupations	91	6		
	92	4		
	95	2		
Unemployed / occupation not stated	99	2	4	4
Students	NC	5		
Total		55	-	100

Not Classified: the LFS does not classify students they are described as ‘economically inactive’.

Item 4.7 asked participants about their employment before their injury. This was coded using the Labour Force Survey User Guide – Volume 5: LFS Classifications 2009. UK Data Archive Study Group Number 33246 – Quarterly Labour Force Survey: March 2009. The LFS does not classify students they are described as ‘economically inactive’.

There were no significant correlations found between these groups and the other variables.

4.2.7 Questionnaires used in the assessment of concurrent validity

Two existing and well tested questionnaires were chosen as external criteria against which selected sub-scales of the N-DQ and S-DQ would be correlated. These questionnaires, completed at the same time as our questionnaires, are theoretically related to the concepts of concealment and disclosure. It was expected that the Brief Fear of Negative Evaluation (BFNE) (Leary, 1983) would be correlated with the N-DQ$_1$ '*concern about negative reactions from others'*, since both ask about the person's fear of the negative reactions of others in social situations. It was expected that the Distress Disclosure Index (DDI) (Kahn & Hessling, 2001) would be correlated with S-DQ$_2$ '*positive benefits from telling others*' because both consider the person's willingness to seek social support from others.

4.2.7.1 Additional Measures

The Brief Fear of Negative Evaluation (BFNE) scale was developed by Leary (1983). The 12-items are rated on a 5 point Likert-type scale consisting of 'Not at all characteristic of me' = 1; 'Slightly characteristic of me' =2; 'Moderately characteristic of me' = 3; 'Very characteristic of me' = 4 and 'Extremely characteristic of me' = 5. Item numbers 2, 4, 7 and 10 are reverse scored. Higher scores indicate fear of negative evaluation. The format was adjusted to resemble the other measures and the word 'characteristic' has been substituted for 'true'.

The Distress Disclosure Index (DDI) developed by Kahn and Hessling (2001) is a 12-item measure of people's readiness to seek out social support when distressed. Items are rated on a 5-point Likert-type scale ranging from 1 strongly disagree (SD) to 5 strongly agree (SA). Item numbers 2, 4, 5, 8, 9 and10 are reverse scored. High scores represent greater readiness to seek support.

4.2.8 Test re-test

We aimed to collect retest data from 20 to 25 participants from the original sample. All participants were asked, and twenty participants consented to complete the questionnaires for a second time, a sample size of 36%. This is in agreement with an ABI study, conducted by Willer, Rosenthal, Kreutzer, Gordon, and Rempel (1993) who obtained a 32% retest sample size and a study on graduates by Watson and Friend (1969) with a 43% retest sample. The time period between the two administrations of the questionnaires was between two and six weeks.

SECTION THREE

4.3 Results

Analysis of the data was carried out in several stages. First the data was examined using item analysis and properties of the N-DQ and S-DQ were evaluated. Concurrent validity was established, followed by an examination of the test re-test data. Data sets are complete with the exception of the DDI where one participant was unavailable to complete this measure.

4.3.1 Item Analysis

The overall aim of item analysis is the removal of unsatisfactory items (Clarke & Watson, 1995; Kline, 2000; Pallant, 2007). We followed clear criteria for excluding items. Some were excluded in order to reduce the length of the questionnaire. We finally selected 10 items for N-DQ$_1$ and S-DQ$_2$, and then 5 for each of the other sub-scales. If there were more than 10 or 5 items respectively that were satisfactory regarding their item total correlation (ITC) and distribution, items were excluded on the basis of having poorer distributions or lower ITCs. In Tables 4-5 and 4-6 the items removed are shown with an ‘X’.

Table 4-5: Item descriptions for non-disclosure questionnaire – part 1

Item Descriptive Statistics for the N-DQ					
Sub-scale or measure	Mean	SD	Item-Total Correlation (ITC)	Cronbach's Alpha if Item Deleted	Removed X
N-DQ$_1$: *Concern about negative reactions from others* - 12 items					
1.4/ss1: other people might think I was mad or dangerous	2.45	1.597	.527	.862	
1.7/ss1: other people might start drawing the wrong conclusions about me	3.16	1.561	.450	.867	X
1.11/ss1: the other person might get annoyed if I talk about it	2.53	1.438	.552	.861	
1.13/ss1: the other person might avoid me in the future if they knew	2.69	1.574	.367	.872	X
1.14/ss1: the other person might start to talk down to me or patronize me	2.96	1.610	.659	.854	
1.17/ss1: the other person might think badly of me	2.53	1.514	.643	.855	
1.19/ss1: people might start to watch closely what I do and say	3.00	1.528	.471	.866	
1.21/ss1: the other person might gossip about me to others	2.87	1.634	.654	.854	
1.23/ss1: I might be made fun of	2.93	1.654	.669	.853	
1.25/ss1: the people I am with might take advantage of me	2.96	1.621	.502	.864	
1.27/ss1: the other person might think I was stupid	2.91	1.746	.646	.855	
1.28/ss1: the other person might be fed up of hearing about it	3.38	1.581	.542	.862	
N-DQ$_2$: *Avoidance of emotional upset* - 6 items					
1.3/ss2: talking about it reminds me of all the bad things that have happened	2.75	1.566	.577	.665	
1.8/ss2: I would feel ashamed if I told them	2.35	1.468	.378	.722	
1.16/ss2: I would not be able to control my feelings	2.96	1.563	.202	.770	X
1.18/ss2: I would get upset if I started to talk about it	2.58	1.652	.666	.634	
1.26/ss2: I know talking about it would make me feel worse	2.62	1.521	.575	.667	
1.29/ss2: I would get embarrassed if I told them	2.24	1.515	.453	.702	
N-DQ$_3$: *Wanting to ‘fit in’* - 7 items					
1.2/ss3: telling others about it makes me feel like I’m not normal	2.89	1.583	.310	.684	X
1.5/ss3: I don’t want to be asked all kinds of questions about it	3.05	1.545	.347	.674	
1.9/ss3: I don’t want to be marked out as ‘the person with the head injury’	2.89	1.652	.434	.650	
1.12/ss3: I think they might make a fuss about it	2.93	1.514	.339	.675	
1.15/ss3: I just want to have a normal conversation with someone	4.07	1.215	.439	.654	X
1.20/ss3: I don’t like the attention I get when I do tell someone	3.38	1.604	.376	.666	
1.24/ss3: I don’t want to have to explain things yet again	3.31	1.574	.593	.604	

Table 4-6: Item descriptions for N-DQ4 and self-disclosure questionnaire – part 2

Item Descriptive Statistics for the N-DQ$_4$ and S-DQ					
Sub-scale or measure	Mean	SD	Item-Total Correlation (ITC)	Cronbach's Alpha if Item Deleted	Removed X
N-DQ$_4$: *No benefits from telling others* - 8 items					
1.1/ss4: I don't need emotional support from others	3.02	1.497	.016	.670	X
1.6/ss4: I don't need help from other people	3.04	1.515	.126	.643	X
1.10/ss4: other people don't need to know	3.51	1.502	.234	.613	X
1.22/ss4: other people don't understand what I've been through	3.98	1.326	.334	.586	
1.30/ss4: other people aren't that interested in what's happened to me	3.45	1.345	.243	.609	
1.31/ss4: not much good ever comes from me telling other people about it	3.31	1.502	.417	.561	
1.32/ss4: I can't see that there's much point talking about it	3.47	1.550	.604	.498	
1.33/ss4: talking about it doesn't help me	3.33	1.540	.639	.487	
S-DQ$_1$: *Need to explain* - 7 items					
2.14/ss5: they might jump to the wrong conclusions about me if I don't tell them	3.33	1.564	.361	.785	X
2.15/ss5: It makes me feel better if they know why I am like this	3.55	1.451	.569	.746	
2.16/ss5: If I don't explain then they might think I'm stupid	3.51	1.489	.656	.728	
2.17/ss5: I don't want them thinking I'm strange or odd	3.02	1.521	.570	.745	
2.18/ss5: I just feel I've got to explain myself to them	3.18	1.645	.530	.752	
2.19/ss5: they might be able to avoid making the same mistakes that I did	3.15	1.671	.268	.805	X
2.20/ss5: I don't want them getting the wrong idea about me	3.35	1.542	.663	.726	
S-DQ$_3$: *Positive benefits from telling others* - 13 items					
2.1/ss6: I want emotional support	3.07	1.451	.622	.863	
2.2/ss6: they help me keep going when I feel like giving up	3.09	1.613	.481	.872	
2.3/ss6: I don't want to bottle up my feelings	2.95	1.508	.609	.864	
2.4/ss6: talking to others helps me understand my difficulties better	3.51	1.426	.727	.858	
2.5/ss6: I feel like I'm not facing my problems alone	3.29	1.474	.621	.863	
2.6/ss6: I wanted more information about my problem	2.96	1.587	.522	.869	
2.7/ss6: once they understand, people are generally helpful	3.60	1.448	.443	.873	
2.8/ss6: I am feeling low and need some emotional support	2.91	1.494	.500	.870	
2.9/ss6: they help me sort my problems out	3.44	1.344	.616	.864	
2.10/ss6: I wanted practical help	3.80	1.380	.466	.872	X
2.11/ss6: I have a problem that I can't sort out myself	3.76	1.305	.530	.869	X
2.12/ss6: If they understand what the problem is, they can help me	3.62	1.254	.493	.870	X
2.13/ss6: I feel better for getting things off my chest	3.64	1.544	.589	.865	

4.3.2 Descriptive statistics and internal reliability for the Non-Disclosure (N-DQ) and Self-Disclosure Questionnaires (S-DQ)

Item analysis, plus the restriction on the length of the questionnaire, led to a reduction in the number of items in the sub-scales for the N-DQ and S-DQ (Table 4-5 and Table 4-6). Correlations for all the sub-scales and the additional measures (the SSQ, BFNE and DDI) are shown in Appendix Table B1.

4.3.2.1 *Exploration of the data – checking for normal distribution and outliers*

Using the ‘explore’ facilities of SPSS 19, descriptive statistics were obtained for all the measures and sub-scales used in this study. Table 4-7 gives the range, mean, standard deviation, the Shapiro-Wilk statistic (for a normally distributed data set a non-significant figure of .05 or above is required), and Cronbach’s alpha.

Table 4-7: Descriptive statistics

Descriptive Statistics							
N = 55	Possible Range		Mean	Standard Deviation	Shapiro-Wilk		Cronbach’s Alpha Coefficient
	Minimum	Maximum			Statistic	Sig.	
NDQ_1	10	50	28.53	10.85	.954	.034	.87
NDQ_2	5	25	12.53	5.58	.945	.013	.77
NDQ_3	5	25	15.56	5.07	.976	.330	.64
NDQ_4	5	25	17.54	5.10	.957	.045	.74
SDQ_1	5	25	16.60	5.78	.934	.005	.81
SDQ_2	10	50	32.45	9.89	.951	.024	.86
SSQ	10	50	31.33	7.12	.955	.039	-
BFNE	12	60	30.07	11.53	.969	.174	.87
DDI	12	60	32.78	9.87	.947	.018	.85

Table 4-7 shows that N-DQ_3 and the BFNE have normal patterns of distribution, the others are significantly positive (Shapiro-Wilk statistic) indicating non-normal distributions of the data, and showing a violation of the assumption of normality (Field, 2009; Pallant, 2007). As the majority of the measures are non-normally distributed, this indicates that non-parametric data analysis should be used.

Internal consistency of the sub-scales was assessed using Cronbach's alpha 'α'. With the exception of N-DQ$_3$ they satisfy the benchmark of .7 for good internal consistency (Pallant, 2007). Cronbach's alpha is not given for the social support questions because they were not intended to be an additional measure. The data were checked for outliers and none were identified.

4.3.3 Social support questions

Correlations are given in the Appendix Table B1 between the social support questions (SSQ) and other measures in this study. Properties of the SSQ are given in Table 4-7. Summary item statistics given in Table 4-8 has a mean of 3.13, with item total correlations ranging from .14 to .57: this indicates relationships between the items were poor. Further analysis showed that items 3.2, 3.4 and 3.6 did fit well together with a Cronbach's alpha level of .81 and a mean of 2.75 for 3 items.

Table 4-8: Descriptive statistics for the social support questions

Item Descriptive Statistics *Social Support Questions* (SSQ)					
Sub-scale or measure	Mean	SD	Item-Total Correlation (ITC)	Cronbach's Alpha if Item Deleted	Consider for removal X
SSQ$_1$: *Do you have people you can talk to?*					
3.1: Do you have family members that you could talk to about your problems?	3.35	1.32	.242	.676	X
3.2: Do you have friends (or neighbours) that you could talk to about your problems if you want to?	2.65	1.64	.527	.618	
SSQ$_2$: *How much do you disclose?*					
3.5: How much do you tell your immediate family about your problems?	2.98	1.45	.340	.659	
3.6: How much do you tell your friends about your problems?	2.44	1.49	.400	.647	
3.7: How much do you tell other people that you're not that close to (e.g. neighbours, acquaintances) about your problems?	1.56	.90	.135	.687	X
SSQ$_3$: *How often do you get support?*					
3.8: How often do you get practical help from your family, friends or neighbours?	3.80	1.38	.225	.680	X
3.9: How often do you get emotional support from your family, friends or neighbours?	3.33	1.53	.354	.657	
SSQ$_4$: *How supported do you feel?*					
3.3: How supportive are your family?	4.09	1.38	.235	.678	X
3.4: How supportive are your friends (or neighbours)?	3.16	1.53	.567	.611	
3.10: Do you feel the help and support you receive is enough?	3.96	1.25	.347	.659	

4.3.4 Concurrent validity

The BFNE and DDI were used to assess concurrent validity with N-DQ$_1$ '*concern about the negative reactions from others*' and S-DQ$_2$ '*positive benefits from telling others*'.

4.3.4.1 Correlation of the N-DQ$_1$ with the BFNE

Properties for the Brief Fear of Negative Evaluation are given in Table 4-7. We hypothesised that the BFNE, a measure of the fear of negative evaluation and loss of social approval, would correlate with N-DQ$_1$ '*concern about the negative reactions from others*'. A Spearman's rho correlation showed a significant positive relationship:

$r_s = .418, n = 55, p = .002$

The correlation between the BFNE and N-DQ$_1$ provides evidence for the validity of the N-DQ$_1$ (measuring negative evaluations) but the fact that the correlation is only modest suggests that the sub-scale also has unique properties; they share 17.5% variance. Spearman's rho correlations for the BFNE, with the N-DQ, S-DQ, SSQ and DDI are given in the Appendix in Table B1. N-DQ$_2$ and N-DQ$_3$ also correlate positively with the BFNE.

4.3.4.2 Correlation of theS-DQ$_2$ with the DDI

Properties for the Distress Disclosure Index are given in Table 4-7. Spearman's rho correlations for the DDI, with the N-DQ, S-DQ, SSQ and BFNE are given in the Appendix in Table B1. One participant was unavailable to complete the DDI, so correlations were measured with 54 participants. We hypothesised that the DDI (a measure of the willingness to confide in others when upset) would correlate with S-DQ$_2$ '*positive benefits from telling others*'. A Spearman's rho correlation showed a significant positive relationship:

$r_s = .595, n = 54, p = .001$

This correlation provides evidence for the concurrent validity of the S-DQ$_2$ but the modest size of the correlation suggests that the sub-scale has unique properties; they share 35.4% variance.

Appendix Table B1 shows a Spearman's rho correlation between N-DQ$_4$ '*no benefits from telling others*' and the DDI, readiness to disclose to others. There is a negative relationship between these variables, with 17% shared variance.

$r_s = -.413, n = 54, p = .002$

This relationship supports the findings between the S-DQ_2 '*positive benefits from telling others*' and the DDI. This is of interest because the other three N-DQ sub-scales related positively to the BFNE.

4.3.5 Test retest reliability

Twenty participants from the original group of 55, agreed to complete the questionnaires for a second time. One participant's data was excluded from the analysis because the difference between his two sets of scores was extreme and this had an undue influence on the results. There was an explanation, in terms of his mental state, of why he might not show stability in his answers to the questionnaire.

Test re-test data analysis was based on intra-class correlation coefficients (ICC). The ICC refers to the correlation between the two sets of scores. The clinical significance of the ICC, using the criteria given in Tate (2010), was taken as:

- Excellent > 0.75
- Good 0.6 – 0.7
- Fair 0.4 – 0.59
- Poor < 0.4

Overall test re-test reliability was observed (intra class correlations (Table 4-9), ranged from .38 to .81).

The F statistic in Table 4-9 is a one-way repeated measure ANOVA of the items in the sub-scale. It is an indication of whether there was a significant change between the two means of administration and provides further evidence of the temporal stability of the measure.

4.3.5.1 N-DQ and S-DQ intra-class correlations (ICC)

To assess the test-retest reliability of sub-scales of the N-DQ and the S-DQ, intra-class correlations were calculated, using a two-way random model focussed on single measures and absolute agreement (McGraw & Wong, 1996; Weir, 2005). ICC values and F test statistics are given in Table 4-9.

Table 4-9: Intra class correlations for the N-DQ test re-test

Intra-class correlations for N-DQ and S-DQ sub-scales					
Sub-scale	ICC	95% confidence limits	p	F	sig.
N-DQ$_1$: '*Concern about negative reactions from others'*	.787	.530 to .912	.001	.402	.534
N-DQ$_2$: *'Avoidance of emotional upset'*	.805	.562 to .920	.001	.124	.729
N-DQ$_3$: '*Wanting to fit in'*	.772	.506 to .905	.001	.878	.361
N-DQ$_4$: *'No benefits from telling others'*	.376	-.066 to .699	.049	1.38	.255
S-DQ$_1$: *'Need to explain (justify behaviour and educate others'*	.428	.028 to .734	.033	.300	.591
S-DQ$_2$: *'Positive benefits from telling others'*	.776	.504 to .908	.001	.076	.787

4.3.5.2 Temporal Stability of the N-DQ and S-DQ

All sub-scales show significant relationships between the scores obtained on the two administrations of the questionnaires (Table 4-9). ICC values of .7 to .8 indicate excellent temporal reliability of four sub-scales (Ageberg, Flenhagen, & Ljung, 2007; Tate, 2010; Weir, 2005). For N-DQ$_4$ the ICC at .38 is poor and S-DQ$_1$ with an ICC of .43 is fair indicating that these sub-scales are somewhat less stable. All the F statistics indicate there was no significant change between the two administrations of the questionnaires, which is the desired outcome. Together these values indicate that most of the sub-scales, when administered to individuals with TBI, are reasonably stable (have temporal stability) over four to six weeks.

4.3.6 Relationship between the N-DQ and S-DQ sub-scales

Appendix Table B1 gives Spearman's rho correlations (2-tailed) between sub-scales of the Non-Disclosure Questionnaire and the Self-Disclosure Questionnaire. There are three positively significant correlations between these two questionnaires:

N-DQ$_1$ '*Concern about negative reactions from others'* and S-DQ$_1$ '*Need to explain*'

$r_s = .411$, n = 55, p = .002 shared variance 17%

N-DQ$_1$ '*Concern about negative reactions from others'* and S-DQ$_2$ '*Positive benefits from telling others'.*

$r_s = .380$, n = 55, p = .004 shared variance 14%

N-DQ$_2$ '*Avoidance of emotional upset'* and S-DQ$_1$ '*Need to explain'.*

$r_s = .273$, n = 55, p = .044 shared variance 7%

The relationship between the N-DQ and S-DQ is discussed in Section 4.4.

4.3.6.1 Social Support Questionnaire and Distress Disclosure Index

The relationship between the Distress Disclosure Index (DDI) (Kahn & Hessling, 2001) and the Social Support Questionnaire (sub-scale SSQ$_2$ 'How much do you tell….') was investigated using a Spearman's rho correlation (Appendix Table B1). There was a positive correlation between the two variables:

$r_s = .407$, n 54, p .002

Social support (SSQ_2) shares 17% of the variance with the distress disclosure index, a measure of willingness to confide in others. The SSQ is discussed in Section 4.4.

4.3.7 Relationship between demographic variables and N-DQ and S-DQ sub-scales

Relationships between demographic variables and other variables were investigated. There were no significant relationships identified between age or gender and the sub-scales for the N-DQ and S-DQ (Appendix Table B3).

SECTION FOUR

4.4 Discussion

Bogdan & Biklen (1998) raised concerns that quantitative methods may not reflect the personal experiences of those who take part: this view was supported by Judd & Wilson (1998) and others (Bowling, 1997; Jick, 1979). Item development for the N-DQ, S-DQ and SSQ was guided by the qualitative information gathered in the first study, which was obtained from those affected by traumatic brain injury and later reviewed by them: this process should counter those concerns. This was in line with research standards suggested by Wilson (2002) and Ponsford et al. (1995). The combination of qualitative and quantitative data (known as mixed methodology) mitigates some of the shortcomings frequently aired about each methodology (Yang, 2007).

4.4.1 Validity and reliability

Correlations between N-DQ_1 and the *Brief Fear of Negative Evaluation (*r_s = .418, n = 55, p = .002*)* and S-DQ_2 and the *Distress Disclosure Index* (r_s = .595, n = 54, p = .001) provide support for concurrent validity, with effect sizes of 17% and 35%.

Reliability was assessed by examining the internal consistencies (measured using Cronbach's alpha) ranged from .64 to .87 (Table 4-7); and the item-total correlations ranged from .24 to .67 (Tables 4-5 to 4-6) these figures indicate the sub-scales are reasonably reliable. Using the rating scale from Tate (2010) intra-class correlations between the test and re-test data show that N-DQ_4 is poor, S-DQ_1 is fair and the rest are excellent. Overall most sub-scales show good temporal reliability.

Disclosure and concealment total scores are moderately positively correlated (Appendix Table B-1). This raises two issues: firstly, that the non-disclosure and self-disclosure questionnaires should not be combined to give a total score, they are distinct measures; secondly, that individuals who reported concealing more often for the specified reasons also reported disclosing more often for the specified reasons. This suggests that the two questionnaires should not be treated simply as measures of how much a person discloses or conceals (if they were, we would expect them to be negatively correlated). They may be sensitive to the degree to which the person engages in impression management and thinking about the reasons why they should or should not disclose. Some people may use impression management heavily so there may be occasions when they conceal (for specified reasons) and occasions when they disclose (for specified reasons); so they may score relatively highly on both measures. Other people may not use impression management at all. There are probably other reasons (perhaps unrelated to their TBI) why they tell or don't tell people things; so they may score relatively lower on both scales. This would require further research.

The SSQ and sub-scales were evaluated against the other variables (Appendix Table B1). SSQ_2 'How much do you tell your….' family, friends and others about your problems was positively significantly related to the distress disclosure index, which is about willingness to disclose to others. Other analysis of the social support questions showed that overall the items fitted poorly together, with low internal reliability. This was not unexpected as they were not intended to be an additional measure. This does mean that the SSQ needs to be modified for future use, or replaced.

No significant correlations were identified between age or gender and the other variables (Appendix Table B-3).

4.4.2 Limitations and strengths of this study

This is a small scale study (N = 55 for the main study and N = 19 for the re-test). These results indicate that a larger study focussed on disclosure and concealment in relation to the use of impression management would be useful. The study focussed on participants with TBI: potential participants with acquired brain injuries were not included but their contributions would widen the scope of the study. The study reflects those issues of concern to individuals with a brain injury rather than clinician-led perceptions of their difficulties

CHAPTER 5

LITERATURE REVIEW PART II

SECTION ONE

5.1 Introduction

In Chapter 2 the methodology for the literature review was presented and literature relating to concealment, disclosure, stigmatization and outcome, and impression management were discussed. This Chapter continues that discussion, but is more closely connected to the hypotheses, specifically considering, self-esteem, social avoidance, loneliness and social support. In relation to our main concerns of concealment and disclosure, self-concealment is defined as the cognitive and emotional process of keeping personal secrets (Kahn & Hessling, 2001) and the tendency to actively hide personal information from others that one perceives as distressing or negative (Ritz & Dahme, 1996). And, self-disclosure is defined as telling others about personal aspects of one's life (Kahn & Hessling, 2001). Within this study different levels of concealment and disclosure were considered as strategies for impression management, which can be used to help portray a desired self-image to others.

SECTION TWO

5.2 Possible Predictors of Disclosure and Concealment Motivations

5.2.1 Self-Esteem

Self-esteem is defined as self-acceptance stemming from one's self-worth (Robson, 1988; Rohner, Naavedra, & Granum, 1978), and is often used as a measure of psychological well-being (Rosenberg, 1965). It is evaluated through the extent to which individuals feel positively about themselves and their life. High self-esteem is thought to augment an individuals strength for personal disclosure (Afifi & Steuber, 2010). Whereas acknowledgement and comprehension of physical, cognitive and behavioural problems resulting from a brain injury can be distressing and may lead to lowered self-esteem (Cooper-Evans, Alderman, Knight, & Oddy, 2008) and reduced quality of life.

Individuals evaluate their abilities, and develop their identity, through interaction with those around them (Argyle, 1967; Krause, Liang, & Yatomi, 1989; O'Callaghan, et al., 2006). This is important as individuals confirm their self-esteem through the reassurance and behaviour of others towards them (Delelis & Descombre, 2005). This includes internalizing the predominant culture and the way society normalises the devaluation of people with specific illnesses or disabilities; which can lead to a sense of personal shame and embarrassment (Argyle, 1967 ; Gauntlett, 2002; Minnes, et al., 2000; Nadell, 1991; Yang, et al., 2007). The resulting emotional stress reduces the likelihood that individuals will share their experiences with others (Simpson, et al., 2000). In this way concealment becomes the norm and in the longer term can affect well-being with a greater risk of ill health (Davison, Pennebaker, & Dickerson, 2000).

Heimpel et al. (2006) carried out a series of questionnaire studies to look at self-esteem levels with three groups of university students (N=210, N=161 and N=150). They showed that greater avoidance was part of a strategy to protect the individual and help to preserve self-esteem. Those with high self-esteem sought positive outcomes and used strategies to further enhance their self-esteem. Further analysis showed that self-esteem mediated avoidance goals. Researchers say they took steps to avoid socially desirable responding; unfortunately the nature of this was not described by Heimpel et al. In relation to goal-directed activity, such as the activities Goldstein (1942) studied and other rehabilitation outcomes, self-determination theory (SDT), specifically cognitive evaluation theory (CET) (Ryan & Deci, 2000) offers an explanation for such behaviour. Their theory distinguishes between those who are motivated to enhance their self-esteem (already have higher levels of self-esteem and apply strategies to improve it); those motivated to protect it (have lower self-esteem or apply strategies to maintain it); and those motivated by the value of the goal itself (desire to achieve a successful outcome). Those with low self-esteem are more likely to be motivated to protect their self-esteem from threats (Adie, Duda, & Ntoumanis, 2008; Heimpel, et al., 2006; Tice, 1991). Overall, emotional protection is applied, and activities may be avoided, to defend one's self-image and self-esteem (keeping-face) (Hopwood & Treloar, 2008; Leary, et al., 1994).

It has been observed that feelings of self-worth, self-esteem and one's self-image can be threatened following a brain injury (Man, Tam, et al., 2003). Threats to self-esteem have, in turn, been linked to activity avoidance in TBI. Goldstein (1942) had worked with forces personnel who were recovering from a traumatic brain injury and he studied the anxiety caused when individuals could not complete tasks that they had managed before their injury. He theorized that this state of anxiety was linked to fear of a negative outcome posing a threat to self-image, and led to subsequent avoidance of those activities as a way of protecting self-esteem. In related research by Riley, Dennis and Powell (2010), 42 participants (N = 33 male and N = 9 females) completed three questionnaires. One person was excluded from the study because of their extreme scores. In situations or activities that are perceived as threatening, individuals assess their ability to cope (threat appraisal). They found that belief in oneself can moderate the threat appraisal, or at least moderate the response to the cause of the anxiety. Those with high self-esteem and high self-belief could cope with threatening situations, and could see them as a challenge. Those with low self-esteem and low self-belief were more likely to deal with their anxieties about participating by avoiding those activities or situations they evaluated as threatening. They found that high self-esteem was associated with low levels of perceived threat. Further, this finding was more prevalent in those whose TBI was recent or due to an assault. Individuals avoid similar events that caused their TBI and loss of trust in others, which also threatens their self-esteem. In their conclusion they were working towards recommending cognitive behaviour therapy (CBT) to help modify coping strategies after a TBI; as recommended by Anson and Ponsford (2006).

In an associated study Kendall and Terry (2009) looked at self-esteem, self-efficacy and well-being. They found that high self-esteem protected well-being from the negative effects of stress in the short term, such as those situations beyond one's ability to deal with them. With high self-efficacy, self-esteem was not related to emotional well-being. So, low self-efficacy and high self-esteem were positively related to well-being. These studies show how self-esteem is related to one's capacity to cope with difficult situations and how personal resources to deal with them impact upon one's behaviour and subsequently well-being. The benefits of high self esteem on well-being can be lost quickly, becoming more complex, so rehabilitation support is required earlier on in the rehabilitation process.

Our general hypothesis is based upon these ideas, and suggests that those with low self-esteem after TBI will be more motivated to protect their self-esteem. Self-esteem is heavily dependent on our perceptions of what others think of us; and so some forms of self-protection may relate to differing levels of disclosure and concealment. So individuals with low self-esteem may choose not to reveal information, or may carefully control their disclosures, if they fear what they say might provoke a negative evaluation from others. Self-esteem has been identified as a moderator between threat appraisal and avoidance (Riley, et al., 2010).

H_1: Those with low self-esteem may be more likely to avoid revealing their difficulties to others because of worries about how others may react: measured by the '*fear of negative reactions from others'* on N-DQ$_1$ and the Rosenberg Self-Esteem Scale (RSE).

Disclosure of brain injury can result in stigmatization of individuals (Simpson, et al., 2000), and other research has shown that stigmatization can lead to reduced status, life chances and employment opportunities (Corrigan & Watson, 2002; Pachankis, 2007; Yang, et al., 2007). Evidence from social psychology suggests that social exclusion and difference are threats to self-esteem, and that people may respond by increasing their attempts to fit in. Combining this with SDT, it may be that those who are low in self-esteem may be more motivated to increase their efforts to fit in (Brewer, 1993; Brewer, Manzi, & Shaw, 1993; Pickett & Brewer, 2001). Applying this to TBI, we might then speculate that those who are low in self-esteem may be more motivated to try to fit in with society. This then leads to our second hypothesis:

H$_2$: That those with low self-esteem will be more likely to avoid disclosure because of '*wanting to fit in*' N-DQ$_3$

Our first hypothesis was that those low in self-esteem will be motivated to conceal because of worries about how others may react. A natural extension of this is to say that some individuals might also take steps to forestall the negative reactions of others by explaining themselves. Informing other people about brain injury was identified by Karlovits and McColl (1999), in their study of 11 adults who were moving back into the community, and was one of the coping strategies they identified for dealing with stressful situations. Individuals with low self-esteem may disclose information about their TBI to try to pre-empt the possibility of negative evaluations from others by explaining or justifying their behaviour, (Karlovits & McColl, 1999). Our third hypothesis links the need to justify with low self-esteem:

H$_3$: Those with low self-esteem will score higher on the '*need to justify*' sub-scale S-DQ$_1$.

SECTION THREE

5.3 Social Consequences of Disclosure Strategies

5.3.1 Social Avoidance

Social avoidance is defined as deliberately avoiding or wanting to avoid others (either to talk to or for company). And social distress is defined as discomfort, upset, distress, fear, anxiety or nervousness (being tense) that is associated with social situations (Watson & Friend, 1969).

Motivation to protect, maintain or enhance self-esteem has been observed to underlie many relationships and behaviours (Volpato & Contarello, 1999) and research with students has shown that avoidance is a strategy used to protect the individual, helping to preserve their self-esteem. Shame and embarrassment may also be specific contributory factors leading to social avoidance (Delelis & Descombre, 2005; Folkman, Lazarus, Gruen, et al., 1986; Karlovits & McColl, 1999; Simpson, et al., 2000; Yang, et al., 2007). With specific reference to TBI, Riley et al. (2004) found that those who were anxious about things going wrong in social interactions were, indeed, likely to avoid social situations as a consequence. In the qualitative study described earlier (Chapter 3), some participants reported anxiety about disclosure because of possible negative reactions from others, and because of their own sense of shame and embarrassment about their TBI and other negative emotional reactions associated with talking about the TBI. This suggests that those who are motivated to conceal because of concern about the negative reactions of others or because of the avoidance of emotional upset, may be more likely to avoid social interactions generally. Wanting to fit in, and the fear of exposure as being different, may also create a threatening aspect to social situations, which may increase the probability of social avoidance.

From our first study we identified '*avoidance of emotional upset*', '*concern about the negative reactions of others*', and '*wanting to fit in*' these are all related to anxiety. Social avoidance might occur as a result of all of these factors. The basis for this hypothesis is the general point that anxiety often leads to avoidance of the situations that cause anxiety. Leading to our hypothesis that:

H_4: Those who have more '*fear of the negative reactions from others'* ($N\text{-}DQ_1$); the *'avoidance of emotional upset*' ($N\text{-}DQ_2$) and '*wanting to fit in'* ($N\text{-}DQ_3$) will be more avoidant of situations that bring them into contact with others.

5.3.2 Loneliness

'Loneliness' is defined in terms of a lack of social interaction and a sense of social alienation and isolation. It is possible to be socially isolated and not feel lonely; and others may feel lonely but not be socially isolated, they may lack social contact. Motivation to conceal may be linked to loneliness via lack of social interaction because of avoidance and not seeking social support (this links H_4 to H_6). Motivation to conceal may also be linked to loneliness through the sense of alienation, being different and not fitting in. Social psychologists Chaudoir and Fisher (2010) found individuals who used avoidance strategies were less skilled at recruiting support and withdrew or concealed more as a response to negative feedback, they theorized that they may be primed to notice negative responses and may consequently feel lonelier and have poorer health outcomes. For avoidance oriented individuals disclosure could be more harmful than therapeutic: brain injury can intensify emotional responses adversely changing the individual's quality of life which is indicated by low self-esteem (Man, Tam, et al., 2003).

Carers and those individuals with a brain injury who concealed because of their anxieties about social reactions of friends, were more likely to feel socially alienated and isolated and reported a greater degree of loneliness due to the lack of understanding about brain injury and behaviour changes (Simpson, et al., 2000). So, are those who choose not to disclose likely to feel more isolated and lonely, as the Simpson study indicated? Similar findings were found in social psychology research, individuals who concealed a potentially stigmatizing disability, of which they were ashamed, were lonelier and more socially anxious (less confident) and had lower self-esteem than those who disclosed (Pachankis, 2007; Russell, Peplau, & Cutrona, 1980). Living with a secret can lead to a preoccupation with it, but disclosure changes the nature of the relationship with others: it can lead to rejection, stigmatization and discrimination or open avenues where support is given. During rehabilitation emphasis is placed upon the maintenance and development of friendships and social networks (Ylvisaker, et al., 2008) but especially upon group memberships, because they can provide moral support to those who are rebuilding their sense of self-identity, life satisfaction and well-being after an ABI (Haslam, et al., 2008), helping them to '*fit in'* (Jones, et al., 2011) and to maintain their self-esteem; this takes more effort for those who are avoidance oriented than for those who are not. Our third hypothesis is:

> H_5: Those who report a greater sense of loneliness measured by the UCLA will score highly on N-DQ_1 '*concern about negative reactions from others'* and N-DQ_3 '*wanting to fit in'.*

5.3.3 Social Support

Social support is defined by Thoits (1982) as help and assistance from an individual or a group of people in one's social network, which is freely given and without obligation. Over time, social support from family, friends, neighbours, professionals and others becomes a supportive network which can act as a buffer for those who are under pressure, helping to relieve mental health problems such as anxiety and depression (Curran & Ponsford, 2000; Douglas & Spellacy, 1996; Leach, Frank, Bouman, & Farmer, 1994) and providing a sense of self-worth (Haslam, et al., 2008; Thoits, 1982, 1989).

Social psychologists have linked social support positively to an improved quality of life (Helgeson, 2003). Graham, Huang, Clark and Helgeson, (2008) asked participants to evaluate stories or re-enactments of situations causing stress and how they would respond, in a series of four studies (N=108 web users, N=45 undergraduates, N=124 undergraduates and N=132 undergraduates): they found it was the disclosure of emotions rather than facts that led to greater support with the development of wider friendship networks. Social support networks were found to encourage individuals to deal with issues they may not otherwise tackle, and provide a sense of belonging which helps to ease distress and enhance self-esteem (Barrera, 1986; Russell, et al., 1980; Wethington & Kessler, 1986). Integration after an ABI involves the development of a social network, and becoming part of the local community (Willer, et al., 1993). However, with regard to brain injury Tomberg, Toomela, Ennok, and Tikk, (2007) found it was the satisfaction with support rather than the amount of support that was important.

There are three major categories of support; the first is social embeddedness which looks at others in one's social network (Barrera, 1986; Krause, et al., 1989; Sandler & Barrera, 1984). The amount of social contact is quantifiable, as it refers to marital status, number of siblings, close relatives, neighbours and friendships; these are all seen as potential sources of support (Underhill, LoBello, & Fine, 2004). The type and closeness of relationships with others also matters; for example how easy it is to maintain these relationships. It is not always clear how social support is related to the easing of distress and stress, but the encouragement of participation in one's community, neighbourhood, social activities, work and groups (religious or secular) is a major aim of rehabilitation programs, this strengthens social embeddedness and potentially widens the network of individuals who could offer support in times of need.

The second type of support is perceived social support: this is one's cognitive appraisal that others are available who could give advice and information which could be useful for dealing with difficult situations. The availability and adequacy of this support is a qualitative measure. The individual expresses a belief that they would have support from those around them should it be needed, to help them overcome stress and distress. According to Hlebec & Kogovšek (2005) members of one's family, friends, neighbours and professionals each provide different types of support. Requests for help may be made because the individual feels they can trust the person or because they are the closest in proximity, regardless of how distant the relationship is. Those who are closest, with stronger ties, usually partners, parents, older children and close friends offer emotional support (predominantly female). Emotional support leads to better emotional outcomes and includes affection and concern, listening to and sharing difficulties, financial support, encouraging, motivating and helping individuals deal with the stresses and challenges presented by life after an injury (Godfrey, et al., 1996; Verhaeghe, et al., 2005). Informational support includes offering advice, guidance and feedback, so they can understand how the injury has affected them. Informational and emotional support, help the individual to adjust to their situation (Helgeson, 2003; Wethington & Kessler, 1986).

The third is enacted social support, where the individual is actually given support. The individual is asked about the type of help they have been given and the circumstances surrounding this. Responses may reflect elements of perceived support, but enacted support is most consistently related to social support seeking and actually obtaining help (Barrera, 1986). Practical support includes the provision of practical help, material aid and material resources, services, doing household chores, running errands, helping with problems, helping with physical tasks around the home and garden, transportation and companionship etc. Practical support from others is important because they can assist the person in carrying out rehabilitation activities and in re-engaging in valued roles, returning to work, accessing community facilities and activities and in enjoying a social life (Becker, Billings, Eveleth, &

Gilbert, 1997; Crisp, 1993, 1994; Endler, et al., 2002; Helgeson, 2003; Sander, et al., 2003; Tomberg, et al., 2007; Tomberg, Toomela, Pulver, & Tikk, 2005; Vohs, et al., 2005; Wethington & Kessler, 1986). Practical support is also referred to as 'instrumental support' (Hlebec & Kogovšek, 2005; Van Der Molen, 1999), 'tangible support' or 'tangible assistance' and 'structural support' (Bowling, 1997),'alliance support' (Chwalisz, 1996) and 'aid' (Cohen & Wills, 1985).

In the qualitative study, it was evident that some participants saw considerable value in seeking support from others by means of disclosing information about the injury and its consequences; whereas others felt that there was little to be gained from telling others and perceived considerable disadvantages in disclosure. It seems plausible to suggest that these motivations may lead to differences in the extent to which the person actually seeks and accesses social support. It is hypothesized that:

H_6: Those who are motivated to obtain the '*benefits from telling others'* (S-DQ_2) are more likely to actually obtain support from others (higher scores on the ESSQ); and, conversely, that those who see '*no benefits from telling others'* (N-DQ_4) or who are motivated to conceal, are less likely to access support from others (lower scores on the ESSQ).

SECTION FOUR

5.4 Broader Consequences that may be Mediated by these Social Consequences

5.4.1 Mediation hypothesis

Accessing appropriate practical support and information might lead to better engagement in valued activities and roles; for example getting transport assistance from friends might enable someone to access more community facilities (Crisp, 1993, 1994). More engagement in valued activities (Willer, et al., 1993) has been associated, in turn, with higher life satisfaction (Eriksson, Kottorp, Borg, & Tham, 2009; Fugl-Meyer, Melin, & Fugl-Meyer, 2002). General life satisfaction is also heavily dependant on how satisfied one is with one's social life.

Social psychologists have found that those who are avoidant of social interaction and who feel alienated (social isolation) and lonely are likely to report reduced life satisfaction (Dahlberg, et al., 2005; Maner, DeWall, Baumeister, & Schaller, 2007). These considerations suggest that motivations to conceal and disclose may be associated with broader rehabilitation outcomes, such as engagement in valued activities and life satisfaction, through the mediation of the social consequences described earlier (avoidance, loneliness and reduced social support). This gives rise to the final hypothesis:

H_7: Motivations to disclose (conceal) will be associated with higher (lower) engagement in valued activities and higher (lower) life satisfaction; and this effect will be mediated through less (more) social avoidance and loneliness and more (less) social support.

5.5 Summary

From the literature review several areas of research are relevant to this study. Those areas include the role of self-esteem as a possible influence on disclosure and concealment; some of the possible social consequences of disclosure and concealment; and the impact of disclosure and concealment on broader rehabilitation outcomes that may be mediated by these direct social consequences.

CHAPTER 6

HYPOTHESIS TESTING

SECTION ONE

6.1 Introduction

In Chapter 5 evidence from the literature was given to support each of our seven hypotheses. The general aim of this study was to investigate some of the potential causal influences on, and consequences of, disclosure and concealment: specifically, to consider how the decision to disclose or conceal issues following a brain injury relate to self-esteem (as a potential causal influence), social outcomes (avoidance, loneliness and accessing social support) and broader rehabilitation outcomes (community participation, and life satisfaction). Within this Chapter these hypotheses are tested. Section two gives the methodology used, section three the analyses are presented and then discussed in section 4.

SECTION TWO

6.2 Methodology

Ethical approval was given in December 2009 for this questionnaire based study which is a continuation of the study described in Chapter 4. The approval letter from the University of Birmingham Ethics Committee is given in Appendix B-1. Recruitment and data collection for this study took place between April 2010 and July 2010.

Questionnaires completed and why they were selected

In addition to the non-disclosure (N-DQ), self-disclosure (S-DQ) and social support questionnaires, questionnaires developed by others were used to assess self-esteem, social avoidance, loneliness, community integration and life satisfaction. Each additional questionnaire is described briefly below:

6.2.1 Self-esteem

The Rosenberg self-esteem scale (RSE) is widely-used in social science research and measures self esteem and feelings of self-worth. The scale is formed of ten-items combined to give a total score. Responses are marked on a four-point Likert-type scale as strongly agree (SA) to strongly disagree (SD) which scores as SA = 3, A = 2, D = 1, SD = 0: item numbers 1, 3, 4, 8, 7 and 10 are reverse scored. Scores range from 0 to 30 with higher scores representing higher levels of self-esteem. The RSE yielded a Cronbach's alpha level of .84 in a study by Fee and Tangney when studying procrastination, shame and guilt with 86 undergraduates. This questionnaire has been used in several TBI studies (see Table 6-5) but the alpha levels found in those studies was not reported. A copy of the RSE is given in Appendix C-3.

6.2.2 Social avoidance

The Social Avoidance and Distress Scale (SAD) was developed by Watson and Friend (1969 - cited in Endler et al., 2007). This is a 28-item true-false measure (scored as 1 or 2) looking at social distress (being upset, tense or anxious) and social avoidance (keeping to oneself and avoiding talking to others). Scores range from 28 to 56 with higher scores indicating more social avoidance and distress. Watson and Friend (1969) report a test-retest correlation level of 0.68 over four weeks for N = 154 students. Details for the SAD are given in Appendix C-4. Results from two other studies using this measure are given in Table 6-6.

6.2.3 Loneliness

Each participant's level of loneliness was assessed using the University of California, Los Angeles Loneliness Scale - revised UCLA Scale (details for the UCLA are given in Appendix C-5). The questionnaire was devised by Russell, Peplau and Cutrona (1980). It had a high internal consistency with a Cronbach's alpha of .94 in their study to revise the UCLA with N=162 students; other properties are given in Table 6-7. The 20 items are summed for a total score: scores range from 20 to 80, with higher scores indicating greater loneliness. Scores for item numbers 1, 4, 5, 6, 9, 10, 15, 16, 19 and 20 are reversed before scoring.

6.2.4 Life Satisfaction

The Life Satisfaction Scale (LiSat-11) is an extension of the LiSat-9, with the addition of two items on physical and psychological health and was devised by Fugl-Meyer, Melin, and Fugl-Meyer (2002), but was developed from an original 800 item survey from 1996. Life satisfaction is measured on a 6-point ordinal self-rating scale ranging from 6 = "very satisfying" to 1 = "very dissatisfying": scores range from 8 to 66 with higher scores indicating greater satisfaction with life. The LiSat-11 assesses life satisfaction in terms of vocational, financial, and leisure situations, social contacts, sexual and family life, self-care, partner relationships, physical and psychological health. Details for the LiSat-11 are given in Appendix C-6. Changes were made to the wording on the LiSat-11 to add more description and clarify the questions (the measure had been translated from Swedish); specifically, we added to item 2 '(employment or voluntary work)': to item 4 '(how I spend my leisure time)': the wording on item 9 was rearranged to 'My relationship with my partner (wife, husband etc.) is' and 'I have no steady partner'; and 'quite' was added and 'a bit' was substituted for 'rather' before dissatisfying and satisfying. For items 2, 8 and 9 where participants have no partner, family or employment they were scored as 0. Examples of four other studies using the LiSat-11 are given in Table 6-8.

6.2.5 Participation in valued activities

The Community Integration Questionnaire (CIQ) was devised by Willer, Rosenthal, Kreutzer, Gordon and Rempel (1993) to assess the level of community integration, after traumatic brain injury. Details for the CIQ are given in Appendix C-7. The CIQ has 15 items rated on varied Likert-type response scales and these cover social participation, daily living skills, education, employment and voluntary work, relationships, social role, independence and mobility. Scores can be collated for 'Home Integration' (HI); participation in social activities 'Social Integration' (SI); and educational, vocational and work participation representing 'Productivity' (P). The overall community integration score is obtained by adding together the three sub-totals with a maximum score of 29, with higher scores indicating greater levels of integration. Willer, et al (1993) reported that the Cronbach's alpha for the CIQ was .76 with N = 49 individuals with moderate to severe TBI. Mean and standard deviations from other studies using the CIQ are given in Table 6-9. This scale was adjusted to match the presentation of the other scales used.

6.2.6 Enacted Social Support Questionnaire

There are several measures of social support but those available did not fully meet our needs. We required a measure of support actually received, so the Enacted Social Support Questionnaire was developed (Appendix C-2). Enacted support is help actually given to an individual (Ergh, Rapport, Coleman, & Hanks, 2002). The ESSQ replaced the social support questions (SSQ) used in the second study because those questions asked about other issues related to social support and was not a unitary construct. The ESSQ consists of 12 items covering '*practical help'*, '*advice or information'*, '*moral or emotional support*', '*socialising*' and about family contact and living arrangements. We wanted to identify the support that was actually received from outside the immediate family. It was decided that it was important to exclude the support given by family members with whom the individual lives. This was on the grounds that family members who live together are constantly receiving support (information, emotional support, practical help etc.) from each other.

We asked for feedback on the ESSQ at each stage of the development (on the initial items, wording and format, specifically the rating scale). We also asked six individuals (N=5 male and N=1 female), to attempt some or all of the questions. The mean age of this group was 55 years (SD 16.5) with an average of 18 years (SD 9.7) since their ABI; these reviewers were outside of our inclusion criteria for this study. From their comments the examples given above each section were amended. The preliminary questions (3a) asked whom the individual lived with (if anyone) and (3b/c) if they had contact with their families. Scores for these items ranged from 12 to 60 with higher scores representing more support actually received. The data in this measure were subjected to a factor analysis, and on the basis of this certain items were excluded from the total score. Further details are given in the Results section.

6.2.7 Recruitment procedures

The recruitment procedures and inclusion/exclusion criteria were the same as those for the previous study except the inclusion criteria were extended slightly to take in those with other forms of acquired brain injury (post surgical brain tumour and ruptured aneurysm, but not stroke). In this way, we had access to more participants and those with a greater range of experience of the effects of an acquired brain injury. Those with a stroke were excluded as Headway is predominantly focussed on the rehabilitation of those post injury and does not ‘specialize’ in post-stroke rehabilitation per se.

6.2.8 Number of participants and power analysis

For this study, we aimed to collect 64 completed responses. This figure was based upon a ‘G-Power’ analysis (Faul & Erdfelder, 1992) which indicated that a sample of 64 completed questionnaires would be required to detect a modest correlation of $r = 0.3$, with an alpha level of .05, and power set at .8. In total 65 completed questionnaires were obtained with no missing data. For this study, all participants who were asked to take part did so. Participants were self-selecting in as much as they decided if they wanted to take part after an initial invitation from staff from their Day Centre. Participants were told they could withdraw at any time; no one withdrew from the study. All interviews took place within either of the two Headway Day Centres participants attended and at a time that fitted in with their rehabilitation schedule.

6.2.9 Descriptive statistics

6.2.9.1 Participants details

Demographic information was requested from participants with 9 questions from section 4 of the questionnaire. Table 6-1 gives demographic statistics for items 4.1 to 4.8 and Table 6-2 gives the statistics for item 3a of the ESSQ regarding accommodation. Comparisons with some national figures are given in Table 6-4.

Table 6-1: Demographic statistics for study 3 (N = 65)

Characteristics of individual with ABI	N = 65	percentage
Gender – item 4.1 and Age – item 4.2		
Male	50	77
Female	15	23
Age (item 4.2)	47 yrs (SD 11.82)	Range 27 to 70 yrs
Marital Status – item 4.3		
Single	26	40
Separated/divorced	13	20
Widowed	4	6
Married/have a partner	22	34
How ABI occurred – item 4.4		
Vehicle driver/passenger	15	23
Pedestrian	1	1
Motorcycle	5	8
Bicycle	4	6
Fall	5	8
Industrial Accident	3	5
Assault	7	11
Sports Injury	1	1
Brain Tumour (post surgical)	11	17
Aneurysm (ruptured)	5	8
Other	8	12
Disability – item 4.5		
Obvious to others	2	3
Both hidden and obvious	36	55
All hidden	27	42
Education – item 4.6		
Primary School	ALL	
Secondary School	37	57
Higher Education	28	43
Current Occupation – item 4.7		
Not working	56	86
Voluntary part-time	8	12.5
Voluntary full-time	-	-
Working part-time paid	-	-
Working full-time paid	1	1.5
Time since accident - item 4.8		
Time since injury	11.85 yrs (SD 8.89)	Range 1 to 35 yrs

Table 6-2: Accommodation post injury from the ESSQ

Who do you live with item 3a		
Accommodation	Frequency	Percent
alone	21	32
shared / supported accommodation	2	3
with carers	3	5
with children	3	5
with parents	15	23
with wife/husband/partner	13	20
with family (partner and children)	8	12

6.2.9.2 Occupation at the time of accident-item 4.9

The employment categories presented in Table 6-3 are from Volume 5: LFS Classifications (Labour Force Survey User Guide, , 2009). The 2009 revisions were too complex for the requirements of this study so the 2000 Classifications (described fully in the LFS) were used. Each participant's occupation (at the time of their accident) was coded with three digits which described their role. These three digit codes (lower numbers equate to higher levels of responsibility and remuneration) were reduced to two as this protected the participant and gave sufficient information for classification/analysis within this study.

Table 6-3: Pre-injury employment coding for N = 65 participants with ABI/TBI (item 4.9)

Employment Code		Frequency	Group	Percentage
Managers and senior officials	11	1	1 N=16	24
	12	3		
Professional occupations	21	3		
	23	2		
	24	2		
Associate professional and technical occupations	31	1		
	32	2		
	34	1		
	38	1		
Administrative and secretarial occupations	41	2	2 N= 22	34
	42	1		
Skilled trades and occupations	51	4		
	52	4		
	53	4		
	54	5		
Personal service occupations	61	2		
Sales and customer service occupations	71	3	3 N=20	31
Process, plant and machine operatives	81	3		
	82	6		
Elementary occupations	91	4		
	92	3		
	95	1		
Caring for children at home	NC	3	4 N=7	11
Students	NC	4		
Total		65	65	100

Not Classified: the LFS does not classify students or those who care for their own children; they are described as ‘economically inactive’.

No meaningful correlations were identified for the employment data and the other variables.

6.2.9.3 National figures

Comparison with other injury statistics:

Table 6-4: Comparison of ABI figures for this study with national and USA average

	Source of information			
	Found in this study	1, 2 and 3	4 and 5	Comment
		National average UK	National average Canada/USA	
Road Traffic Accidents Including RTA Pedestrians	25%	25 %	23 - 28%	
Motorcycling (peak age 21-25 and 31-35)	8%		6%	Between 36 and 53 years of age
Falls/industrial accidents	12%	22%	20 - 35%	
Assaults	11%	10%	9 - 15%	
Sports/recreational injuries	1.5%	15%	N/A	
Bicycling	6%		>2%	
Brain and CNS tumours (post surgical)	17%	1.3%	N/A	Much higher than national average
Haemorrhage (not stroke)	8%	12%	N/A	Ratio of females to males was 3:2

Source: Hospital Episode Statistics (HES) data on traffic injuries in England for the five years 1999-2004

[2] Trends in serious head injuries among cyclists in England: analysis of routinely collected data. Department of Primary Health Care and General Practice, Imperial College School of Medicine, London W2 1PG

[3] Headway 2010-11-24 http://www.headway.org.uk/facts.aspx#

[4] Epidemiology and Long-term Outcomes following Acquired Brain Injury: Teasell, R., Aubut, J., Bayley, M. and Cullen, N. 2010. http://www.abiebr.com/modules/modules/1_4_assets/module2.pdf

[5] Faul, Xu, Wald, & Coronado (2010)

To put the demographic data from our study into a wider context, brain injury statistics from other research are given in Table 6-4. These figures showed that our data was fairly representative of this population (with the exception of post surgical brain tumours which are higher). Demographic variables from our sample N=65 were compared with figures given by Simpson et al. (2000) for N=18 participants with TBI. Our sample was almost four times (3.6 times) the size but the percentage figures correspond for gender distribution, family support/relationships, marital status, and ‘living with’. ABI events such as road accidents, falls and assault figures are also comparable. For the vocational status, our sample is inclusive of more individuals who are not in employment (voluntary or paid): these details were given in Tables 6-1 and 6-3.

6.2.9.4 Additional measures used in other studies

Tables 6-5 to 6-9 give the results for the RSE, SAD, UCLA, LiSat-11 and the CIQ, the results from this study are also given.

Table 6-5: Means and standard deviations from 4 studies using the RSE scale

Statistics from Rosenberg Self-Esteem Scale (RSE) studies						
RSE Rosenberg, 1965 High scores = higher self-esteem ** Lower scores = higher self-esteem	General population (GP) or ABI	statistic		N		
		mean	SD	male	female	total
Study 1 ** Fee, R.L. and Tangney, J.P. (2000)	GP	4.10	0.54	34	52	86
Study 2 ** Cooper-Evans, S., Alderman, N., Knight, C. and Oddy, M. (2008)	ABI	21.86	8.14	17	5	22
Study 3 ** Riley, G.A., Dennis, R. K. and Powell, T. (2010).	ABI	21.46	6.14	32	9	41
This study (2011)	ABI	17.86	5.67	50	15	65
This study - Rev scores **	ABI	12.14	5.67	50	15	65

According to the Rosenberg Foundation, on the original scale, high scores mean high levels of self esteem (Rosenberg, 1965). The results given in Table 6-5 have been reverse scored ** (see bottom row of table) where low scores mean higher self-esteem because that is how this measure has been calculated in the other studies cited in the table. They show the self-esteem of our participants is higher than those from other ABI studies, and lower than those from a study for the general population (undergraduates). Please note that we have given both sets of scores for our study. In the Cooper-Evans et al. study they initially state that strongly agree (SA) is scored as 4 and strongly disagree (SD) is scored as 1, they later say that they have reversed their scoring, but these figures do not relate to reverse scoring.

Despite this uncertainty the mean given for their sample is taken to be reversed. Higher self-esteem was identified in this study than the other ABI studies.

Table 6-6: Means and standard deviations from 4 studies using the SAD scale

Statistics from Social Avoidance and Distress Scale (SAD) studies					
SAD Watson & Friend(1969) High scores = more social avoidance	General population (GP) or ABI	statistic	N	mean	SD
Study 1 Garcıa-Lopez, L. J., Olivares, J., Hidalgo, M. D., Beidel, D. C. and Turner S. M. (2001)	GP	Male	112	11.7	5.7
		Female	191	12.2	6.7
Study 2 Watson, D. and Friend, R. (1969)	GP	Male	60	11.20	-
		Female	145	8.24	-
Study 3 Turner, S. M., McCanna, M. and Beidel, D.C. (1987)	GP	Total	206 (although figures add up to 226)	Ranged from	
				9.9	8.4
				to 22.7	7.1
This study (2011)	ABI	Male	50	34.88	6.1
		Female	15	39.87	6.9

Social avoidance scores were higher for participants in this study than those from the general population.

Table 6-7: Means and standard deviations from 2 studies using the UCLA studies

Statistics from UCLA studies				
Revised UCLA Russell, Peplau and Cutrona, 1980 High scores = social isolation	General Population		ABI	
	Study 1 Russell, D., Peplau, L. A. and Cutrona, C. E. (1980)		This study 2011	
	Male = 102	Female = 128	Male = 50	Female = 15
Mean	37.06	36.06	39.52	41.53
SD	10.91	10.11	11.93	11.45
median	35.38	34.17	39.00	41.00

Loneliness scores for participants were similar to those for the general population.

Table 6-8: Means and standard deviations from 4 studies using the Life Satisfaction Scale (LiSat-11)

<table>
<tr><td colspan="8">Logits and SDs, Median, Variance and Mean for General Population from existing studies using LiSat-11</td></tr>
<tr><td colspan="8">Research Paper and Journal: Using LiSat-11 by Fugl-Meyer (2002)</td></tr>
<tr><td colspan="8">Higher scores = greater satisfaction with life</td></tr>
<tr><td colspan="4" rowspan="3">Eriksson, G., Kottorp, A., Borg, J. and Tham, K. (2009)</td><td colspan="4">ABI Mean</td></tr>
<tr><td colspan="4">Male N = 60 Female N = 56
Mean -0.19 logits* Range -2.2 to 2.15 (SD .077)</td></tr>
<tr><td colspan="4">*logits (log odds probability units) = raw scores converted to equal interval measures</td></tr>
<tr><td rowspan="5">LiSat-11 item</td><td colspan="2">Fugl-Meyer, A. R., Melin, R. and Fugl-Meyer, K. S. (2002). Study 1</td><td>Silvemark, A. J., Källmén, H., Portala, K. and Molander, C. (2008). Study 2</td><td colspan="3">Stålnacke, B., Elgh, E. and Sojka, P. (2007). Study 3</td><td rowspan="2">This study (ABI)</td></tr>
<tr><td>Male</td><td>Female</td><td>Male Female</td><td>Control (GP)</td><td>Group 1 (ABI) Don’t seek support</td><td>Group2 (ABI) Seek support</td></tr>
<tr><td>N = 1326</td><td>N= 1207</td><td>N = 101 N = 193</td><td>N = 16</td><td>N = 52</td><td>N = 16</td><td>N = 65</td></tr>
<tr><td colspan="4">General Population (GP)</td><td colspan="3">ABI/TBI</td></tr>
<tr><td>Median</td><td>Variance</td><td>Range and SD</td><td colspan="4">Mean and SD</td></tr>
<tr><td>Life as a whole</td><td>5</td><td>0.82</td><td>3.14 (1.26) to 4.45 (1.15)</td><td>4.7 (0.7)</td><td>4.6 (0.9)</td><td>3.6 (1.5)</td><td>4.25 (1.47)</td></tr>
<tr><td>Vocation</td><td>5</td><td>1.67</td><td>2.00 (1.30) to 3.24 (1.46)</td><td>4.9 (0.6)</td><td>4.1 (1.0)</td><td>3.2 (1.5)</td><td>1.46 (2.14)</td></tr>
<tr><td>Financial / economy</td><td>4</td><td>1.43</td><td>2.46 (1.24) to 4.10 (1.30)</td><td>4.2 (0.7)</td><td>4.0 (1.4)</td><td>3.6 (1.4)</td><td>3.88 (1.55)</td></tr>
<tr><td>Leisure</td><td>5</td><td>1.21</td><td>2.83 (1.25) to 4.08 (1.23)</td><td>4.9 (0.9)</td><td>4.3 (1.1)</td><td>3.1 (1.8)</td><td>4.11 (1.44)</td></tr>
<tr><td>Friends / contacts</td><td>5</td><td>1.03</td><td>3.60 (1.31 to 4.55 (1.06)</td><td>5.0 (0.8)</td><td>4.6 (1.0)</td><td>4.1 (1.5)</td><td>4.15 (1.54)</td></tr>
<tr><td>Sexual Life</td><td>5</td><td>1.32</td><td>2.87 (1.38) to 4.38 (1.52)</td><td>4.6 (0.8)</td><td>4.1 (1.3)</td><td>3.7 (1.4)</td><td>2.37 (1.72)</td></tr>
<tr><td>Activities for daily living (ADL)</td><td>6</td><td>0.41</td><td>3.97 (1.27) to 5.35 (0.77)</td><td>5.6 (0.8)</td><td>5.3 (0.9)</td><td>5.4 (0.6)</td><td>5.26 (0.99)</td></tr>
<tr><td>Family Life</td><td>5</td><td>0.82</td><td>4.01 (1.15) to 5.27 (1.05)</td><td>5.2 (0.8)</td><td>4.8 (1.3)</td><td>3.9 (1.5)</td><td>4.31 (1.89)</td></tr>
<tr><td>Relationship with partner</td><td>5</td><td>1.03</td><td>3.78 (1.29) to 5.20 (1.00)</td><td>5.0 (0.9)</td><td>4.8 (1.4)</td><td>4.0 (1.6)</td><td>1.95 (2.60)</td></tr>
<tr><td>Physical / somatic Health</td><td>5</td><td>0.98</td><td>2.06 (1.00) to 3.50 (1.16)</td><td>5.3 (0.7)</td><td>4.8 (1.1)</td><td>3.7 (1.7)</td><td>3.94 (1.55)</td></tr>
<tr><td>Psychological Health</td><td>5</td><td>0.87</td><td>3.16 (1.28) to 4.65 (1.14)</td><td>5.1 (0.7)</td><td>4.8 (1.2)</td><td>3.9 (1.4)</td><td>3.62 (1.51)</td></tr>
</table>

Life satisfaction scores are lower for vocation, sexual life and relationship with their partner, the rest are equivalent.

Table 6-9: Means and standard deviations from 4 studies using the CIQ

Statistics for Community Integration Questionnaire (CIQ) studies														
CIQ Willer , Rosenthal, Kreutzer, Gordon and Rempel, 1993 High scores = greater community integration	Study 1 Willer, B., Rosenthal, M., Kreutzer, J. S., Gordon, W. A. and Rempel, R. (1993).				Study 2 Galski, T., Tompkins, C. and Johnston, M.V. (1998)		Study 3 Stålnacke, B. M. (2007).				This study 2011			
	General Population (GP)		ABI mean (ABI)		GP	ABI	ABI				ABI			
	male	female	male	female			male		female		male		female	
N	105	132	241	111	10	30	95		68		50		15	
statistic	mean		mean		mean		mean	SD	mean	SD	mean	SD	mean	SD
Home Integration Score (HIS)	4.53	5.76	3.30	5.27	-	-	5.15	2.84	6.61	2.38	4.78	2.78	4.47	2.20
Social Integration Score (SIS)	8.97	9.39	6.46	7.44	9.30	7.67	9.23	1.89	9.29	1.80	7.18	2.34	6.87	2.42
Productivity (PROD)	6.29	5.83	3.48	3.35	-	-	5.27	1.83	5.18	2.12	2.60	1.47	2.60	2.13
TOTAL	19.70	20.98	13.24	16.06	20.93	15.32	19.52	4.75	21.12	2.12	14.56	4.11	13.93	4.67

Scores for participants are equivalent to those in other studies for the general population and those with an ABI, with the exception of HIS which was significantly lower for males. The SIS, Prod and overall social integration was significantly lower for both males and females in our study.

6.2.10 Comparison of the means

Means from the studies given in each of the Tables 6-5 to 6-9 were evaluated against the means for this measure in our study (the mean, SD and number of participants were required for this analysis). These figures were calculated using single sample t-tests (Field, 2009); a non-parametric alternative was not available, so these figures should be accepted with some caution where the data are non-normally distributed (Table 6-11). Significant results from the single t-tests are given in Table 6-10; the full data and other results are in Appendix C11 – C13.

Results indicate that participants in our study recorded significantly higher levels of self-esteem than in the ABI studies '2' by Cooper-Evans et al. (2008) and '3' by Riley et al. (2010) given in Table 6-5, but significantly lower than the general population with study '1' by Fee et al. (2000). For social avoidance and distress (Table 6-6) the comparison with study '1' by Garcıa-Lopez et al. (2001) was significantly higher for both males and females with ABI compared to the general population.

There were no notable significant differences in the scores for loneliness (Table 6-7) between our study and those of the general population found by Russell et al. (1980). For life satisfaction (Table 6-8) compared to study '3' by Stålnacke et al. (2007), there were no significant differences between the groups for variables: life as a whole, financial, and ADL. The results of the differences between the groups for variables: leisure, friends, family life, physical health, and psychological health, were mixed with no major differences. There were however significant differences between the groups for variables on vocation, sexual life, and relationship with partner. For community integration (Table 6-9), compared to study '3' by Stålnacke (2007), our participants scores were significantly lower in relation to home integration, for male participants only. For both social integration and productivity male and females scores were significantly lower. Overall the CIQ scores were significantly lower.

Table 6-10: Results of single t-test for the RSE, SAD, CIQ and LiSat-11

This study compared to:		df	t	sig	Effect size d
RSE - Study 2 ABI		85	-6.19	.005	-1.54
RSE - Study 3 ABI		104	-7.98	.005	-1.61
RSE - Study 1 GP		149	13.09	.005	2.17
SAD - Study 1 GP	Males	160	23.39	.005	4.00
SAD - Study 1 GP	Females	204	15.37	.005	4.14
CIQ - Study 3 HIS	Female	81	-3.19	.005	-.92
CIQ - Study 3 SIS	Male	143	-5.71	.005	-1.00
	Female	81	-4.42	.005	-1.27
CIQ - Study 3 Prod	Male	143	-8.91	.005	-1.57
	Female	81	-4.26	.005	-1.23
CIQ - Study 3 CIQ Total	Male	143	-6.25	.005	-1.10
	Female	81	-9.21	.005	-2.66
LiSat-11 Vocation Cont		79	-6.34	.005	-1.79
LiSat-11 Vocation Group 1		115	-8.20	.005	-1.54
LiSat-11 Vocation Group 2		79	-3.07	.005	-.87
LiSat-11 Sex Life Control		79	-5.04	.005	-1.42
LiSat-11 Sex Life Group 1		115	-6.01	.005	-1.13
LiSat-11 Sex Life Group 2		79	-2.86	.01	-.81
LiSat-11 Relationship Partner Control		79	-4.61	.005	-1.30
LiSat-11 Relationship Partner Group 1		115	-7.12	.005	-1.34
LiSat-11 Relationship Partner Group 2		79	-3.01	.005	-.85

6.2.11 Reliability

Additional questionnaires, with reliability measurements provided by their authors, are provided with the descriptions above. Properties, found in this study for each additional questionnaire used, are given in Table 6-11.

6.2.12 Descriptive statistics for N-DQ and S-DQ

The descriptive statistics (means, range and the standard deviation) for the N-DQ and S-DQ are given in Table 6-11. The Kolmogorov-Smirnov test (given in the last column of Table 6-11) gives an indication of the normality of distribution: a significant result below .05 showed that some of the data was not normally distributed and violated the assumption of normality (Field, 2009; Pallant, 2007).

Table 6-11: Descriptive Statistics for the N-DQ and S-DQ and five additional questionnaires used in this study

Descriptive Statistics * Lower bound of true significance

N = 65 Missing = 0	Cronbach's alpha	Range of scores	Actual Range	Mean	Std. Deviation	Kolmogorov-Smirnov	
						Statistic	Sig.
N-DQ$_1$: *'Concern about negative reactions from others'*	.86 (10 items)	10 – 50	10 – 49	25.83	10.46	.097	.200*
N-DQ$_2$: *'Avoidance of emotional upset'*	**.81 (5 items)**	**5 – 25**	**5 – 25**	**11.00**	**5.61**	**.155**	**.001**
N-DQ$_3$: *'Wanting to 'fit in'*	.78 (5 items)	5 – 25	5 – 25	13.48	5.82	.098	.200*
N-DQ$_4$: *'No benefits from telling others'*	.77 (5 items)	5 – 25	5 – 25	15.15	5.87	.119	.024
Non-Disclosure Total	.92 (25 items)	25 – 125	25 – 121	65.46	23.42	.101	.094
S-DQ$_1$:*'Need to explain'*	**.88 (5 items)**	**5 – 25**	**5 – 25**	**16.63**	**6.67**	**.139**	**.003**
S-DQ$_2$: *'Positive benefits from telling others'*	.89 (10 items)	10 – 50	10 – 50	34.46	11.21	.120	.021
Self-Disclosure Total	**.92 (15 items)**	**15 – 75**	**16 – 75**	**51.09**	**16.28**	**.118**	**.026**
ESSQ Total	.86 (12 items)	12 – 60	14 – 56	30.42	10.11	.094	.200*
RSE Total	.87 (10 items)	0 – 30	0 – 29	17.86	5.67	.079	.200*
SAD Total	**.94 (28 items)**	**28 – 56**	**28 – 54**	**36.03**	**7.63**	**.176**	**.001**
CIQ Total	.58 (15 items)	0 – 29	5 – 23	14.42	4.21	.078	.200*
CIQ home integration score	**.77 (5 items)**	**1 – 10**	**1 – 10**	**4.71**	**2.65**	**.171**	**.001**
CIQ social integration score	.42 (6 items)	1 – 12	1 – 12	7.11	2.35	.128	.010
CIQ productivity	**.31 (4 items)**	**0 – 7**	**0 – 7**	**2.60**	**1.63**	**.275**	**.001**
LISAT-11 Total	.698 (11 items)	11 – 66	13 – 55	39.29	9.43	.095	.200*
UCLA Total	.899 (20 items)	20 – 80	22 – 67	39.98	11.76	.094	.200*

6.2.13 Descriptive statistics for social support questions SSQ

Table 6-12: Descriptive statistics for the ESSQ

Item Descriptive Statistics for the ESSQ

Sub-scale or measure	Mean	SD	Item-Total Correlation (ITC)	Cronbach's Alpha if Item Deleted	Removed from analysis X
Enacted Social Support Questions (ESSQ)					
3.a: Who do you live with?	2.92	2.30	-.202	.858	X
3.b/c: Have no family or have no contact with your family	1.85	.40	.275	.787	X
ESSQ: practical help – 3 items					
3.1: Practical help - from family members	3.17	1.32	.351	.779	
3.2: Practical help - from friends	2.52	1.35	.613	.756	
3.3: Practical help - from neighbours or acquaintances	2.18	1.31	.537	.763	
ESSQ: Advice or information – 3 items					
3.4: Advice or Information - from family members	2.68	1.47	.411	.774	
3.5: Advice or Information – from friends	2.12	1.22	.640	.756	
3.6: Advice or Information – from neighbours or acquaintances	1.85	1.20	.607	.759	
ESSQ: Moral or emotional support – 3 items					
3.7: Moral or emotional support - from family members	2.77	1.40	.543	.762	
3.8: Moral or emotional support - from friends	2.37	1.39	.635	.753	
3.9: Moral or emotional support - from neighbours or acquaintances	2.00	1.29	.559	.762	
ESSQ: Socializing – 3 items					
3.10: Socializing - with family members	3.09	1.25	.479	.769	
3.11: Socializing - with friends	3.17	1.3	.346	.779	X
3.12: Socializing - with neighbours or acquaintances	2.49	1.50	.531	.762	

Table 6-12 shows how the items in the ESSQ fit together. They indicate that further analysis of the structure is required.

SECTION THREE

6.3 Preparatory analyses

The sub-scales were checked for missing data before detailed analysis was undertaken and none were found. Analysis using SPSS 19 showed that some of the scores were not normally distributed (Table 6-11). Further investigation, using the 'explore' facility, revealed different outliers for different sub-scales. We also used self-reported and ordinal response scales. For these reasons, non-parametric statistical analysis was used for most of the analysis. Parametric statistics were used where specific testing was required and the data met the other criteria required (Bryman, 1984; Field, 2009). For example, in this section, results of a factor analysis on the ESSQ are given, as well as factor analysis of the non-disclosure and self-disclosure questionnaires for the combined results from studies 2 and 3 (N = 120). Descriptive statistics for all the measures used to test our hypotheses are given in Table 6-11 above. Results from the hypothesis testing, using Spearman's rho (two tailed) correlations, are given in Table 6-17 (complete Tables are given in Appendix C-1 and C-3) and, for gender, the results of a Mann-Whitney test are given in Table 6-20. Mediation analysis, using bootstrapping, was carried out to investigate the relationships between six variables, as specified in hypothesis 7.

6.3.1 Exploratory Factor Analysis of the ESSQ

Factor analysis (FA) was used to explore the data, and to investigate the underlying structure of the 12 items in the ESSQ. The Kolmogorov-Smirnov test results given in Table 6-11 showed that the ESSQ was normally distributed, using a significance level of .05. Following an initial look at these items, three factors were saved as new variables; a

Pearson’s correlation suggested they were not related: The rotation strategy can be selected with this evidence, and varimax was selected. If the underlying factors are related, or thought to be related, oblique rotation is recommended (Field, 2009; Pallant, 2007).

The Kaiser-Meyer-Olkin value of the ESSQ was .76 and Bartlett’s Test of Sphericity was statistically significant at χ^2 (66) = 441.67, p .001. We acknowledge that the figures are low to be using factor analysis (FA) with a ratio of 5:1, but they did reach the levels required, shown by the KMO above .6 and the BTS being significant (Field, 2009; Pallant, 2007).

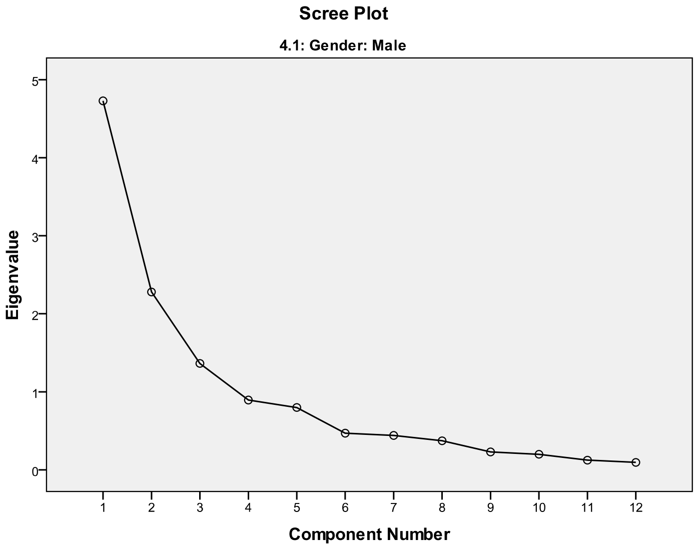


Figure 6-1: Scree plot of loadings for the ESSQ items (12)

Inspection of the scree plot indicated a two factor solution was preferable to three (Figure 6-1). These two factors accounted for almost 60% of the variance; the first component explained 41.12 %, the second component 17.78%. Eigenvalues are given in Appendix Table C-4.

Table 6-13: Summary of exploratory factor analysis results for ESSQ (N = 65)

Pattern and Structure Matrix with Communalities (C)	Factor 1	Factor 2	C
3.8: Moral or emotional support - from friends	.878	.067	.775
3.9: Moral or emotional support - from neighbours or acquaintances	.816	.001	.666
3.5: Advice or Information - from friends	.806	.156	.674
3.6: Advice or Information - from neighbours or acquaintances	.666	.265	.515
3.3: Practical help - from neighbours or acquaintances	.644	.131	.431
3.2: Practical help - from friends	.609	.242	.429
3.12: Socializing - with neighbours or acquaintances	.530	.191	.317
3.11: Socializing - with friends	.388	.111	.163
3.1: Practical help - from family members	-.038	.894	.801
3.7: Moral or emotional support - from family members	.230	.775	.654
3.4: Advice or Information - from family members	.190	.674	.490
3.10: Socializing - with family members	.213	.556	.354
Extraction Method: Principal Axis Factoring. Rotation Method: Varimax with Kaiser Normalization. Rotation converged in 3 iterations.			

Table 6-13 shows a two factor solution: Factor 1 related to ‘*friends and others’* and factor 2 to ‘*family*’. The lowest communalities were for the three ‘*socialising’* items 3.11 then 3.12 and 3.10; they explained the least amount of variance across the factors. A two factor structure still required the removal of item 3.11, and because each factor requires a minimum of three items these questions were removed (Field, 2009). Revised statistics for the ESSQ modified are given in Table 6-14.

Table 6-14: Revised descriptive statistics for the ESSQ modified

Revised Descriptive Statistics for ESSQ mod * Lower bound of true significance							
N = 65 Missing = 0	Cronbach's alpha	Range of scores	Actual Range	Mean	Std. Deviation	Kolmogorov-Smirnov	
						Statistic	Sig.
ESSQ modified	.85 (9 items)	9 - 45	9 - 41	21.66	8.12	.114	.035

6.3.1.1 Factor Analysis of the N-DQ and S-DQ

The structure of the non-disclosure and self-disclosure questionnaires was investigated using principal axis factoring (Field, 2009) and Direct Oblimin rotation for the combined data bases for study 2 (discussed Chapter 4) and study 3 (this chapter). The Kaiser-Meyer-Olkin value was .83 and Bartlett's Test of Sphericity was statistically significant at χ^2 (780) = 2549.66, p .001. A scree plot of the items (Figure 6-2) showed that a two factor solution would account for almost 40% of the variance; the first component explained 26.69% and the second component 13.11%. The strength of the relationship between these two factors, given in the 'factor correlation matrix' was quite low at -.22.

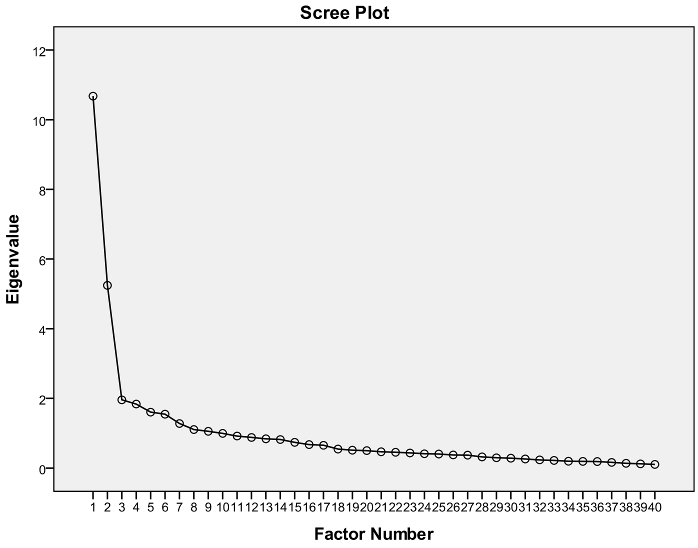


Figure 6-2: Scree plot of loadings for the N-DQ and S-DQ items (N=120) indicating two factors; related to Tables 6-15 and 6-16.

Eigenvalues (are reproduced in the Appendix as Table C-5) and the Pattern and Structure Matrix Tables for the exploratory principal axis factoring for N = 120 are given in Tables 6-15 and 6-16. They showed a simple structure, following the lines of concealment items in factor one and disclosure items in factor two. This indicates that a total score could be used for each questionnaire. The two total scores were accordingly used in the mediation analysis for testing H_7.

Table 6-15: Summary of exploratory factor analysis results for N-DQ and S-DQ (N = 120) part 1 (using principal axis factoring and Direct Oblimin rotation)

Pattern and Structure Matrix with Communalities (C)	Pattern Matrix		Structure Matrix		C
	1	2	1	2	
1.5/ss3: I don't want to be marked out as 'the person with the head injury'	.676	-.012	.678	-.164	.460
1.21/ss2: I would get embarrassed if I told them	.639	-.087	.659	-.230	.441
1.19/ss1: the other person might think I was stupid	.637	-.113	.662	-.256	.451
1.16/ss3: I don't want to have to explain things yet again	.613	.069	.597	-.068	.361
1.13/ss1: the other person might gossip about me to others	.604	-.235	.657	-.370	.484
1.14/ss4: other people don’t understand what I've been through	.594	.066	.579	-.067	.340
1.6/ss1: the other person might get annoyed if I talk about it	.593	-.091	.614	-.224	.384
1.4/ss2: I would feel ashamed if I told them	.568	-.089	.588	-.217	.354
1.1/ss2: talking about it reminds me of all the bad things that have happened	.562	.029	.556	-.097	.310
1.3/ss3: I don't want to be asked all kinds of questions about it	.556	.058	.543	-.067	.298
1.2/ss1: other people might think I was mad or dangerous	.556	-.087	.575	-.212	.338
1.18/ss2: I know talking about it would make me feel worse	.553	-.014	.556	-.138	.309
1.9/ss1: the other person might think badly of me	.552	-.184	.593	-.308	.384
1.8/ss1: the other person might start to talk down to me or patronize me	.535	-.077	.553	-.197	.311
1.12/ss3: I don't like the attention I get when I do tell someone	.533	.011	.531	-.108	.282
1.22/ss4: other people aren't that interested in what's happened to me	.529	-.018	.533	-.136	.284
1.20/ss1: the other person might be fed up of hearing about it	.521	-.122	.549	-.239	.315
1.10/ss2: I would get upset if I started to talk about it	.521	-.186	.563	-.303	.350
1.24/ss4: I can't see that there's much point talking about it	.506	.338	.430	.225	.294
1.15/ss1: I might be made fun of	.502	-.336	.577	-.449	.441
1.25/ss4: talking about it doesn't help me	.492	.278	.430	.168	.258
1.23/ss4: not much good ever comes from me telling other people about it	.478	.255	.421	.148	.239
1.7/ss3: I think they might make a fuss about it	.455	.027	.449	-.075	.203
1.17/ss1: the people I am with might take advantage of me	.423	-.309	.492	-.403	.332
1.11/ss1: people might start to watch closely what I do and say	.348	-.247	.404	-.325	.221
Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization. a. Rotation converged in 4 iterations.					

Table 6-16: Summary of exploratory factor analysis results for N-DQ and S-DQ (N = 120) part 2 (using principal axis factoring and Direct Oblimin rotation

Pattern and Structure Matrix with Communalities (C)	Pattern Matrix		Structure Matrix		C
	1	2	1	2	
2.4/ss6: talking to others helps me understand my difficulties better	.041	-.697	.198	-.707	.501
2.8/ss6: I am feeling low and need some emotional support	-.182	-.684	-.029	-.643	.445
2.10/ss6: I feel better for getting things off my chest	.023	-.674	.174	-.679	.462
2.3/ss6: I don't want to bottle up my feelings	.077	-.668	.227	-.685	.475
2.1/ss6: I want emotional support	-.048	-.661	.100	-.651	.426
2.9/ss6: they help me sort my problems out	-.088	-.654	.058	-.634	.410
2.11/ss5: It makes me feel better if they know why I am like this	.104	-.642	.248	-.665	.452
2.6/ss6: I wanted more information about my problem	.040	-.629	.181	-.638	.409
2.14/ss5: I just feel I've got to explain myself to them	.134	-.602	.269	-.632	.417
2.7/ss6: once they understand, people are generally helpful	-.140	-.588	-.008	-.557	.329
2.5/ss6: I feel like I'm not facing my problems alone	.100	-.582	.231	-.604	.375
2.2/ss6: they help me keep going when I feel like giving up	.060	-.560	.186	-.574	.333
2.12/ss5: If I don't explain then they might think I'm stupid	.165	-.538	.286	-.575	.356
2.15/ss5: I don't want them getting the wrong idea about me	.317	-.534	.436	-.605	.461
2.13/ss5: I don't want them thinking I'm strange or odd	.347	-.446	.447	-.523	.388
Extraction Method: Principal Axis Factoring. Rotation Method: Oblimin with Kaiser Normalization. a. Rotation converged in 4 iterations.					

6.3.2 Descriptive Statistics for questionnaires

The results of the K-S test indicated that the total scores for the S-DQ, ESSQ modified and the SAD were not normally distributed: our sample size was sufficient to use this method but small enough for the results to be reliable.

6.3.3 Hypotheses Testing

Higher N-DQ and S-DQ scores mean greater presence of the measured motivations. In brief our 7 hypotheses are:

FACTORS THAT MAY INFLUENCE THE USE OF DISCLOSURE STRATEGIES

$H_{1:}$ Those with low self-esteem may be more likely to avoid revealing their difficulties to others because of the '*fear of the negative reactions from others' (*N-DQ_1).

$H_{2:}$ Those with low self-esteem will be more likely to avoid disclosure because of '*wanting to fit in' (*N-DQ_3).

$H_{3:}$ Those with low self-esteem will score higher on the '*need to justify'* (S-DQ_1).

Self-esteem was measured with the RSE scale; higher scores represent higher levels of self-esteem.

SOCIAL CONSEQUENCES OF DISCLOSURE

$H_{4:}$ Those who have *'fear of the negative reactions from others'* (N-DQ_1); *'avoidance of emotional upset*' (N-DQ_2) and '*wanting to fit in'* (N-DQ_3) will be more avoidant of situations that bring them in to contact with others.

Social avoidance was measured with the SAD; higher scores mean more social avoidance.

H_5: Those who score highly on the UCLA loneliness scale will also score highly on the '*concern about the negative reactions from others'* N-DQ_1 and '*wanting to fit in'* (N-DQ_3).

Loneliness was measured with the UCLA; higher scores mean more loneliness.

6.3.3.1 *Social Support*

H_6: those who are motivated to obtain the '*benefits from telling others*' (S-DQ_2) are more likely to actually obtain support from others (higher scores on the ESSQ); and, conversely, that those who see '*no benefits to telling others'* (N-DQ_4) or who are motivated to conceal, are less likely to access support from others (lower scores on the ESSQ).

Social support was measured with the ESSQ modified; higher scores mean more support has actually been received.

THE BROADER CONSEQUENCES THAT MAY BE MEDIATED BY THESE SOCIAL CONSEQUENCES

Mediation hypothesis:

$H_{7:}$ Motivations to disclose (conceal) will be associated with higher (lower) engagement in valued activities and higher (lower) life satisfaction; and this effect will be mediated through less (more) social avoidance and loneliness and more (less) social support.

This hypothesis relates to all the sub-scales of the N-DQ and S-DQ in relation to the CIQ and LiSat-11, mediated through SAD, UCLA and ESSQ modified scales.

6.3.4 Testing the Hypotheses

In addition to the results arising from each hypothesis, total scores are given following the factor analysis, as they will be used in the mediation analysis to test H_7.

Table 6-17: Results of hypothesis testing for first six hypotheses

Results from hypothesis testing N = 65			
Results for hypotheses 1, 2 and 3 relate to factors that may influence the use of disclosure strategies			
Hypothesis	Spearman's rho correlation (two tailed) between:	r_s	Significance
H$_1$	**RSE and N-DQ$_1$**	**-.250***	**.044**
H$_2$	**RSE and N-DQ$_3$**	**-.360****	**.003**
	RSE and N-DQ total	**-.357****	**.003**
H$_3$	RSE and S-DQ$_1$	-.220	.078
	RSE and S-DQ total	-.069	.586
Results for hypotheses 4, 5 and 6 relate to social consequences of disclosure strategies			
H$_4$	**SAD and N-DQ$_1$**	**.266***	**.032**
	SAD and N-DQ$_2$	**.388****	**.001**
	SAD and N-DQ$_3$	**.315***	**.011**
	SAD and N-DQ total	**.345****	**.005**
H$_5$	**UCLA and N-DQ$_1$**	**.415****	**.001**
	UCLA and N-DQ$_3$	**.325****	**.008**
	UCLA and N-DQ total	**.380****	**.002**
H$_6$	ESSQ mod and S-DQ$_2$	.055	.662
	ESSQ mod and N-DQ$_4$	-.060	.638
**Correlation is significant at the 0.01 level (2-tailed) * Correlation is significant at the 0.05 level (2-tailed)			

Table 6-17 shows that the hypotheses relating to self-esteem were partly supported: Lower self esteem was significantly associated with higher scores on '*wanting to fit in'* and '*concern about negative reactions from others'*; but the correlation with '*need to explain'*, although in the predicted direction, was not significant.

The hypothesis relating to social avoidance was supported: higher levels of social avoidance correlated with higher scores on '*concern about the negative reactions from others'*, '*avoidance of emotional upset'* and '*wanting to fit in'*.

Hypothesis 5 relating to loneliness was supported: higher levels of loneliness were associated with higher scores on ‘*concern about the negative reactions from others’* and ‘*wanting to fit in’*.

Hypothesis 6 related the positive and negative benefits of disclosure to the level of social support obtained. This hypothesis was not supported but the negative correlation between N-DQ_4 and the ESSQ and the positive correlation between S-DQ_2 and the ESSQ shows that the relationships were in the direction predicted.

Investigating the Broader Consequences That May Be Mediated By These Social Consequences

The broader consequences of ABI in relation to concealment (N-DQ) and disclosure (S-DQ) may be reflected in terms of reduced community integration (CIQ) and reduced life satisfaction (LiSat-11), mediated by social support (ESSQ modified), social avoidance and distress (SAD) and loneliness (UCLA). Correlations relevant to this mediation hypothesis are given in Appendix Table C-1 and later in Table 6-21.

6.3.4.1 Mediation hypothesis

SPSS 19 and AMOS 7.0 software (SPSS, 2006) was used to test hypothesis 7. The size and significance of the indirectly mediated effect of disclosure and concealment on broader rehabilitation outcomes (community integration and life satisfaction) were calculated. Reporting indirect effects from structural equation modelling (SEM) as a measure of the meditation effect is supported by several researchers who built on the work of Baron and Kenny (1986) (Bullock, Green, & Ha, 2010; Hayes, 2009; Imai, Keele, & Tingley, 2010; Zhao, Lynch, & Chen, 2010). Twelve analyses were carried out to investigate mediation effects for the variables shown in Figure 6-3 and these are given in Appendix Table C-9.

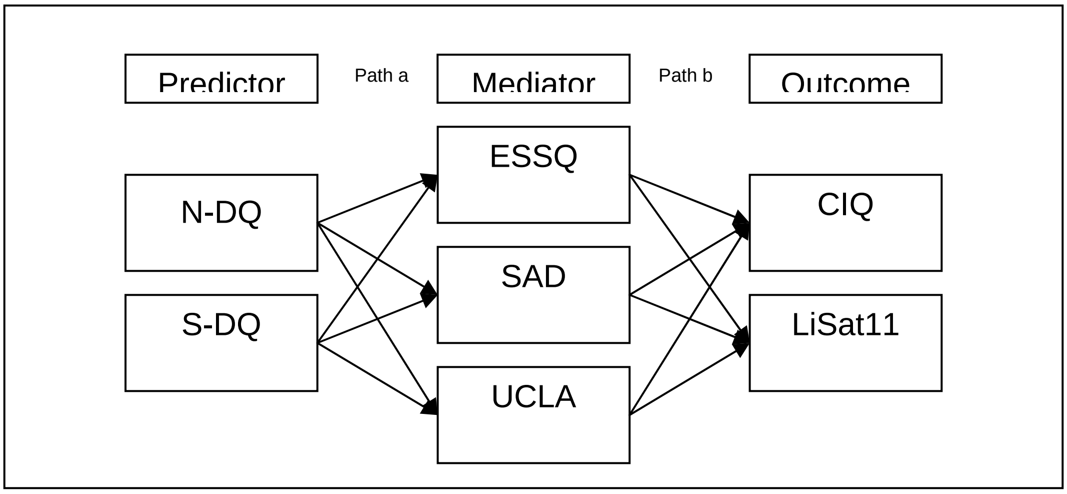


Figure 6-3: Hypothesised associations for mediation analysis, between the N-DQ, S-DQ and potential mediating variables and outcomes.

In addition, a model for the N-DQ and S-DQ (Appendix Table C-10 and Figures C-1 and C-2) and a combined model including all the variables relating to hypothesis 7 (Figure 6-4) were calculated. Only the combined model is described here. Analysis of all variables simultaneously in the total model reduces the probability of Type I errors occurring because of multiple testing (slightly different figures were observed due to the different relationships between the variables). Standardized values are given as these enable comparison with other studies where required.

The total scores for the N-DQ and S-DQ were entered into the mediation analysis following the factor analysis (Figure 6-2, Tables 6-15 and 6-16 and Appendix Table C-5). The two factors were linked in the model as they correlate: linking them means that neither takes precedence over the other in the path analysis (Bryman & Cramer, 1997). Bootstrapping was used, as this technique does not require normal distribution and is useful for small studies (20 to 80 cases) (Shrout & Bolger, 2002). Bias-corrected confidence intervals were set at 95%. The indirect effects for the hypothesised associations for the 'total model' using path analysis and SEM are given in Table 6-18.

Table 6-18: Critical figures from path analysis for N-DQ and S-DQ

AMOS 7.0 (bootstrapped) – Standardized Indirect Effects (SIE) of mediation for N-DQ and S-DQ with ESSQ, UCLA and SAD and CIQ and LISat-11 for total model							
Variables			SIE	Confidence Intervals bias corrected (BC)		p two tailed	Bootstrap Standard Error (SIE SE)
predictor	mediator	outcome		Lower	Upper		
N-DQ	ESSQ m	CIQ	-.050	-.218	.086	.473	.077
	SAD **UCLA**	**LiSat-11**	**-.300**	**-.482**	**-.110**	**.002**	**.094**
S-DQ	ESSQ m	CIQ	-.024	-.130	.073	.590	.050
	SAD UCLA	LiSat-11	.110	-.035	.276	.136	.079

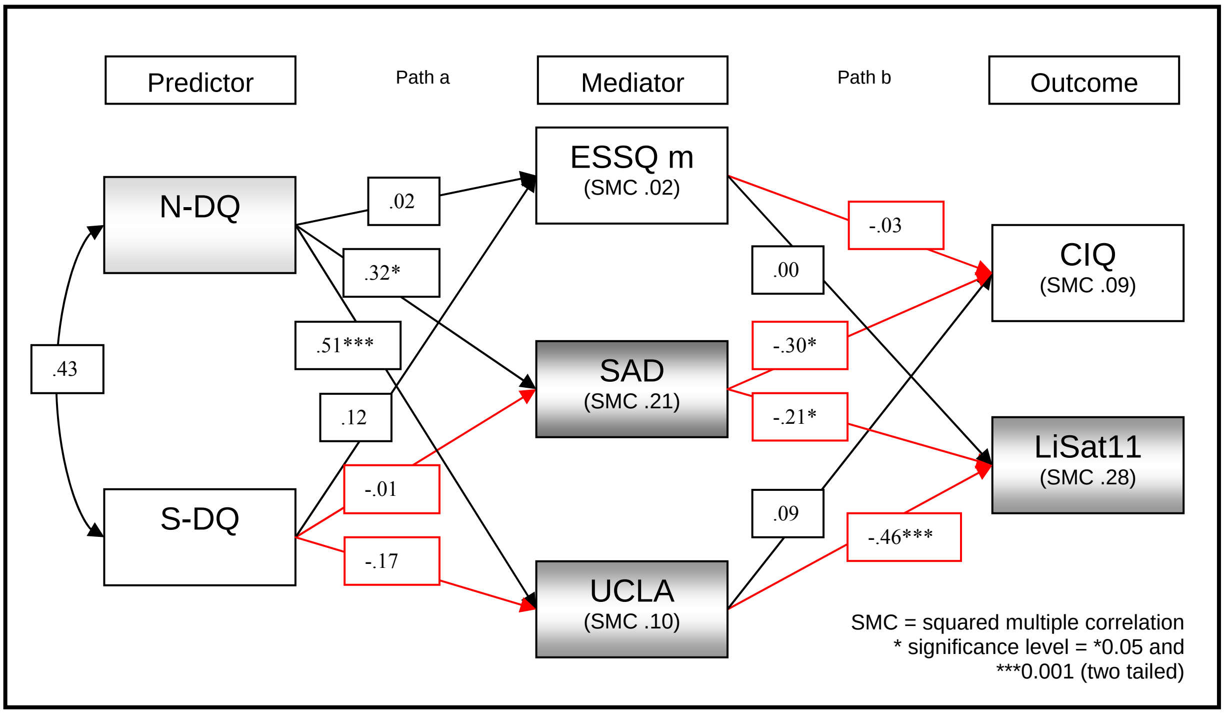


Figure 6-4: N-DQ and S-DQ association with mediators ESSQ m, SAD and UCLA to outcomes CIQ and LiSat-11. Red arrows are negative and black arrows are positive

Figure 6-4 offers a model for the association between non-disclosure of issues regarding the effects of brain injury (N-DQ), and potential mediating variables enacted social support (ESSQ), social avoidance (SAD) and loneliness (UCLA) and outcomes community integration (CIQ) and life satisfaction (LiSat-11). The values given in the box on each arrow show the degree to which the two variables are related: as the predictor variable goes up by one standard deviation the outcome variable goes up or down by the amount shown in the box. The analysis for the combined model (supported by the individual analyses) showed that being motivated to conceal (N-DQ total) had a significant negative impact on life satisfaction (LiSat11), and that this impact was mediated by social avoidance (SAD) and loneliness (UCLA), but not by enacted social support (ESSQm). Being motivated to disclose (S-DQ total) did not have a direct impact on life satisfaction and neither concealment nor disclosure had a direct impact on community integration (CIQ). Overall, 28% of the variance in life satisfaction was explained by the model.

6.3.5 Additional investigation

6.3.5.1 Analysis of the N-DQ and S-DQ to investigate impression management

The potential use of impression management was investigated. Frequency counts were made (Table 6-19) of the responses where participants had selected ‘probably true’ and ‘definitely true’ (the extent to which the person was motivated by that reason to disclose or conceal): It was the deliberate selection of these responses we were interested in. These figures together suggest that the majority of participants reported at least some degree of impression management.

Table 6-19: Assessment of the use of Impression Management (IM)

Number of responses to ‘definitely true’ or ‘probably true’ for both questionnaires	
Frequency	N-DQ and S-DQ
0%	1
1 – 25%	13
26 – 50%	23
51 – 75%	20
76 – 100%	8
Totals	65

To assess the use of impression management (IM) we counted the number of times participants responded ‘probably true’ and ‘definitely true’ to the N-DQ and S-DQ items. Table 6-19 shows that 1 (1.5 %) participant did not endorse any of the reasons for disclosing or concealing; this individual probably did not make use of IM. Although there may be other reasons, not covered by the questionnaires that did motivate them to disclose or conceal issues related to their ABI. For the other groups, 36 (55%) participants were not motivated to disclose or conceal for fewer than fifty percent of the reasons given and 28 (43%) participants disclosed or concealed information about their ABI for more than fifty percent of the reasons given; indicating they were using some degree of IM.

6.3.5.2 Community Integration (CIQ)

Reduced participation in community activities may occur because of reduced self-esteem (Riley; 2010), which may also underlie the unwillingness to disclose. To see if the N-DQ, CIQ and RSE correlate, a Spearman’s rho analysis was undertaken, showing that the CIQ related positively to the RSE: $r_S = .354$, $n = 65$, $p = .004$. The N-DQ related negatively to the RSE: $r_S = -.357$, $n = 65$, $p = .003$; but the N-DQ did not correlate directly with the CIQ: $r_S = .064$, $n = 65$, $p = .615$.

6.3.5.3 Associations between gender and the additional questionnaires

Associations between gender, N-DQ and S-DQ and the additional questionnaires were investigated using the Mann-Whitney test (2-tailed). Significant results are given in Table 6-20 (all the results are given in Appendix Tables C-6 and C-7). Effect sizes are given in the last column where .1, .3 and .5 are considered as the thresholds for small, medium and large effects respectively (Cohen, 1988; Pallant, 2007).

Table 6-20: Significant Mann-Whitney results for gender and questionnaires

Questionnaire		Mean Rank	Median	M-W U	Z	Exact sig. p	Effect size r
RSE	Male (50)	35.91	19	229.50	-2.27	.022	-0.28
	Female (15)	23.30	15				
SAD	Male (50)	30.10	33	230.00	-2.27	.023	-0.28
	Female (15)	42.67	36				
N-DQ1	Male (50)	29.38	23	194.00	-2.82	.005	-.035
	Female (15)	45.07	32				
N-DQ2	Male (50)	29.57	9	203.50	-2.68	.007	-0.33
	Female (15)	44.43	14				
N-DQ3	Male (50)	30.37	13	243.50	-2.05	.040	-0.25
	Female (15)	41.77	17				
N-DQ4	Male (50)	30.18	13.5	234.00	-2.20	.028	-0.27
	Female (15)	42.40	19				
N-DQ Total	Male (50)	29.23	58	186.50	-2.94	.003	-0.36
	Female (15)	45.57	81				
S-DQ1	Male (50)	29.18	15.5	184.00	-2.98	.003	-0.37
	Female (15)	45.73	23				
S-DQ2	Male (50)	29.48	32	199.00	-2.74	.006	-0.34
	Female (15)	44.73	44				
S-DQ Total	Male (50)	29.08	48	179.00	-3.05	.002	-0.38
	Female (15)	46.07	64				

In Table 6-20 all the significantly different gender scores are given. For concealment (N-DQ), disclosure (S-DQ) (totals and sub-scales), and avoidance (SAD) female participants scored higher. For self-esteem (RSE) male participants' scores were higher; these are all medium sized effects.

6.3.5.4 Associations between the additional questionnaires

To complete the analysis for this study Spearman's rho correlations for the additional measures are given in Table 6-21 (see Appendix Table C-8 for N-DQ and S-DQ). We found greater participation (CIQ) was associated with less social avoidance (but this is low helping to explain only 7 percent of the variance in respondents' scores on community integration and social avoidance); and higher self-esteem (which helps to explain 12.5% shared variance). More social avoidance (SAD) is associated with lower self-esteem (11% shared variance);

with greater loneliness (25% shared variance); with lower life satisfaction (12% shared variance) and receiving less social support (13 – 15% shared variance). Higher self-esteem is associated with reduced loneliness (19% shared variance) and higher life satisfaction (28% shared variance). Greater loneliness is associated with lower life satisfaction (23% shared variance) and receiving less social support (6 – 15% shared variance). Finally, higher life satisfaction is associated with more social support (9% shared variance).

Table 6-21: Analyses of additional measures used in this study, and the ESSQ and ESSQ modified (Spearman's rho)

Correlations of additional measures and ESSQ and ESSQ modified

Spearman's rho		SAD Total	RSE	UCLA	LISAT Total	ESSQ modified	ESSQ Total
CIQ Total	Correlation Coefficient	-.260*	.354**	-.097	.241	.116	.070
	Sig. (2-tailed)	.037	.004	.442	.053	.357	.581
SAD Total	Correlation Coefficient		-.333**	.500**	-.349**	-.362**	-.383**
	Sig. (2-tailed)		.007	.001	.004	.003	.002
RSE Total	Correlation Coefficient			-.435**	.534**	.122	.205
	Sig. (2-tailed)			.001	.001	.335	.101
UCLA	Correlation Coefficient				-.483**	-.252*	-.384**
	Sig. (2-tailed)				.001	.042	.002
LISAT Total	Correlation Coefficient					.180	.302*
	Sig. (2-tailed)					.151	.014

*. Correlation is significant at the 0.05 level (2-tailed).
**. Correlation is significant at the 0.01 level (2-tailed).

SECTION FOUR

6.4 Discussion

6.4.1 Self-esteem

Descriptive statistics are given in Table 6-11 for the RSE and other sub-scales. We hypothesised that individuals with low self-esteem may be more likely to avoid revealing their difficulties to others because of worries about how they may react. The results supported hypothesis 1 and 2: Low scores on the RSE indicating low self-esteem were associated with high scores on N-DQ_1 '*concern about negative reactions from others*' (Table 6-17). Controlling what, how and when information is disclosed to others takes time (planned disclosure), and trust and a belief (or hope) that the information given will be accepted in good faith and will not lead to rejection. Both the fear of negative reactions from others and the fear of exposure pose a threat to one's self esteem (Afifi & Steuber, 2010; Jambor & Elliott, 2005; Olney & Brockelman, 2003; Simpson, et al., 2000). When self-esteem is already low, disclosure would be a significant step to take.

We also hypothesised that individuals with low self-esteem would be more likely to avoid disclosure because of '*wanting to fit in*' (N-DQ_3) (Table 6-17). Again, the results supported the hypothesis. 'Fitting in' matters because, in part, we define ourselves by reference to those we associate with (Jones, et al., 2011) and their feedback affects our self-esteem (Tod, Thatcher, & Rahman, 2010). If individuals feel they do not belong to a group, the threat of this loss (of companionship and belonging) may encourage them to increase their efforts to fit in (Pickett & Brewer, 2001). Those individuals whose self-esteem is already low will be motivated to protect themselves from further threat and anxiety (Adie, et al., 2008; Heimpel, et al., 2006; Tice, 1991).

We hypothesised that those individuals with low self-esteem would score higher on S-DQ_1 '*need to justify scale'* (Table 6-17). There was a negative correlation between these variables but this was not significant and so our third hypothesis was not supported. This may not be that surprising given our previous two findings. To suddenly change coping strategies and disclose rather than conceal could be a risky decision for some to take because of longer term effects on their self-esteem and well-being (Chaudoir & Fisher, 2010). Using impression management takes effort, like many habits, a part of who that individual is. According to Cooper-Evans, Alderman, Knight and Oddy (2008) knowing what you've lost relates to lower self-esteem; but people with more severe injuries may have less insight into what they have lost, and so their self-esteem is less affected. In this study participants' scores were higher for self-esteem (Table 6-5) than those reported in other ABI studies (Cooper-Evans, et al., 2008; Riley, et al., 2010), but lower than those for the general population (Table 6-10). Male participants were found to have significantly higher self-esteem than females within our study (Table 6-20). Correlations were carried out between the additional measures (Table 6-21), these helped to put the study results into context. To answer one of our questions we can say (for this study) that high self-esteem was highly significantly associated with reduced loneliness and with greater life satisfaction. This means that individuals, who have low self-esteem, may well have higher levels of loneliness and reduced life satisfaction.

6.4.2 Social avoidance and distress

Based upon the research cited in Chapter 5 (for example Goldstein and later Riley et al.), we suggested that individuals who were concerned about negative responses would be more avoidant of situations where they come into contact with others, to avoid being upset and protect their self-esteem. Spearman's rho correlations between the social avoidance and distress scale (SAD) and N-DQ$_1$ '*concerns about negative reactions from others'*, N-DQ$_2$ '*avoidance of emotional upset'* and N-DQ$_3$ '*wanting to fit in'* showed positive significant relationships. Descriptive statistics are given in Table 6-11. High scores on the SAD were found to relate to high scores on these three variables indicating both avoidance of social situations and social distress; supporting our fourth hypothesis (Table 6-17). Significant gender differences were found, females scored more highly for social avoidance than males (Table 6-20). Those who have more fear of negative responses and wished to avoid emotional upset were more avoidant of social situations. Higher scores for social avoidance and distress were found for participants in this study compared to those found in the general population (Table 6-6 and 6-10). Social Psychologists Afifi and Steuber (2010) found that being on guard because of the fear of negative reactions from others (for example, protection from shame, ridicule and hurt), including comment from family members, could lead to a cycle of concealment which becomes deep-rooted. This would impact upon the individual due to negative feedback; they may as a consequence habitually conceal as a form of self protection. Correlations between social avoidance and additional measures (Table 6-21) showed that more social avoidance was related to low self-esteem, greater loneliness, lower life satisfaction and less social support.

6.4.3 Loneliness

Our fifth hypothesis was related to non-disclosure and loneliness, which is an important outcome (Table 6-7); descriptive statistics are given in Table 6-11. There was a significantly positive relationship between '*concern about negative reactions*', '*wanting to fit in'* and loneliness (Table 6-17). One possible explanation for this comes from Dahlberg et al. (2005) who cited research that found loneliness often increased after a TBI, due to communication difficulties and loss of employment, which leads to a reduction in life satisfaction. Tables 6-1 and 6-10 show that more participants were economically inactive in our study; this is also supported by the data in Table 6-9 regarding community integration and productivity. Life satisfaction was lower with regard to vocation, sex life and relationships (Tables 6-8 and 6-10). The loss of social skills as a contributory factor to loneliness was found by Shorland and Douglas (2010). Hoofien, Gilboa, Vakil and Donovick (2001) found high levels of loneliness, but reported greater levels of employment in those approximately 14 years post-injury, than we found. Morton and Wehman (1995) found that loneliness increased during the first two years post-injury due to loss of friendships and increased dependence on family for social integration, with the loss of self-esteem as a result. The impact of loneliness on self-esteem was also reported by Ponsford, Sloan and Snow (1995). To overcome this Struchen et al. (2011) recommended the use of mentoring as a way to increase social integration and reduce loneliness. However, Russell et al., (1980) explained that reports of loneliness may be affected because of stigma: though the levels of loneliness in this study were comparable with the general population (Appendix Table C-11). There were no significant gender differences identified in the level of loneliness reported (Appendix Table C-6). Further analysis showed that greater loneliness is associated with lower life satisfaction and less social support (Table 6-21).

6.4.4 ESSQ m – mediators

Our sixth hypothesis was related to the positive benefits of disclosure and obtaining social support and conversely, feeling that there were no benefits to disclosure and obtaining little if any social support (Table 6-17). There are a number of possible reasons for failing to support this hypothesis. Was the ESSQ an adequate measure? Table 6-12 indicated further analysis was required. Factor analysis of the social support questionnaire suggested three factors, accounting for 70% of the variance (Figure 6-1): factor 1 '*support from friends, neighbours and acquaintances*'; factor 2 '*support from family*'; and factor 3 '*socializing*'. The '*socializing*' items shared little variance with the other two factors and were removed (Table 6-13). Re-analysis of the 2 factor structure, without the 'socializing' items, showed the nine items were not normally distributed (Table 6-14).

Part of the reason for the ESSQ not performing as anticipated may be due to other factors. The inclusion of those without a family, or with no family contact, may have made responses to some items difficult for them. Whereas individuals who live with their family may rely upon them for social support: Their families would be aware of their brain injury and so disclosure may not be necessary for them to get practical help. The Simpson et al. (2000) study showed that individuals disclosed to their family but were reluctant to disclose to others. Whereas the Crisp (1993) study showed that individuals did not disclose to their families because they were aware they only wanted to hear positive news, they must therefore have concealed some issues, but still obtained support; this problem is referred to by Krefting (1990) as a "double bind" (cited in Cloute, et al., 2008). So people who are reluctant to disclose generally may nevertheless get adequate social support because they rely on their family, or they rely upon others. They get this support through considered disclosure and concealment.

Family support should probably be treated differently from other support. The measures of concealment and disclosure were not designed to be sensitive to a willingness to disclose to family and close others. This difference between disclosure to family and others may also call into question the psychometric validity of the ESSQ because there was a mix of family and other items (Tables 6-11 to 6-14). We considered the issue of whether to ask explicitly about disclosure and concealment in relation to the family and concluded that this was different to the issue of revealing things to one's wider social network. This might have been reflected here, with some separation between family and other support. The ESSQ resolved some of the issues we had with regard to existing measures, but has raised others in its analysis. To complete the analysis the ESSQ and ESSQ modified were correlated with the additional measures used in this study (Table 6-21): we found significant correlations between both of these measures and social avoidance. Less social support is related to more social avoidance and greater loneliness. There is also an indication with the ESSQ that life satisfaction is higher if support is given.

6.4.5 Life Satisfaction (LiSat-11)

Tables 6-8, 6-10 and Appendix Table C-13 show that 'vocational', 'sex life' and 'relationship with partner' scores are lower in our study than scores observed in the study by Stålnacke et al. (2007). Vocational outcome has been associated with the severity of brain injury; those in employment were found by Fleming, Tooth, Hassell and Chan (1999) to have required less acute hospital care than those who are not in employment. It is possible that this also accounts for the high level of unemployment found in our study. Close relationships (sex life and partner relationships) are said by Graham, Huang, Clark and Helgeson (2008) to require individuals to disclose their concerns. If as we found male participants scored lower for disclosure (Table 6-20), this may be a contributing factor to their lack of relationships. In a study of 131 adults with brain injuries, 49 percent were divorced or separated (Wood & Yurdakul, 1997): in our study those who were single, separated/divorced and widowed totalled 66 percent (Table 6-1). Descriptive statistics are given in Table 6-11. No significant gender differences were found for life satisfaction (Appendix Table C-6). Life satisfaction was assessed within the mediation analysis H_7 (Table 6-18 and Figure 6-4); social avoidance and loneliness are mediators between non-disclosure and life satisfaction. Further analysis showed that lower life satisfaction was significantly related to more social avoidance and greater loneliness; and higher life satisfaction was associated with high self-esteem and to a lesser extent enacted social support (Table 21).

6.4.6 Community Integration (CIQ)

Table 6-9 shows that scores for participants are equivalent to those in other studies for the general population and those with an ABI. But, statistical analysis of our figures with those from the Stålnacke (2007) study shows several significant differences (Table 6-10 and Appendix C-12). The home integration scores were significantly lower for females and the social integration, productivity and overall social integration were significantly lower for both males and females in our study. There were no significant gender differences for community integration within our study (Appendix Table C-6). Additional analysis (Table 6-21) showed that reduced participation in community activities was significantly associated with low self-esteem and greater social avoidance, as predicted by Riley, et al. (2010). Low self-esteem was correlated with high levels of motivation to conceal (explaining 13% of the variance). The correlation between reduced participation and concealment, although non-significant in a direct correlation, may occur because both stem from low self-esteem.

6.4.7 Hypothesis 7

We found that concealment (N-DQ) was mediated through social avoidance and distress (SAD) to reduced life satisfaction (LiSat-11); and concealment (N-DQ) was mediated through loneliness (UCLA) to reduced life satisfaction (LiSat-11) (Table 6-18, Figures 6-3 and 6.4).

In Appendix Table C-1, using a Spearman's rho correlation, the N-DQ total and LiSat-11 are not significantly correlated. Because these two measures are normally distributed, as defined by the Kolmogorov-Smirnov test results given in Table 6-11, a Pearson's correlation could be carried out. This shows a moderately significant negative relationship:

$r = -.297$, $n = 65$, $p = .016$ (shared variance of 9 %)

Mediation analysis as defined by Baron and Kenny (1986) would require a significant relationship between the predictor (N-DQ total) and the outcome (Life satisfaction, LiSat-11) as the first step. 'Indirect effect' refers to the value shown between the predictor (path a) and the mediator (M) and then to the outcome (path b); the direct effect is the value of the correlation between the predictor (X) and the outcome (Y). Baron and Kenny (1986) explained that mediation and moderation are distinct effects. Moderators are effectively third variables that affect the direct correlation of the predictor and outcome variables. Ideally a moderator is an independent variable that is uncorrelated with the predictor. A mediator (which is considered in this hypothesis in terms of social support, social avoidance and loneliness) is a variable that intervenes between the predictor and the outcome variable. With mediation, the direct path (c') between the predictor variable 'X' and outcome variable 'Y' is reduced. However, this claim has been disputed by others. According to Hayes (2009) the reliance upon the causal steps approach, (and often the Sobel test which requires the indirect variables to be normally distributed, when they are usually not) may prevent many researchers from analysing their data using mediation analysis and in this way mediating variables may not be identified. The use of (non-parametric) bootstrapping, SEM is seen as a better approach (Zhao, et al., 2010) the data is analysed in one step, and overcomes problems identified with the use of skewed data as the distributions do not need to be normal. In this study 5000 iterations (5000 estimates of the indirect effect) were applied to the analysis, and the bias-corrected confidence intervals derived from this are provided (see also sections 6.3, 6.3.4.1 and 6.4.8, Table 6-18 and Appendix Tables C-9 and C-10).

Self-disclosure did not have the same impact on life satisfaction or community integration as concealment. There may be several reasons for this, for example, the link to others for support. Living with one's family may not require the same level of motivation to disclosure to obtain access to community services and events as living independently or in shared accommodation. And life satisfaction may be gained from having someone close to offer help and support when and if it is needed. Participants who live with their families may already have relationships that do not require them to explain their needs, so their life satisfaction and community integration may currently be satisfactory for them.

The ESSQ (enacted social support) did not act as a mediator as hypothesised. This may be related to the non-normal distribution of the data following the removal of items relating to socialization, but this was required as the three items shared little variance with the two factors. This suggests further evaluation of the ESSQ would be beneficial. This result may also be due to the combination of questions relating to family and to friends. Perhaps those who live with their families rely more on their families for support than those who do not; or perhaps they use the support of other people (for example friends and acquaintances) in a different way. Further investigation of those who live with their families and those who don't may shed light on this.

Neither the N-DQ nor the S-DQ had a direct impact upon community integration. Although in an additional analysis low self-esteem was found to link to non-disclosure and to community integration. This supports the view that self-esteem is reduced by the loss of one's status through TBI (Ponsford, et al., 1995). The sensitivity of the CIQ (Willer, et al., 1993) is directed towards complete independence, which achieves higher scores. This perspective was supported by Fleming, Tooth, Hassell and Chan (1999) who saw returning to work or other vocational activity as a measurable outcome of successful rehabilitation; but explained that a return to work failed for half of their participants.

It is possible that reliance on family for community access and integration, which achieves lower scores, may mean that concealment has less of an impact in terms of community integration for participants (discussed above). The CIQ does not place as much value on activities that require support as those that are undertaken alone; and yet socialization and making friends (building a social support network) is a major aim of rehabilitation (Douglas & Spellacy, 1996; Morton & Wehman, 1995).

According to Larson and Chastain (1990 - cited in Endler, et al., 2002) self-concealment is positively related to self-disclosure and yet they are distinct factors. This phenomenon was indentified within the factor and mediation analysis. There was a positive association between the N-DQ and S-DQ in the mediation model, but a negative one in the factor analysis. In part this was due to using Direct Oblimin (delta set to 0) as a rotation strategy; this was applied because concealment and disclosure are said to be related (oblique). Varimax was also applied because concealment and disclosure are said to be unrelated (orthogonal) (Endler, et al., 2002; Field, 2009; Pallant, 2007). Using Direct Oblimin (Tables 6-15 and 6-16) there was a negative and low relationship between the factors of -.22. A factor analysis using varimax also gave a two factor split, exactly along the lines of concealment and disclosure, but there was a positive and strong relationship between the factors at .78. This observation may also reflect the fact that the factor analysis sample was related to a combined sample size of N=120. The mediation analysis was carried out on a sample of N=65 and the relationship between motivation to conceal and disclose was .43. The results given in Figure 6-4 suggest that concealment has a wider impact on outcome after brain injury in terms of life satisfaction. As such concealment may be an important focus for rehabilitation work.

6.4.8 Limitations and strengths of this study

Limitations related specifically to this study are discussed here; broader implications in relation to the whole study, further suggestions for future research and implications are discussed in Chapter 7.

Two main issues arose from this study in relation to sample size. Firstly, the sample size for the factor analysis of the ESSQ was low with a ratio of 5:1; this may have contributed to the poor performance of the ESSQ. Secondly, for the mediation analysis the sample size was very low, but this procedure was used to explore the data, while reducing the chance of a Type I error. Non-parametric statistics were required in this study, for the same reasons they were used in other ABI studies, because the data were ordinal (Dahlberg, et al., 2005); and some of the measures used (S-DQ, SAD and ESSQ modified) were not normally distributed (Eriksson, et al., 2009). Where these three variables were not involved in the analysis it would be acceptable to use parametric statistics. For mediation analysis non-parametric bootstrapping was used with 5000 bootstrap samples selected (Linting, Meulman, Groenen, & van der Kooij, 2007a, 2007b).

In Chapter 4, it was shown that N-DQ$_4$ had poor and S-DQ$_1$ had fair test-retest reliability. There were two options with this, to remove these sub-scales from the overall questionnaire or to use the total score as indicated by the factor analysis. Cronbach's alpha for the sub-scales and total scores were .7 and above, showing they had acceptable internal reliability. The two main questionnaires developed for this study (N-DQ and S-DQ) showed concurrent validity with questionnaires completed at the same time (discussed in Chapter 4).

Some of the questions in the additional measures were difficult for participants to complete: for example, the negatively worded items on the revised UCLA '*my interests and ideas are not shared by those around me'*, with 'never' to 'often' as a response. We subsequently found this mismatch of question and response had been identified by others in relation to ordinal response scales (Dawes, Palmer, Allison, Ganiats, & Jeste, 2011). This could have led some participants to respond in the opposite way to how they intended, but their strategy for dealing with this was to talk themselves through the questions. The issue of double negatives in the wording of questionnaire items was discussed by Russell (1996) in relation to elderly participants.

The length of time post-injury was also a consideration. Some participants have lived with their brain injury for many years so they may have dealt with the decision to disclose, or not, a long time ago and it may no longer be significant to them. One participant in our first study expressed this as:

> I felt I needed to explain myself, because I was, well I felt I was quite different and I needed to justify why I couldn't remember things and why I wasn't particularly good at time keeping. Now, before my head injury I was. I need to sort of justify why there had been the change. So at that point I did try to explain things quite a lot. But now, other than a few people who show an interest, I don't really explain very much at all (John 2008).

Participants were asked to complete a total of eight questionnaires for this study; this was the maximum we felt we could ask them to do for us. They could complete them at their own pace, taking one or two sessions if they wanted to; this was to reduce any pressure the participant felt they might be under and accommodate tiredness and mental fatigue (Paterson & Scott-Findlay, 2002).

There is the issue about using self-report questionnaires in a population who may lack self-insight (Dyer, et al., 2006; Galski, et al., 1998). Following a study of 24 participants with TBI, Dyer et al. (2006) explained that under reporting and socially desirable responding were associated with a lack of self-awareness, bias and denial; but further studies counter this perspective. Denial is the inability to accept or come to terms with changes after a brain injury, so other issues are not reported. Denial may be linked to changes in one's personal coping style leading to underreporting, avoidance or minimization of difficulties. Alternatively, denial may be linked to an individual's personality (which is seen as a stable trait and not necessarily affected by brain injury) (Ownsworth, et al., 2002). Strategies applied in this situation include response bias, self-deception, defensiveness, minimization, downplaying of negative attributes and socially desirable responding. Such socially desirable responses in self reports of behaviour have been observed in both clinical and general populations. In a study by Hart, White, and Polansky (2003; cited in Dyer, et al., 2006) self-reports of aggression by individuals with a brain injury were shown to informed others who confirmed the responses were accurate; this was taken as evidence that self-reports were more reliable than previously thought. Other researchers have also found personal reports to be accurate (Goldfinger, 2001).

Applied Psychologists Barrick and Mount (1996) described social desirability as response distortion, formed of two constructs self-deception (holding a favourable view of oneself) and impression management (adjusting self-presentation or presenting a positive social image to obtain social approval). However, social desirability can suppress motivation towards impression management (van Leeuwen & Täuber, 2011). Finally, in support of our proposition that individuals with brain injuries are using impression management (IM) we counted the number of times participants responded ‘probably true’ and ‘definitely true’ to the N-DQ and S-DQ items (Table 6-19). One participant did not endorse any of the reasons for disclosing or concealing; this individual probably did not make use of IM. Although there may well be other reasons, not covered by the questionnaires that motivated them to disclose or conceal issues related to their ABI. Using this criterion indicated that the majority of participants were probably using some degree of IM. Assessment of the N-DQ and S-DQ against other measures that relate to impression management would be beneficial.

CHAPTER 7

SECTION ONE

7.1 Introduction

In this Section, the most influential literature on concealment, disclosure and impression management is considered in relation to our study, this is followed by a review of the three studies. In Section Two, the results of the three studies are summarised. In Section Three limitations and strengths are discussed including issues related to validity and reliability. Suggestions are made for future research and the implications of this study are discussed in relation to rehabilitation. Our quotations are given in italics in this chapter to highlight them.

7.1.1 Major influences from the literature

We have identified many links between our findings and those from other areas of research both within the TBI literature and elsewhere (Tables 7-1 and 7-2). In Chapter 2 the broader literature in relation to concealment, disclosure and impression management was discussed. In Chapter 3 more specific literature was provided in relation to concealment, disclosure and impression management and this led into the presentation of the findings from the qualitative study. Links were made in the discussion to the existing literature. Our major influence regarding brain injury research came from a cross-cultural study by Simpson, Mohr and Redman (2000) who looked at stigma and discrimination, which was found in our study to be experienced by most, if not all participants with brain injury. The work of social psychologists Chaudoir and Fisher (2010) was the key reference regarding disclosure, concealment and a stigmatized identity. Both of these studies are discussed in Chapter 2. The major influence regarding impression management was from the studies by Leary (Leary, 1983, 1992; Leary & Kowalski, 1990; Leary, et al., 1994). These authors helped to provide a thread throughout the whole thesis, because they considered many of the core areas of our research.

We asked three questions in addition to our seven hypotheses. The first question related to concealment: what motivates individuals (carer or person with a TBI) to conceal their situation? The second question related to disclosure: what motivates individuals (carer or person with TBI) to disclose their situation? And the third question related to impression management: do individuals recovering from traumatic brain injury, and carers, use impression management? We make some suggestions for further work later in this chapter.

7.1.2 A brief review of the three studies

This was a three-part study, beginning in October 2007, designed to investigate self-disclosure after traumatic brain injury (TBI). We sought information as to why people choose to disclose, or conceal, information about their brain injury to other people; and to investigate how these reasons relate to psychological outcomes (such as self-esteem, social avoidance, loneliness, participation and life satisfaction). These studies were carried out with the support of individuals who attended two Day Centres specializing in the rehabilitation of people with head injuries. The preliminary qualitative study consisted of eighteen semi-structured, one to one interviews, with family carers and individuals with a head injury. The analysis revealed a number of different reasons why the participants disclosed or concealed information to others about brain injury and its effects (Chapter 3 and summarized in Tables 3-3 and 3-4).

The second and third quantitative studies built upon this earlier qualitative work. The second study focussed on the development and evaluation of the Non-Disclosure Questionnaire (N-DQ) and Self-Disclosure Questionnaire (S-DQ). Subscales and items for these questionnaires were drawn from the earlier quantitative investigation. Social support questions were asked in the form of a questionnaire (SSQ). Two additional measures were used to help assess concurrent validity; the BFNE (which measures fear of negative evaluation) and the DDI (which measures disclosure to others when distressed). Fifty five participants took part in this study, twenty of whom also completed the N-DQ and S-DQ questionnaires between two and six weeks later to help us evaluate temporal reliability. The internal consistency of the subscales was also evaluated. In relation to the BFNE, Leary (discussed earlier) produced this measure in 1983 and he went on to do major work in the field of impression management. It is interesting to note that in Chapter 4 the N-DQ$_1$, $_2$ and $_3$, which measure responses related to anxiety, were positively correlated with the BFNE, yet N-DQ$_4$ was negatively related to the DDI. This suggests that our questionnaires may be sensitive to some level of impression management (but it may not!).

In the third study we investigated the association of self-disclosure on rehabilitation outcomes and some of the underlying psychological factors, using the final versions of the questionnaires. We concentrated on self-esteem (a possible predictor of disclosure/concealment motivation), social avoidance, social support and loneliness (possible outcomes of disclosure/concealment motivations). Sixty-five people took part in this study.

SECTION TWO

7.2 <u>Results from the three studies</u>

From our first two research questions, we sought to identify motivations to disclose or conceal issues related to TBI. We identified four themes relating to the concealment of information and two themes relating to the disclosure of information. We were given various reasons for these decisions: protection, education and support. The third research question asked if impression management was being used. The interviews provided examples of the use of IM, both by carers and those with a TBI.

From the interviews, we found that most people actively managed what they said to others about their brain injury. According to the literature, the opportunity to do so would be greater if their injuries were hidden rather than apparent (Olney & Brockelman, 2003; Olney & Kim, 2001). However, there were no statistically significant results relating to the observable or hidden nature of participants' disabilities (Table C-2), from this study. There could be a number of reasons for this, but this may be due in part to the size of the sample.

We were able to identify some of the reasons behind the motivations for concealment and disclosure: these are given in Tables 3-3 and 3-4 of Chapter 3. The main reasons for concealment included protecting others from worry and distress, protecting self and avoiding the loss that may be associated with disclosure (for example, potential exploitation, ridicule or stigma). Reasons for disclosure included the need to explain to others about personal changes and difficulties they face, in order to obtain support. For example, "*when I explain the effects that the head injury has had, it tends to be explaining things that are not as good now as they used to be*" (John, 2008).

We found that disclosure and concealment appear to be used as forms of impression management to protect individuals from perceived and actual stigma and discrimination. How others respond to the person with the disability and the nature of their disability is, in turn, dependent on how the person deals with the issue of disclosure and impression management. Someone who reveals the extent of their disability to unsympathetic colleagues may elicit hostility and ridicule: "*When I, when I don't feel very well I stagger, get called a* *boozer"* (Harry, 2008). And someone who does not disclose to others that they are emotionally distressed is unlikely to receive emotional support from others in overcoming their despair; this is also an example of impression management:

> *It's all focussed on X which is great but nobody ever says 'How are you?' or 'Is there something we can do for you?' Not that I [deep sigh] that sounds awful, that sounds selfish. Not that I want them to, because I'll probably say 'Oh no, I'm fine'. 'I don't want anything'* (Louise, 2008 - Carer).

Concealment, which is explained by Akintola (2008) as an emotion-focussed coping strategy, could contribute to an increase in stress levels if the individual actively keeps information hidden; this has been linked to depression and anxiety, hence reduced well-being (Karlovits & McColl, 1999; Matheson & Cole, 2004; Tomberg, et al., 2007). But as Chaudoir and Fisher (2010) explained, the decision to disclose or conceal will depend upon the individual's ability to deal with the responses to those disclosures and for some, concealment is the better option.

Using structural equation modelling (SEM) we found that concealment strategies (measured by the N-DQ) impact upon the amount of loneliness an individual reports (measured by the UCLA) and in turn this affects their life satisfaction (LiSat-11). Those who reported concealing more often for the specified reasons also reported disclosing more often for the specified reasons. This suggests that the two questionnaires should not be treated simply as measures of how much someone discloses or conceals (they would be negatively correlated if this was the case). They may be sensitive to the degree to which the individual engages in impression management, and thinking about the reasons why they should or should not disclose. Some individuals may be heavily into impression management and so there may be occasions when they conceal (for the specified reasons) but also many occasions when they disclose (for the specified reasons), so they may score relatively highly on both measures (which was found for female participants). By contrast, some individuals may not be interested in impression management. Presumably there are other reasons (perhaps unrelated to their TBI) why they do or do not tell people things: these individuals may score relatively lower on both scales. This suggestion, that the questionnaires should not be treated simply as measures of how much an individual discloses or conceals, may make sense of why, in our third study, the questionnaires were not related to the enacted social support measure (ESSQm) (Chapter 6). If they are more sensitive to impression management, then we wouldn't expect a high correlation, because being motivated by impression management may not be closely related to how often one seeks social support. Further research would be needed to confirm or otherwise, this hypothesis. The results from the analyses carried out in this study are given in Tables 7- 1 and 7-2.

Table 7-1: Table of results relating to N-DQ and S-DQ

Table of results for motivation to conceal and disclose Linked = significant Spearman's rho correlation					
*Higher score = more motivation			Example(s) of evidence from the literature cited in the thesis	Motivated to conceal - not telling others	Motivated to disclose - telling others
Measure		Description		Results from this study	Results from this study
1*	N-DQ$_1$	Concern about the negative reactions	Garssen (2007) Pachankis (2007) Shotton et al. (2007) Simpson et al. (2000)	Linked to fear of neg. evaluation (BFNE) Linked to low self-esteem (H_1) Linked to higher social avoidance (H_4) Linked to greater loneliness (H_5)	
2*	N-DQ$_2$	Avoidance of emotional upset	Kawamura & Frost (2004) Tomberg et al. (2007)	Linked to fear of neg. evaluation (BFNE) Linked to higher social avoidance (H_4) Linked to low self-esteem Linked to lower life satisfaction Linked to greater loneliness	
3*	N-DQ$_3$	Wanting to 'fit in'	Brewer (1993) Jones et al. (2011) Pickett & Brewer (2001) Turnley & Bolino (2001)	Linked to fear of neg. evaluation (BFNE) Linked to low self esteem (H_3) Linked to higher social avoidance (H_4) Linked to greater loneliness (H_5)	
4*	N-DQ$_4$	No benefits	Afifi & Steuber (2010) Simpson et al. (2000) Yang et al. (2007)	Linked negatively to distress disclosure (DDI) No significant link to social support (H_6) Linked to low self-esteem Linked to greater loneliness	
5*	N-DQ Total	Motivation to conceal	Chaudoir & Fisher (2010) Karlovits and McColl (1999) Leathem (1998) Simpson (2000) Yeates et al. (2007)	Linked to low self-esteem Linked to higher social avoidance (H_7) Linked to greater loneliness (H_7) Gender differences in motivation to conceal	
6*	S-DQ$_1$	Need to explain	Karlovits and McColl (1999) Argyle (1967)		No significant links (H_3) Less need to explain for those who are married/have a partner
7*	S-DQ$_2$	Positive benefits	Olney & Brockelman (2003) Vohs et al. (2005)		Linked to distress disclosure No significant links (H_6)
8*	S-DQ Total	Motivation to disclose	Chaudoir & Fisher (2010) Rusbult & Van Lange (2003)		No significant links (H_7) Gender differences in motivation to disclose
9	ESSQm	Social support actually received	Chaudoir & Fisher (2010) Cohen & Wills (1985) Jones (2011) Simpson et al. (2000) Tomberg (2007) Ylvisaker et al. (2008)	No significant links to the motivation to conceal (H_6 and $_7$) Less social support linked to greater avoidance Less social support linked to greater loneliness More social support linked to higher life satisfaction	No significant links (H_6 and $_7$)
10	ESSQ				

Table 7-1: analysis of the N-DQ yielded relationships with self-esteem, loneliness, social avoidance, community participation and life satisfaction. N-DQ sub-scales 1 to 3 related to the BFNE and sub-scale 4 to the DDI. Gender differences in motivation to conceal were identified (Table 6-20). Analysis of the S-DQ showed a significant relationship between S-DQ$_1$ and BFNE and S-DQ$_2$ and distress disclosure (DDI), and significant gender differences in motivation to disclose. There were no significant associations identified with the N-DQ or S-DQ and social support.

Table 7-2: Table of results relating to all the additional measures

Table of results for the additional measures				
Measure		Description	Evidence from the literature/author	Significant results from this study
11	RSE	Self-esteem	Burkley & Blanton (2007) Cooper-Evans et al. (2008) Kendall & Terry (2009) Livneh & Antonak (2005) Nochi (1997) Rosenberg (1965)	Low self-esteem linked to higher motivation to conceal Higher life satisfaction linked to high self-esteem Higher self-esteem linked to more community participation and voluntary work Low self-esteem linked to greater avoidance Low self-esteem linked to greater loneliness
12	UCLA	Loneliness	Akintola (2008) Crisp (1993, 1994) Livneh & Antonak (2005) Pachankis (2007) Russell et al. (1980) Simpson et al. (2000) Yeates et al. (2007)	Greater loneliness linked to high motivation to conceal (H_7) Greater loneliness linked to more social avoidance Greater loneliness linked to low self-esteem Greater loneliness linked to lower life satisfaction (H_7) Greater loneliness linked to less social support
13	SAD	Social avoidance	Karlovits & McColl (1999) Pachankis (2007) Riley et al. (2010) Shotton (2007) Simpson et al. (2000) Watson & Friend (1969)	Greater avoidance linked to high motivation to conceal Greater avoidance linked to less comm. participation Greater avoidance linked to low self-esteem Greater avoidance linked to greater loneliness Greater avoidance linked to lower life satisfaction (H_7) Greater avoidance linked to less social support
14	CIQ	Community participation and integration	Livneh & Antonak (2005) Tomberg (2007) Willer et al. (1993)	Lower community participation linked to greater avoidance Greater participation linked to high self esteem Age linked negatively to productivity
15	LiSat-11	Life satisfaction	Cooper-Evans et al. (2008) Dahlberg et al. (2005) Eriksson et al. (2009) Fugl-Meyer et al. (2002) Maner et al. (2007)	Lower life satisfaction linked to more social avoidance (H_7) Higher life satisfaction linked to high self-esteem Lower life satisfaction linked to greater loneliness (H_7) Greater life satisfaction is linked to more social support Greater life satisfaction linked to relationships
16	DDI	Distress disclosure	Olney & Brockelman (2003)	Those with hidden injuries are less willing to seek support from others

Table 7-2 gives a summary of the significant findings from the study, associated with each additional measure. Only with these additional measures was a significant association identified with social support (ESSQ) (Table 6-21).

SECTION THREE

7.3 Final Summary

In this final section, the limitations and strengths of the three studies are discussed and suggestions for future research are offered. Implications for rehabilitation are then discussed. It is important for clinicians to understand that their patient with a brain injury may not be fully disclosing their difficulties/needs during consultations. This may not always be due to lack of, or poor insight, but could be due to management by the patient of what they disclose and to whom and when. The right questions need to be asked to elicit an accurate response. Failure to do this could lead to inappropriate treatment and rehabilitation being provided, wasting resources and scarce funding.

7.3.1 Limitations and strengths

In the first qualitative study, both individuals with a brain injury and carers contributed. This mixed sample may be seen as unsatisfactory due to their different needs. Following evaluation of this data, at the beginning of the questionnaire development, the decision was made to concentrate upon those who had a TBI/ABI. The questionnaires were tailored to meet this decision.

Steps were taken in the construction of the non-disclosure (N-DQ) and self-disclosure (S-DQ) questionnaires to ensure they were as representative as possible. Literature searches, the initial interviews on which the questionnaires were based, reviewing and checking the clarity of the items with individuals with brain injuries (outside of our criteria), obtaining feedback from stakeholders (professionals, carers, academics and members of Headway, trustees and volunteers etc.), all helped to establish validity. Sub-scales within the questionnaires were evaluated against well established and tested questionnaires to ensure they had a reasonable level of construct validity. Reliability tests showed that the scales were stable over time, with the exception of N-$DQ_{4,}$ '*no benefits from telling others'* and S-DQ_1 the '*need to explain'.*

The use of self-report questionnaires, by participants following brain injury, has been questioned when used due to their potential lack of insight and amotivation (Douglas & Spellacy, 1996; Ylvisaker, et al., 2008). Each participant in this study was supported, or offered support to complete their questionnaire; in particular, help was provided by reading the questions and filling in their response. Doing this may be seen as a limitation, but each participant was treated in the same way and their responses marked onto their questionnaire with them. Participants put a great deal of effort into their responses, many offering scenarios of when they had been in that situation and how they dealt with it, or they responded immediately if they knew they had not used a particular strategy.

The use of postal questionnaires for data collection, which are to be completed with or without the help of a carer, may yield low response rates or responses that may reflect the carers view rather than the person with the brain injury, and this would lead to poor validity. All our data were collected personally so we know how the questionnaires were completed.

7.3.2 Suggestions for future research

The study has possible consequences for changes to intervention programmes that individuals take part in when recovering from traumatic brain injury. Despite the potential value, little previous research has focussed on the motivation to disclose or conceal information about the effects of a traumatic brain injury.

The N-DQ and S-DQ were measures of motivations to disclose or conceal in relation to brain injury, and possibly at a broader level of impression management. They did not measure whether disclosure or concealment actually occurred. To measure that, for example, participants' would need to be recorded actually disclosing or concealing issues regarding their TBI. The measurement of impression management is difficult not least because participants can be applying these strategies in their responses to the questions that are attempting to measure IM. Some questionnaires have two or three items that are phrased in such a way that the authors believe they will pick up if IM is being used (Dawes, et al., 2011), this is not always a reliable indicator. More research in this area would be of considerable use.

The three studies in this thesis were not about the immediate/short-term effects of disclosure or concealment per se, though there were instances in the qualitative study in which it was clear that disclosure could sometimes work well. Harry explained, "*I've got a friend who lives next door….He does the Samaritans. And I've been chatting to him and he's been, been quite helpful with me*" (Harry, 2008): but sometimes disclosure works badly. "*People ask me and they're trying to walk away then….I start reeling off a story and they'll start edging away from me*" (Collin, 2008). This is an area that needs further study. What are the effects of actual disclosure and concealment on psychological and social outcomes? Our study provided provisional results for concealment and life satisfaction, mediated through loneliness and social avoidance; but those findings would need to be replicated. Part of this would be a study of how much stigma and discrimination people with a TBI do actually encounter in the real world. Our qualitative study provides examples that this does happen.

The qualitative study also provided evidence that some people were careful about the circumstances in which they chose to disclose or conceal. For instance one participant explained that for him disclosure was "*different with different people….people who I know quite well I tend to try and tell them quite a lot"*, continuing that with *"people who I don't know very well, I tell them a lot less"* (John, 2008). So another area for future research could be about the circumstances that influence whether or not the person discloses. There is also the issue of what the circumstances are that help determine whether a disclosure or concealment is beneficial or not.

Another area could be about the difference between disclosure within the family and circle of close friends versus disclosure to other people. Examples were given in Chapter 3.3.1 about how some carers kept difficulties to themselves and withheld information from their children, and yet another carer felt they needed to share this at a level their children could understand. Disclosure (concealment) within the family obviously isn't about whether they have a TBI or not – it is more about the consequences of talking about something or keeping it a secret. For example, Betty explained how the TBI injuries affected their family life, discussing the physical problems as well as the emotional and behavioural ones that Koskinen (1998) found that carers focussed upon (cited in Draper and Ponsford, 2008):

> *He's in so much pain every day, even though he doesn't tell you. I know he is….that's why he don't want to do things. He doesn't want to go anywhere, you know. A walk to the car is a big effort* (Betty, 2008 - Carer).

This was not confined to carers; "*X does the shopping. I used to go with her, but I didn't like it*" (Rebecca, 2008). People who are reluctant to disclose generally, may nevertheless get adequate social support because they rely for it on their family, and they may be happy to disclose to or conceal information from their family because their family are fully aware already. For those outside of the family and other members of the public, the issue might be more about whether to disclose the fact that one has had a brain injury. So exploring the similarities and differences between these two is another possible avenue for future research. All these studies would build on the work of Simpson et al. (2000) and Chaudoir and Fisher (2010).

Additional research, related to the use of the N-DQ and S-DQ could be about the beliefs about one's ability to deal with the possible negative consequences of disclosure which relates to self-efficacy. Higher self-efficacy beliefs may predict lower scores on the avoidance of emotional upset, fear of negative response from others and wanting to fit in sub-scales of the N-DQ. To do this would require the use of a measure of self-efficacy. Those with avoidant coping styles may be more likely to respond to their problems with avoidance rather than seeking support. So they may be less likely to report having disclosed because of perceived benefits, and more likely to score higher on the avoidance of emotional upset sub-scale.

7.3.3 Implications for rehabilitation

The negative outcomes investigated in the two quantitative studies were associated with certain motivations to conceal. We cannot conclude from this that concealment is necessarily a bad thing – it is these motivations that are associated with poorer outcomes. So it would be wrong to conclude that clinicians should simply encourage people to disclose more often. In fact, the qualitative study makes clear that people with a TBI face real stigma and discrimination in society; and that on occasion, disclosure about their TBI would not be in their best interests and concealment is a better option; this view is supported by the findings of the Simpson et al. (2000) cross-cultural study relating to TBI and a social psychology study by Chaudoir and Fisher (2010). Instead, the rehabilitation implication might be that people with a TBI need to learn how to be better at impression management: They may need to learn more about the circumstances in which disclosure may be beneficial; and about the circumstances in which it may be better to conceal. They may also need to learn about how to disclose and conceal in an effective way, ensuring they obtain the benefits that can come from disclosure, and avoid the potential disadvantages. Finally, they may also need to learn about dealing with the negative consequences of disclosure and concealment.

The present study is relevant to this rehabilitation aim of helping people with TBI to become better at impression management. Awareness of the motivational incentives and barriers relating to disclosure and concealment (provided by these studies and potentially by those suggestions for further research) is important for clinicians. If people with a TBI are to become effective impression managers, underlying motivations that may make it difficult to disclose (or mean that the person doesn't see the point of disclosure) need to be addressed first – otherwise they may prevent the person from developing and implementing impression management skills. Also understanding these motivations may be helpful in assisting the person in developing effective ways of responding to the negative consequences of disclosure (for example stigma, ridicule etc). A wider implication is that the qualitative study revealed that people with a TBI do face extensive stigma in society, and work needs to be done to tackle the ignorance and lack of empathy that may drive this stigma.

Another important rehabilitation implication of the results is that many of the participants were anxious about the negative reactions of others to their injury; were keen to fit in and not be different; and wanted to avoid the emotional upset of talking about their injury. These things were, in turn, associated with social avoidance, loneliness and reduced life satisfaction. A good social life is an important part of life for most people; and poor social functioning is associated with many negative outcomes (such as poorer mental health).

These studies have identified some of the possible underlying motivations that may contribute to social avoidance, and have also identified a role for low self-esteem. Targeting these motivations and low self-esteem may be an appropriate aim of rehabilitation, since they may assist the person to achieve a better social life, and thereby better life satisfaction and better mental health.

APPENDICES

APPENDIX A

Appendix A-1 Ethical approval letter

Appendix A-2 Information Sheet

Appendix A-3 Consent Form

Appendix A-4 Thematic Analysis

Appendix A-2

INFORMATION SHEET - 1

Title of the research project:
Secret Lives: Maladaptive Coping Strategy or Impression Management?

Principle Investigator:
Dr G. A. Riley
Senior Tutor
School of Psychology
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Edgbaston
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B15 2TT

Tel: (removed)
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Research Student:
Barbara Hagger
PhD Student
School of Psychology
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Edgbaston
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B15 2TT

Tel: (removed)
E-mail:

We would like to invite you to take part in a research study. This information sheet is to help you to understand why the research is being done and what it would involve. Please take your time to read this information carefully. Talk to others about the study if you wish. Please contact us if there is anything that is not clear, or if you would like more information before you decide whether or not you wish to take part.

The purpose of the study?

To look at why you may sometimes discuss your traumatic brain injury with others and why sometimes you may wish to keep this information to yourself.

Why have I been invited?

You are aged between 18 and 70 years of age, and recovering from a traumatic brain injury. For this particular study it is important that the difficulties you have experienced since your injury are not those immediately obvious to another person. If you are unsure about this please contact the researcher or centre Manager. You also need to be able to provide informed consent to be eligible to take part. Your support with this study is greatly appreciated but if there are concerns about your ability to provide informed consent, you will be withdrawn from the study.

Do I have to take part?

Your participation in this study is completely voluntary; you do not have to take part if you do not wish to. Once you have expressed an interest in this study, by calling the researcher on the number provided, we will contact you and go through this information sheet. If you decide to continue you will be asked to sign a consent form to show you have agreed to take part in this study and that the information you provide (which will not include your name) may be written up for possible publication. Your decision to participate or not in this study, will have no effect on your relationship with the University of Birmingham or on any social or medical care you receive.

Expenses and payments

Your interview will be arranged at a time and on a day that you usually attend the Day Centre, or is convenient to you. Your participation will be on a purely voluntary basis.

What will I have to do?

You do not have to prepare for your interview. Just come to the centre the same as you usually do. You will be invited into one of the interview rooms (with which you may already be familiar); you may take refreshments and breaks when you require them. You will be asked questions about the information you share with others about your injury. The interview will, with your consent, be audio-taped and should take about an hour, but will be stopped if you feel tired or just wish to stop.

What are the possible disadvantages and risks of taking part?

During this interview we will be discussing issues that you may find difficult at times. If you do and you feel you cannot continue then we will stop. You may request this at any time if you feel uncomfortable in any way.

If I agree to take part in this research study, will I be told of any new risks that may be found during the course of the study?

This study involves your participation in a semi-structured interview. The interview is about your opinions about your life, and it does not involve any assessment or investigations of your condition. If during your interview you feel that the way you manage your situation is causing you some difficulties, you may wish to talk about this further.

What are the possible benefits from taking part?

You will receive no direct benefit from taking part in this study. Your contributions will help us to understand more about the ways individuals with brain injuries and carers discuss their situation with others, and will help with the development of a questionnaire for many more individuals, like yourself, to complete.

What happens when the research study stops?

We will contact you 7 days after your interview to see if you still wish for the information you provided to be used in this study. Interviews will be written-up for use in papers, to help with the development of a questionnaire and added into a PhD thesis. We will be happy to give you a copy of the study findings when these become available. If you would like a copy or any other details regarding the study, please ask.

What if there is a problem?

If for any reason you are not satisfied with information that you are given or have anything else causing you concern regarding the study please contact: Dr G.A.Riley on (removed) or Barbara Hagger on (removed).

Will my taking part in the study be kept confidential?

The information you provide in your interview will only be used for the purposes already described above; will be available to the investigators listed on this Information Sheet and where necessary personnel supporting this study at the University of Birmingham. All records related to your involvement in this research study will be stored in a locked filing cabinet. Data gathered from this study will be maintained as long as required by regulations, which is up to 5 years following the publication of any articles or communications describing the results of the study. Every effort will be taken to protect the names of the participants in this study. Your identity will not be recorded as part of your data, and will not be revealed in any publication that may result from this study. All information you provide will be kept confidential, except as governed by law.

What will happen if I don’t want to carry on with the study?

Please contact the researcher on (removed) if you wish to withdraw your participation and have your interview data destroyed. You will need to do this within 7 days of your interview. After 7 days the researcher will contact you to see if you are willing for your interview to be used in the research. After this contact, transcription of the interviews will begin and your right of withdrawal will come to an end.

Will my doctor be told about my participation in this study?

There is no requirement for your doctor to be informed of your participation in this study.

What will happen to the results of the research study?

The interview with you, if you agree to take part, will be audio-tape recorded. Once this is written-up, the audio-tape will be cleared. You may see the transcription of your interview if you wish; but you may not see interviews of others who take part. The only information we will have about you will be your written-up interview with your name and personal details removed and your signed consent form. Your interview will help in two ways:

1. The information arising from all the interviews will be written up as a paper and may be presented at conferences or printed as a journal article. Your personal details on any papers that are written as a result of these interviews will be coded. In this way the chance of anyone identifying you are reduced
2. The information you provide will be used to produce a questionnaire; this will enable a larger number of individuals and family carers to comment upon their experiences of traumatic brain injury.

Who is organising and funding the research?

This research is funded by the researcher; no organizations have a financial input into the study.

Further information and contact details

If you would like to contact the researcher about this study please call (removed) or Dr G.A. Riley on (removed).

Appendix A-3

CONSENT FORM

Title of Project: Secret Lives: Maladaptive Coping Strategy or Impression Management?

Supervisor: Dr G.A. Riley
Senior Tutor

Tel: (removed)

Name of Researcher: Barbara Hagger.
PhD Researcher

Tel: (removed)

Postal Address: School of Psychology
University of Birmingham
Edgbaston
Birmingham B15 2TT

Please initial the box

1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and unpaid and that I am free to withdraw without giving any reason. ☐

3. I understand that information collected during this study, may be looked at by individuals from the University of Birmingham or from regulatory authorities. I give permission for these individuals to have access to my records. ☐

4. I understand that the interview will be audio-tape recorded. Any references to names and information that would allow me to be identified will be removed. I agree to the interview being recorded. ☐

5. I agree to quotations I provide during the course of this study being used for publication ☐

6. I agree to take part in the above study. ☐

____________________	____________________	____________________
Name of Participant	Date	Signature
____________________	____________________	____________________
Name of Person taking consent	Date	Signature

A-4

Thematic Analysis

4.1 Data Corpus

This refers to all the data gathered for the study; the interviews, field notes, biographical information, comments and notes about ideas that arose following the interviews, as well as paintings by four of those interviewed. All this information was combined using Nvivo 7 software. The literature pertaining to this study was recorded in an ‘EndNote’ Library along with PDF documents where these were available, as described below. Only a selection of this material is included in the write up. Documents collected and deemed to fit a predefined criterion were temporarily recorded in an ‘EndNote’ electronic library. The criteria consisted of a combination of two or more key words, and research in related fields that shared those key words, the guiding condition was traumatic brain injury referred to as TBI. Notes of articles, papers or books referencing these keywords were recorded along with necessary citation details, authors’ contact details and extracts from articles that relate to this study. The areas researched (accessed via the University library, e-library, manual search, recommendations and personal library) include literature discussing methodological issues, structure, content and analysis as well as literature directly related to traumatic brain injury and issues around disclosure, concealment and impression management. Notes from articles, papers and book chapters entered into ‘EndNote’ were filed using their reference number to enable these notes to be retrieved whenever required for clarification. The articles obtained to date have helped to guide further reading, data collection, analysis and writing-up. References provided within these documents were searched for follow up references and related fields of research.

4.1 Data Set

The data set refers to the selected materials that were chosen from the ‘data corpus’ that were used in this study; the material that relates to the main areas of interest to the researchers, and directed by the research question. Selected citations from the literature, the transcribed interviews, associated links such as field notes, biographical information, comments and notes and photographs of paintings. This reduction in data helps the researcher to come to terms with their study and to focus on the specific task of addressing the research question. The material not directly used in the study is acknowledged, briefly discussed but put to one side, outside the remit of the study. This material may well be of use in the future or retained until the holding time required by the Research Ethics Sub-Committee or Research Ethics Panel has expired.

4.1.1 Data Item

Each individual piece of data collected, interview, painting, biographical data, field note about the interview or thoughts about the way the interview went, and memos about the issues raised by a particular participant as well as the selected literature, are data items. Together these items form the data set. They have been coded directly or linked as external data to individual cases (all the information about a participant) and stored together on Nvivo 7. Back up copies have been made in case of problems with the system.

Data Extract

Data extracts are selections made from data items that are judged to be

- directly relevant to the study (traumatic brain injury and the willingness or unwillingness of those affected to disclose information to others) or
- peripheral and which may prove to be of interest later (for example pain management and lack of information).

Judgement regarding the selection of extracts was based upon readings of existing papers and articles and experience gained from carrying out the interviews and observations made over the previous eighteen months (as a participant-observer). It is not always possible to know how additional data extracts may be of use in the future, so significant issues raised by the interviewees were also coded. Citations from research papers may also be seen as ‘data extracts’. Particular issues, themes, patterns, areas of interest, words or phrases were selected as data extracts from the transcribed interviews. These extracts were put into temporary folders as ‘free nodes’ and given a title to represent the contents.

After a few data extracts had been coded, associated ‘free nodes’ were combined and designated as a ‘Tree Node’ and given a collective title to reflect the contents. These ‘tree nodes’ can hold as many ‘free nodes’ as the researcher feels relate to a particular category. They can easily be rearranged, if as we found, some of the categories could be combined. To show this more clearly a table of the initial coding given to the data extracts using Nvivo is shown below.

Table A-1: Main themes arising from interviews

	Tree Nodes						
	Behaviour	Emotional Effects	Life before the accident	Life changes since the accident	**Main areas of study**	Reports of the accident	Support
Sub nodes	Anger or temper Annoyed Compassion for animals Consideration for others Drug and alcohol abuse Inappropriate behaviour Poor behaviour in public Revenge Self awareness Violence	Discrimination Emotional Effects Guilt Memory No memories Recovered memories Sense of humour Shame or embarrassment	Accident prone Childhood abuse Employment before the accident Life before the accident Pets	Care support Education Effects on marriage Effects on the family Employment after the accident Finances Partners or relatives - comments Personal care Physical problems Reality Social effects	Concealment Coping strategies Disclosure Hidden difficulties Impression management	Accident Face swelling and bruising Good hospital care Pain Poor treatment	Carer support Headway Social support Support organizations

Table 1 shows seven areas of coding, the 'tree nodes' with the sub-nodes (previously free-nodes) below each heading. The classification system used within Thematic Analysis complemented the use of 'Nvivo 7' software and 'EndNote' systems. There are a number of ways of combining these nodes together; the table above shows the first arrangement considered. The majority of these nodes are outside the scope of this study. This is in part due to the use of semi-structured interviews, which left openings for interviewees to raise issues of concern. The main areas of the study were identified and consisted of concealment, disclosure, hidden difficulties and impression management.

4.1.2 Theoretical Stance

Braun and Clarke (2006) suggest that researchers position themselves within a particular theoretical stance. They suggest three theoretical positions that would blend with the use of Thematic Analysis, namely -

- 'Contextualist' (social construction of reality);
- 'Essentialist or Realist' (from the participants perspective) or
- 'Constructionist' (participant's perception of their life within the social-cultural contexts they reside).

This study is guided by the 'constructionist' stance, a combination of researcher interest and participant understanding, experience and behaviour in relation to the questions:

- Do individuals affected by traumatic brain injury and their carers' use concealment and selective disclosure as techniques of impression management; as a way of protecting themselves, and projecting a desired self-image?
- If so what are the circumstances that give rise to this, as people regulate the amount of information they disclose in different circumstances?
- Finally, is the use of impression management related to their level of self-awareness, self-esteem and self-image?

The research undertaken for this study initially considered all issues that were raised, however loosely related to the central questions and it expanded and contracted recursively as data was collected and assimilated. The selection of most data extracts was guided by 'theoretical thematic analysis' and the coding of those data extracts was related in some respects to the findings of researchers within brain injury, mental health and associated fields. Examples were highlighted that supported or refuted existing work.

'Prevalence' is the percentage of respondents who use disclosure and concealment. So data extracts that show the use of concealment or disclosure and the context in which this occurred were recorded as sub-nodes, under the main tree node as shown above. Some data extracts may remain as a unique record where the transcript contained a specific issue of concern (as found with childhood abuse or revenge) or may be found to be common to two or more participants, as with most of the other data extracts. This is in line with the guidelines for Thematic Analysis offered by Braun and Clarke (2006) as each of these data extracts are taken from a data item, which collectively form the data set and data corpus, in a hierarchical relationship. This application was carried out consistently within the study, storing on Nvivo each occurrence of an issue which was coded across the entire data set. Doing this began the analysis; sorting the data, highlighting the issues of concern that were selected from the data in relation to the research question. Additional information was collected and coded but seen to be peripheral to the central themes.

Most of the coding was carried out using a ‘semantic approach’. The data was largely taken at face value, and the coding categorises what has been found in relation to the original question (theorizing) and its possible implications. However, the alternative approach of using a ‘latent theme’, (where the direction taken by the researcher is guided by the initial data analysis – as in grounded theory) reflects the coding approach for peripheral data extracts. These ‘latent themes’ arose as a consequence of the semi-structured interviews and offered different directions for the study to take. This required ‘inductive theoretical analysis’; where the meaning was read into or placed upon the data collected.

Coding the data purely with one approach in mind, could have lead to a loss of information so the subsequent analysis could have been misleading. Braun and Clarke (2006) suggest that researchers identify the theoretical positions they take regarding the analysis of their data. They suggest that using Thematic Analysis involves using alternative stances, but having worked through this process it would appear that different stages of the analysis are better represented by these different theoretical positions rather than the whole analysis reflecting one stance. Thematic analysis is said by Braun and Clarke (Dyer, et al., 2006; Gan, et al., 2006; Macrae & Bodenhausen, 2000; McNamara, et al., 2003; Prigatano, 1992; Randhawa, et al., 2007) to be a method for identifying and reporting patterns and themes identified by the researcher, in the data. This is seen as a more comprehensive, ‘theoretically and methodologically sound’ way of describing the data set. The method offers a clear and effective way to organize qualitative data, it does not describe the data in rich detail; this is done when the collected material regarding the research questions, the findings and the stance taken are written-up.

4.1.3 Analysis – step 1: Transcription

With the consent of all those who took part, each interview was recorded onto a small digital tape recorder an Olympus VN-3100 PC. These recordings were put into electronic files and stored until they could be transcribed. Additional free software ‘Express Scribe’ was obtained to adjust the speed of the recording when played back.

The interviews were between twenty five minutes in length and almost three hours; transcription of each interview took between six hours and eight days. This involved listening to the digital recording and playing back difficult parts many times. Slowing the recording down helps with some texts where the interviewee talks too fast; stutters or mumbles. Transcribing very descriptive details of accidents and injuries can be difficult at times, not just because of the content but because of the distress of the interviewee.

The transcript was checked by playing the recording back while reading the text. In this way, if the transcription was correct the two flowed smoothly. If there was an error then the recording appeared to jump at the point where adjustments needed to be made to the text. Transcribing the recordings provides a good start to the analysis (Braun & Clarke, 2006). Comments relating to the main themes of the study and other ideas for coding were noted down. Notes were taken about the overall impression the interview made: this was useful as the transcription was usually carried out on a different day to the interview. Where the interviewee had given family names or identifiable information, excluding the nature of their injuries or relationship to a person with a traumatic brain injury, the information was not fully transcribed; or was amended (given a pseudonym) to protect confidentiality and the identities of those involved.

4.1.4 Analysis – step 2: Coding

All the interviews, as word documents, were imported onto the Nvivo 7 software, as ‘data sources’ described as ‘Interviews’, under ‘Documents’. Before coding these documents were divided into either the sub-folder for ‘carers’ or the sub-folder for those with ‘TBI’ (traumatic brain injury). Sub-folders were created for extracts of the ‘audio’ recordings (this was not used); ‘paintings’ (containing photographs of four paintings) and a folder for ‘memos’. Selections of the recordings were not placed onto the system as the digital recordings were sufficient along with the transcript to meet the University and ethical committee requirements for data storage. Data for each interviewee is stored in a separate electronic folder which contains the digital recording of the interview and the transcribed text as a word document. The computer is password protected.

Nvivo software facilitates

- data sets,
- searches for specific information,
- formulation of models from the data and
- links between folders.

Under the ‘classifications’ field, in a sub-folder for ‘attributes’, age, gender, relationships and group membership were recorded. All the information related to each of the eighteen interviewees is stored as a case. This enables the material to be accessed in more detail. Relationships can be linked; these are stored under a folder within the ‘Nodes’ section ‘relationships’. In this study there are 4 two way links which relate the interviews of husband and wife (2), mother and daughter (1) and father and son (1); information could be added or changed whenever needed. When the folders and sub-folders that are initially required are set up and the text documents have been put onto the system, coding can be carried out electronically using the coding buttons on the program. Under ‘nodes’ all the coding can be carried out. There is a folder for ‘free nodes’, here the coding of the text could be stored under a title that represents the contents. When a particular theme or issue become prevalent it was possible to put those free nodes together under a particular theme as a ‘Tree Node’. The categories are shown in table 1 above. The amount of information stored under any ‘free node’ or ‘tree node’ can be seen on the statistics provided for each node.

Once a data extract has been highlighted it can be dragged to an existing node or it can be placed into a new one with a new heading. When a particular ‘Tree Node’ is selected, all the headings for the data coded within that node can be seen. Clicking on any of these headings will show all the text from the data extracts that have been coded there, each with its own reference number. For example details of the interviewees and number of extracts made from each interview. Also shown is the percentage of the interview that has been coded under that node. This enables an understanding to be built up of the data, possible linkages and patterns and themes start to emerge from the coded data extracts. The Nvivo system enables systematic coding: each interview text can be read and coded, with the extracts selected in the same way.

All issues of interest that arose within the texts were coded. The constructionist/semantic approach adopted, meant that the data that was particularly related to the research question was selected as the data set. The extra data offered ideas for future or alternative studies. This step reduced the huge volume of information, to a more manageable size, giving time for more detailed analysis.

4.1.5 Analysis – step 3: Themes

As the data extracts were coded they were combined under a specific theme as a ‘Tree Node’. Ideas and thoughts, formed when reading the existing literature helped the researcher to combine the data into related sections, and allowed for further analysis. The information in any section can be moved electronically, or physically using paper until a thematic slot is found for the data extract, or a new one is created. Producing a thematic map (a schematic diagram showing the anticipated relationships between the ‘tree nodes’) can help the researcher to highlight the links between ideas and encourages further research and analysis. The selected themes for discussion in this research include

- the reasons given for not disclosing information to others; especially when due to fear of negative evaluation;
- avoidance of emotional distress;
- the desire for normality, to fit in; and
- the view that no benefits would be derived from disclosure.

Specific issues around disclosure to family and close friends are to be included in a separate section. Another section will cover reasons for disclosure and will cover the justification of disclosure linked with the desire to educate others; this is supported with a section on the benefits that may arise following disclosure.

4.1.6 Analysis – step 4: Reviewing

When coding the interviews, it was necessary to ensure that there were clear differences between the ‘tree nodes’ themselves. The data extracts within each sub-category of each ‘tree node’ needed to be related, or be reallocated to other ‘tree nodes’ with a more appropriate heading, if they were mismatched. Unrelated data extracts remained on their own as ‘free nodes’, or were attached to supporting material so they were not overlooked. Data extracts and themes that were not followed up were identified and while acknowledged, played little part in further analysis. In this way the data was reduced in volume, becoming more concentrated and more inter linked.

When the data extracts within and between the ‘tree nodes’ linked together as a theme, and the extracts merged, relating to a particular topic, they could be checked against the data set. Reading all the interviews and coding within each ‘tree node’ helped when checking the hypotheses about the relationships within the data. This was an iterative process. As mentioned earlier, creating a visual ‘thematic map’ of the information supported this process; this needed to be kept in line with the recoding of any data extracts or collection of more extracts when re-reading of the transcripts. Nvivo, did not entirely replace cutting and manipulating documents, but substantially reduced it.

4.1.7 Analysis – step 5: Refining

In this step, information collected was sorted for use in the write-up. The information and thematic map (if made) needed to reflect understanding of the contents (data corpus and data set). This thematic map would be different for those taking a different theoretical stance; they would focus on other aspects of the interviews. Thus it is possible to start putting together the story that explains the material and the issues involved, and how they related to the initial questions asked in the study. The data extracts relating to specific areas of interest were linked to existing literature. These were then available to be used to support specific points that we wish to make when reporting our findings. The structure of the write-up began to form when the themes of each ‘tree node’ and related sub-category were combined. The relationships within and between them showed that a hierarchical relationship exists; this helped when relating the findings to existing literature. This can also work the other way around, that the work of other researchers may show that the information collected has a hierarchical structure that was not appreciated earlier.

4.1.8 Analysis – step 6: Reporting

The work of writing-up is where the researcher presents their view of the data they have collected. The researcher combines selected data extracts and data items that relate to (support or refute) a specific point that they are making. In this way they are providing evidence for a point of view and this helps to validate their claims. This is combined with current literature covering their fields of interest, and any links new or previously identified that they have found. Telling the story behind the information collected in an accessible way takes time, patience and reworking. So in keeping with this guideline from Braun and Clarke the findings are given in the main text.

APPENDIX B

Appendices for Chapter 4

B-2: Participant Information Sheet - stage 2

Study Title: an exploration of self-disclosure after traumatic brain injury

I am a research psychologist at The University of Birmingham, conducting this study as part my PhD. Before you decide whether to take part, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully, or ask someone who you trust to go through this with you. Please contact me (or ask someone to do this on your behalf), if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

To look at why you may sometimes discuss your traumatic brain injury with others and why sometimes you may wish to keep this information to yourself.

Why have I been chosen?

You have been chosen to take part in this research because you had an accident in which you sustained a traumatic brain injury from which you are recovering. For this study we are seeking support from individuals whose accident happened no earlier than 12 months ago and no later than ten years ago. And you are aged between 19 and 70 years of age.

Do I have to take part?

Participation in the study is entirely voluntary. If you decide not to take part, this will not affect the service you receive in any way. If you do decide to take part, you are free to withdraw from the study at any time and you do not have to give a reason.

What will happen to me if I take part?

If you would like to take part, please either contact me (contact details below) or ask the person who gave you this leaflet to contact me. Once I know that you are interested, I will arrange to meet you at the day centre you attend, or send the questionnaires to your day centre for you to complete with the support of your carer, a member of staff or a volunteer.

What do I have to do?

If you agree to participate, you will be asked to complete three questionnaires which will take about an hour to complete. If you wish, someone will be present to answer any questions or concerns you may have. You may choose to read through the questionnaire and record the answers yourself. If you prefer, the questions will be read out to you and your answers put onto the questionnaire.

Before you begin you will be asked to complete a consent form to confirm that you agree to take part in this study. In signing this you confirm that you have read, or had read to you, these guidelines for the study and that you understand them and have had the opportunity to ask questions should you wish to do so. Even if you complete this form, you may withdraw at any time, without explanation.

What are the possible disadvantages and risks of taking part?

It is possible that you may find some of the questions distressing. If this does happen, then you are free to miss out those questions. In the event that you do feel distressed, advice will be given about where you can seek further assistance if this is required.

What are the possible benefits of taking part?

We hope that the findings from the study will help us to understand more about the ways individuals with brain injuries discuss their situation with others. However, we do not expect that there will be any direct benefit to you personally.

What happens when the research study stops?

The results of this study will be written up and submitted as part of my PhD. A report will also be submitted to an academic journal. We will be happy to give you a summary of this report when it becomes available. If you would like a copy or any other details regarding the study, please ask.

A summary will be made available to your day centre on completion of the study, so that you may read it, or have this read to you. Your name will not appear on any of these reports.

What if there is a problem?

You are free to withdraw from the study at any time. If for any reason you are not satisfied with information that you are given or have anything else causing you concern regarding the study please contact us (see below).

Will my taking part in the study be kept confidential?

Yes, all information that is collected will be kept confidential. Your name will be recorded only on the consent form that I will ask you to sign. This form will be kept in a locked filing cabinet at the University for up to 5 years, and then be destroyed. A code number will be written on the questionnaire you complete. This will allow your three completed questionnaires to be matched up to those you may complete later. The information you provide will be available to the investigators listed on this Information Sheet and where necessary personnel supporting this study at the University of Birmingham. All records related to your involvement in this research will be stored in a locked filing cabinet. Information gathered from this study will be held for up to 5 years following the publication of any articles or communications describing the results of the study. Your identity will not be recorded as part of your data, and will not be revealed in any publication that may result from this study. All information you provide will be kept confidential, except as governed by law.

Contact Details:

If you would like any further information about the study or are interested in taking part, please contact: Barbara Hagger, telephone number (removed) or (removed) or write to Barbara Hagger, Post Graduate Researcher, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT
Or
If you wish to raise any concerns about this project, please contact the academic researcher Dr G. Riley on (removed) or (removed) or by writing to Dr G. Riley, School of Psychology, University of Birmingham, Edgbaston, Birmingham, B15 2TT

If you feel you would like to talk to someone about your head injury please contact:
Headway helpline on 0808 800 2244 or visit their web-site on helpline@headway.org.uk

Thank you for taking time to read this information sheet and considering offering your support to this study.

Yours sincerely

B-3: Consent Form

Title of Project: an exploration of self-disclosure after traumatic brain injury

Name of Researcher: Barbara Hagger

Please initial box

1. I confirm that I have read and understand the covering letter and information provided for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

3. I understand that data collected during the study, may be looked at by individuals from the University of Birmingham, or from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

4. I agree to give my contact details below, so that I may be approached to help further with this study. I understand that this is voluntary and that if I change my mind I may withdraw my consent without giving any reason. ☐

5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Name……………………………………………………………………………………….

Contact address…………………………………………………………………………….

…………………………………………………………………………………………….

…………………………………………………………………………………………..

Telephone Number………………………………………………………………………

E-mail Address……………………………………………………………………………..

B-4: N-DQ and S-DQ Questionnaires and SSQ

UNIVERSITY OF
BIRMINGHAM

An exploration of self-disclosure after traumatic brain injury

Completing the *survey* – please read this before you begin

This survey is to help us to understand how you manage your day to day life, since you had your traumatic brain injury. In particular, we are interested in what you tell other people about the injury. Your answers to these questions will help us greatly; we hope you will not find them too intrusive. You do not have to complete this survey in one attempt, unless you wish to do so. What is important is that you answer as many questions as you can.

Please return the completed survey in the envelope provided by the __________

Example for completion of the survey:

Please will you respond by marking or circling the number you feel most describes your situation. For example:

2.13	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I feel better for getting things off my chest**				
	Often	[✓ Sometimes]	Not sure	Rarely	Never

The scale has been placed underneath each question, so that you can mark your response directly onto it.

Please do not put your name onto this document; your responses to these questions should remain anonymous.

Please send your completed consent form and surveys back in the envelopes provided. For those of you who are helping with the second part of this study we will be in touch in a few weeks time…thank you.

If you would like to receive a summary of the findings, please contact us, we would be quite happy to e-mail or post you a copy. If there is anything else you would like to add or comments you wish to make about this study please feel free to do so. Contact details are on the enclosed covering letter and for the University at the bottom of each page.

Thank you, once again, for your help.

Appendix B4

Section 1

Reasons you may have for not sharing information with others

1.1	I don't say too much about my injury (or the problems it causes me) because: **I don't need emotional support from others**				
	Often	Sometimes	Not sure	Rarely	Never

1.2	There have been times when I've not told someone about my injury (or the problems it causes me) because: **telling someone makes me feel like I'm not normal**				
	Often	Sometimes	Not sure	Rarely	Never

1.3	There have been times when I've not told someone about my injury (or the problems it causes me) because I knew: **talking about it would just remind me of all the bad things that have happened**				
	Often	Sometimes	Not sure	Rarely	Never

1.4	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might think I was mad or dangerous**				
	Often	Sometimes	Not sure	Rarely	Never

1.5	There have been times when I've not told someone about my injury (or the problems it causes me) because: **I didn't want them asking me all kinds of questions about it**				
	Often	Sometimes	Not sure	Rarely	Never

1.6	I don't say too much about my injury (or the problems it causes me) because: **I don't need help from other people**				
	Often	Sometimes	Not sure	Rarely	Never

1.7	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **people with me might start drawing the wrong conclusions about me**				
	Often	Sometimes	Not sure	Rarely	Never

1.8	There have been times when I've not told someone about my injury (or the problems it causes me) because I knew: **I would feel ashamed if I told them**				
	Often	Sometimes	Not sure	Rarely	Never

1.9	There have been times when I've not told someone about my injury (or the problems it causes me) because: **I don't want to be marked out as 'the person with the head injury'**				
	Often	Sometimes	Not sure	Rarely	Never

1.10	I don't say too much about my injury (or the problems it causes me) because: **other people don't need to know**				
	Often	Sometimes	Not sure	Rarely	Never

1.11	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might get annoyed**				
	Often	Sometimes	Not sure	Rarely	Never

1.12	There have been times when I've not told someone about my injury (or the problems it causes me) because: **I thought they would make a fuss about it**				
	Often	Sometimes	Not sure	Rarely	Never

1.13	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might avoid me in the future if they knew**				
	Often	Sometimes	Not sure	Rarely	Never

1.14	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might start to talk down to me or patronize me**				
	Often	Sometimes	Not sure	Rarely	Never

1.15	There have been times when I've not told someone about my injury (or the problems it causes me) because: **I just wanted to have a normal conversation with them**				
	Often	Sometimes	Not sure	Rarely	Never

1.16	There have been times when I've not told someone about my injury (or the problems it causes me) because I knew: **I would not be able to control my feelings**				
	Often	Sometimes	Not sure	Rarely	Never

1.17	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might think badly of me**				
	Often	Sometimes	Not sure	Rarely	Never

1.18	There have been times when I've not told someone about my injury (or the problems it causes me) because I knew: **I would get upset if I started to talk about it**				
	Often	Sometimes	Not sure	Rarely	Never

1.19	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **people with me might start to watch closely what I did and said**				
	Often	Sometimes	Not sure	Rarely	Never

1.20	There have been times when I've not told someone about my injury (or the problems it causes me) because: **I don't like the attention I get when I do tell someone**				
	Often	Sometimes	Not sure	Rarely	Never

1.21	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might gossip about me to others**				
	Often	Sometimes	Not sure	Rarely	Never

1.22	I don’t say too much about my injury (or the problems it causes me) because: **other people don’t understand what I’ve been through**				
	Often	Sometimes	Not sure	Rarely	Never

1.23	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **I might be made fun of**				
	Often	Sometimes	Not sure	Rarely	Never

1.24	There have been times when I’ve not told someone about my injury (or the problems it causes me) because: **I didn’t want to have to explain things yet again**				
	Often	Sometimes	Not sure	Rarely	Never

1.25	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the people I am with might take advantage of me**				
	Often	Sometimes	Not sure	Rarely	Never

1.26	There have been times when I’ve not told someone about my injury (or the problems it causes me) because: **I knew talking about it would make me feel worse**				
	Often	Sometimes	Not sure	Rarely	Never

1.27	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might think I was stupid**				
	Often	Sometimes	Not sure	Rarely	Never

1.28	There have been times when I have kept quiet about my injury (or the problems it causes me) because: **the other person with me might be fed up of hearing about it**				
	Often	Sometimes	Not sure	Rarely	Never

1.29	There have been times when I’ve not told someone about my injury (or the problems it causes me) because I knew: **I would get embarrassed if I told them**				
	Often	Sometimes	Not sure	Rarely	Never

1.30	I don’t say too much about my injury (or the problems it causes me) because: **other people aren’t that interested in what’s happened to me**				
	Definitely false	Probably false	Not sure	Probably true	Definitely true

1.31	I don’t say too much about my injury (or the problems it causes me) because: **not much good has ever come from me telling other people about it**				
	Definitely false	Probably false	Not sure	Probably true	Definitely true

1.32	I don’t say too much about my injury (or the problems it causes me) because: **I can’t see that there’s much point**				
	Definitely false	Probably false	Not sure	Probably true	Definitely true

1.33	I don't say too much about my injury (or the problems it causes me) because: **talking about it doesn't help me**				
	Definitely false	Probably false	Not sure	Probably true	Definitely true

Section 2
Reasons for sharing information with others

2.1	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I wanted emotional support**				
	Often	Sometimes	Not sure	Rarely	Never

2.2	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **they have helped me keep going when I felt like giving up**				
	Often	Sometimes	Not sure	Rarely	Never

2.3	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I don't want to bottle up my feelings**				
	Often	Sometimes	Not sure	Rarely	Never

2.4	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **talking to others helps me understand my difficulties better**				
	Often	Sometimes	Not sure	Rarely	Never

2.5	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **If I talk to others I feel like I'm not facing my problems alone**				
	Often	Sometimes	Not sure	Rarely	Never

2.6	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I wanted more information about my problem**				
	Often	Sometimes	Not sure	Rarely	Never

2.7	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **once they understand, people are generally helpful**				
	Often	Sometimes	Not sure	Rarely	Never

2.8	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I was feeling low and needed some emotional support**				
	Often	Sometimes	Not sure	Rarely	Never

2.9	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **they have helped me sort my problems out**				
	Often	Sometimes	Not sure	Rarely	Never

2.10	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I wanted practical help**				
	Often	Sometimes	Not sure	Rarely	Never
2.11	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I had a problem that I couldn't sort out myself**				
	Often	Sometimes	Not sure	Rarely	Never
2.12	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **If they understand what the problem is, they can help me**				
	Often	Sometimes	Not sure	Rarely	Never
2.13	There have been times when I have talked to other people about my injury (and the problems it causes me) because: **I feel better for getting things off my chest**				
	Often	Sometimes	Not sure	Rarely	Never
2.14	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **people might jump to the wrong conclusions about me if I don't tell them**				
	Often	Sometimes	Not sure	Rarely	Never
2.15	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **It makes me feel better if they know why I am like this**				
	Often	Sometimes	Not sure	Rarely	Never
2.16	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **If I don't explain then they might think I'm stupid**				
	Often	Sometimes	Not sure	Rarely	Never
2.17	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **I don't want people thinking I'm strange or odd**				
	Often	Sometimes	Not sure	Rarely	Never
2.18	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **I just feel I've got to explain myself to them**				
	Often	Sometimes	Not sure	Rarely	Never
2.19	There have been times when I have explained to other people about my injury (and the problems it causes me) because: **they might be able to avoid making the same mistakes that I did**				
	Often	Sometimes	Not sure	Rarely	Never
2.20	There have been times when I have explained to other people about my injury (or the problems it causes me) because: **I don't want them getting the wrong idea about me**				
	Often	Sometimes	Not sure	Rarely	Never

Section 3
Social Support (SSQ)

3.1	Do you have family members that you could talk to about your problems?				
	no one	1 person	2 people	3 people	4 or more

3.2	Do you have friends (or neighbours) that you could talk to about your problems if you want to?				
	no one	1 person	2 people	3 people	4 or more

3.3	How supportive are your family?				
	not at all supportive	not as much as I would really like	enough	quite supportive	very supportive

3.4	How supportive are your friends (or neighbours)?				
	not at all supportive	not as much as I would like	enough	quite supportive	very supportive

3.5	How much do you tell your immediate family about your problems?				
	very little	some things	enough	quite a lot	everything

3.6	How much do you tell your friends about your problems?				
	very little	some things	enough	quite a lot	everything

3.7	How much do you tell other people that you’re not that close to (e.g. neighbours, acquaintances) about your problems?				
	very little	some things	enough	quite a lot	everything

3.8	How often do you get practical help from your family, friends or neighbours?				
	every day	a few times each week	once a month	only when I ask	never

3.9	How often do you get emotional support from your family, friends or neighbours?				
	every day	a few times each week	once a month	only when I ask	never

3.10	Do you feel the help and support you receive is enough?				
	definitely	probably	not sure	probably not	definitely not

Section 4: additional information
(please mark the appropriate box)

4.1	Gender
Male	Female

4.2	Please would you tell us which age group you are in or state your age					
19-26 yrs	27-35 yrs	36-44 yrs	45-53 yrs	54-62 yrs	63-70 yrs	actual age

4.3	Please would you tell us your status? Are you		
single	separated/divorced	married / have a partner	widowed

4.4	Please would you tell us how your accident happened?			
Vehicle driver/passenger	Motorcycle	Fall	Assault	Other please specify
Vehicle pedestrian	Bicycle	Industrial Accident	Sports Injury	

4.5	How obvious are your disabilities to other people?	
All Hidden	Obvious to others	Have both hidden and obvious injuries

4.6	Please would you tell us which level of schooling you reached?	
Higher Education	Secondary Education	Primary School

4.7	Please would you tell us what your occupation was at the time of the injury?

4.8	Please will you indicate which of these apply to you now? This may be either paid 'P' or voluntary 'V' work.	
Working Full-time 'P'	Working Part-time 'P'	Not Working
Working Full-time 'V'	Working Part-time 'V'	

4.9	Please would you tell us when your accident happened, was it?			
1998/1999	2000	2001	2002	2003
2004	2005	2006	2007	2008/2009

Thank you for taking part in this survey

B-5: Brief Fear of Negative Evaluation Scale (BFNE)

The BFNE scale by Professor Mark R. Leary was used in this study.

If you wish to see the scale please refer to the following article, where it is available on page 373.

Leary, M. R. (1983). A Brief Version of the Fear of Negative Evaluation Scale. *Personality and Social Psychology Bulletin* (9), 371 - 376.

B-6: The Distress Disclosure Index (DDI)

The DDI was used in this study with the kind permission of Professor Jeffrey Kahn.

If you wish to see the scale please refer to the following article, where it is available on page 62.

Kahn, J. H., & Hessling, R. M. (2001). Measuring the tendency to conceal versus disclose psychological distress. *Journal of Social and Clinical Psychology, 29* (1), 41-65.

Table B-1: Non-parametric correlations of all questionnaires and sub-scales used in the first quantitative study

Spearman's Rho N = 55 except DDI N = 54		SSQ Total	SSQ$_1$ Item3.1 Item3.2	SSQ$_2$ Item3.5 Item3.6 Item3.7	SSQ$_3$ Item3.8 Item3.9	SSQ$_4$ Item3.3 Item3.4 Item3.10	DDI N = 54	NDQ$_1$	NDQ$_2$	NDQ$_3$	NDQ$_4$	NDQ Total	SDQ$_1$	SDQ$_2$	SDQ Total
BFNE	Corr. Coeff.	.045	-.011	.124	.271*	-.204	.119	.418**	.504**	.537**	.195	.541**	.365**	.317*	.364**
	Sig. (2-tailed)	.744	.934	.366	.046	.134	.390	.002	.001	.001	.154	.001	.006	.018	.006
DDI N = 54	Corr. Coeff.	.407**	.127	.460**	.365**	.154		.066	.018	-.174	-.413**	-.119	.224	.595**	.535**
	Sig. (2-tailed)	.002	.362	.001	.007	.267		.634	.897	.207	.002	.390	.103	.001	.001
NDQ$_1$	Corr. Coeff.	-.202	-.149	-.057	.104	-.486**			.575**	.536**	.320*	.879**	.411**	.380**	.398**
	Sig. (2-tailed)	.139	.276	.678	.450	.001			.001	.001	.017	.001	.002	.004	.003
NDQ$_2$	Corr. Coeff.	-.084	.011	.028	.043	-.296*				.619**	.141	.756**	.273*	.208	.229
	Sig. (2-tailed)	.540	.937	.840	.757	.028				.001	.304	.001	.044	.128	.093
NDQ$_3$	Corr. Coeff.	-.101	.081	-.076	.095	-.349**					.229	.750**	.223	.187	.199
	Sig. (2-tailed)	.462	.557	.584	.488	.009					.093	.001	.102	.171	.146
NDQ$_4$	Corr. Coeff.	-.244	-.202	-.352**	.057	-.149						.515**	.078	-.059	-.027
	Sig. (2-tailed)	.073	.138	.008	.678	.278						.001	.570	.667	.847
NDQ Total	Corr. Coeff.	-.192	-.090	-.125	.117	-.429**							.369**	.264	.298*
	Sig. (2-tailed)	.160	.515	.364	.395	.001							.006	.051	.027
SDQ$_1$	Corr. Coeff.	.011	-.037	.115	.205	-.107								.675**	.835**
	Sig. (2-tailed)	.939	.791	.402	.133	.436								.001	.001
SDQ$_2$	Corr. Coeff.	.144	.030	.315*	.297*	-.116									.964**
	Sig. (2-tailed)	.293	.828	.019	.027	.401									.001
SDQ Total	Corr. Coeff.	.124	.013	.286*	.289*	-.101									
	Sig. (2-tailed)	.366	.927	.034	.032	.462									

Significant Spearman's rho correlation coefficients (2 – tailed) between the N-DQ, S-DQ, SSQ, DDI and BFNE are highlighted in grey; where these are different to the Pearson correlations (parametric analysis) they are highlighted in green.

Appendix Table B-2

Table B-2: Demographic data and sub-scales - Spearman's rho (2-tailed) and Mann-Whitney U tests

Demographic Correlations

Spearman's rho N = 55		BFNE	DDI N= 54	N-DQ$_1$	N-DQ$_2$	N-DQ$_3$	N-DQ$_4$	N-DQ Total	S-DQ$_1$	S-DQ$_2$	S-DQ Total	SSQ Total	SSQ$_1$ Item3.1 Item3.2	SSQ$_2$ Item 3.5 Item 3.6 Item 3.7	SSQ$_3$ Item3.8 Item3.9	SSQ$_4$ Item3.3 Item3.4 Item3.10
4.1: Gender	Corr. Coeff.	.227	.197	.099	.143	.097	.114	.127	.143	.192	.205	-.131	-.116	-.057	-.154	.011
	Sig. (2-tailed)	.096	.152	.474	.297	.480	.409	.356	.297	.161	.133	.340	.401	.679	.261	.937
4.2: Age group	Corr. Coeff.	-.109	-.219	-.069	-.062	.020	.129	-.045	-.169	-.195	-.215	-.081	-.015	-.206	-.177	.091
	Sig. (2-tailed)	.426	.111	.618	.653	.882	.348	.747	.216	.153	.116	.554	.916	.131	.197	.507
4.4: How your TBI occurred	Corr. Coeff.	.115	-.157	-.001	.130	.160	.195	.124	.004	-.062	-.028	-.200	-.198	.042	-.060	-.300
	Sig. (2-tailed)	.404	.257	.996	.343	.245	.155	.365	.978	.654	.837	.142	.147	.760	.665	.026
4.6: Education	Corr. Coeff.	.102	.083	.013	-.036	-.084	-.177	-.050	.065	.134	.135	-.057	-.006	.118	-.135	-.120
	Sig. (2-tailed)	.458	.551	.926	.794	.543	.196	.717	.637	.331	.327	.679	.966	.390	.325	.384
4.7: Employment at time of TBI	Corr. Coeff.	.010	-.049	.300	.233	.034	.039	.236	.050	.045	.042	-.101	-.182	.099	-.049	-.169
	Sig. (2-tailed)	.941	.724	.026	.087	.806	.778	.082	.717	.744	.758	.461	.183	.472	.725	.217
4.8: Current occupation	Corr. Coeff.	.125	-.034	.094	.217	-.005	-.065	.068	-.084	-.179	-.157	-.163	-.095	-.173	-.191	-.023
	Sig. (2-tailed)	.362	.808	.493	.112	.969	.638	.620	.540	.190	.252	.234	.489	.208	.163	.868
4.9: Time since your TBI	Corr. Coeff.	-.023	-.134	.043	-.011	-.037	-.071	-.045	-.039	-.143	-.116	-.043	-.020	-.197	-.019	.077
	Sig. (2-tailed)	.867	.332	.754	.938	.789	.605	.744	.777	.298	.401	.753	.887	.149	.893	.577

Mann-Whitney U Tests (Mn = mean)

4.1 Gender	All p values for the Mann-Whitney are approximate to those for the Spearman's rho, so are not recorded twice; there were no significant differences.
4.3: Marital Status	Significant difference between Marital status and S-DQ$_1$ '*need to explain*': Single (Mn=26.52, N=22) and Married/Partner (Mn=14.61, N=19), U = 87.50, Z = -3.183, p = .001, r = 3.38 (medium effect size). Feel less need to explain for those in a relationship than for those who are not.
4.5: Overt/covert disability	Significant difference between overt/covert disability and distress disclosure (DDI): 'Have both obvious and hidden injuries' (Mn=27.27, N=24) and 'All hidden' (Mn=18.12, N=21), U = 149.50, Z = -2.334, p = .02, r = .333 (medium effect size). Those with hidden injuries are less willing to seek support from others.

Appendix Table B3

Table B-3: Correlation between age and gender and the N-DQ and S-DQ

Correlation between age and gender and the N-DQ and S-DQ		
N = 55	AGE	GENDER
N-DQ_1	r_s = .099, p = .474	r_s = -.069, p = .618
N-DQ_2	r_s = .143, p = .297	r_s = -.062, p = .653
N-DQ_3	r_s = .097, p = .480	r_s = .020, p = .882
N-DQ_4	r_s = .114, p = .409	r_s = .129, p = .348
S-DQ_1	r_s = .143, p = .297	r_s= -.169, p = .216
S-DQ_2	r_s = .192, p = .161	r_s= -.195, p = .153

There were no significant associations identified between age and gender using a Mann-Whitney U Test.

APPENDIX C

Appendices for Chapter 6

C-1 N-DQ, S-DQ and C2 ESSQ

UNIVERSITY OF BIRMINGHAM

Appendix C-1: N-DQ and S-DQ
Appendix C-2: ESSQ – is section 3 of this document

An exploration of self-disclosure after traumatic brain injury

Completing the survey – please read this before you begin

This survey is to help us to understand how you manage your day to day life, since you had your brain injury. In particular, we are interested in what you tell other people about the injury. Your answers to these questions will help us greatly; we hope you will not find them too intrusive. You do not have to complete this survey in one attempt, unless you wish to do so. What is important is that you answer as many questions as you can.

Example for completion of the survey:

Please will you mark or circle the response you feel most describes your situation. For example:

2.10	There are times when I talk to other people about my injury because: I feel better for getting things off my chest				
	Definitely true	[✓ Probably true]	Not sure	Probably false	Definitely false

The scale has been placed underneath each question, so that you can mark your response directly onto it.

Please do not put your name onto this document; your responses to these questions should remain anonymous.

If you would like to receive a summary of the findings, please contact us, we would be quite happy to e-mail or post you a copy. If there is anything else you would like to add or comments you wish to make about this study please feel free to do so. Contact details are on the enclosed covering letter and for the University at the bottom of each page.

Thank you for your help V3

Appendix C1

N-DQ

Hagger & Riley (2010)

Reasons you may have for not sharing information with others

1.1	There are times when I keep quiet about my injury because: talking about it reminds me of all the bad things that have happened				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.2	There are times when I keep quiet about my injury because: other people might think I was mad or dangerous				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.3	There are times when I keep quiet about my injury because: I don’t want to be asked all kinds of questions about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.4	There are times when I keep quiet about my injury because: I would feel ashamed if I told them				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.5	There are times when I keep quiet about my injury because: I don’t want to be marked out as ‘the person with the head injury’				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.6	There are times when I keep quiet about my injury because: the other person might get annoyed if I talk about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.7	There are times when I keep quiet about my injury because: I think they might make a fuss about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.8	There are times when I keep quiet about my injury because: the other person might start to talk down to me or patronize me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.9	There are times when I keep quiet about my injury because: the other person might think badly of me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.10	There are times when I keep quiet about my injury because: I would get upset if I started to talk about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.11	There are times when I keep quiet about my injury because: people might start to watch closely what I do and say				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.12	There are times when I keep quiet about my injury because: I don’t like the attention I get when I do tell someone				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.13	There are times when I keep quiet about my injury because: the other person might gossip about me to others				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.14	There are times when I keep quiet about my injury because: other people don’t understand what I’ve been through				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.15	There are times when I keep quiet about my injury because: I might be made fun of				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.16	There are times when I keep quiet about my injury because: I don’t want to have to explain things yet again				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.17	There are times when I keep quiet about my injury because: the people I am with might take advantage of me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.18	There are times when I keep quiet about my injury because: I know talking about it would make me feel worse				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.19	There are times when I keep quiet about my injury because: the other person might think I was stupid				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.20	There are times when I keep quiet about my injury because: the other person might be fed up of hearing about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.21	There are times when I keep quiet about my injury because: I would get embarrassed if I told them				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.22	There are times when I keep quiet about my injury because: other people aren’t that interested in what’s happened to me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.23	There are times when I keep quiet about my injury because: not much good ever comes from telling other people about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.24	There are times when I keep quiet about my injury because: I can’t see that there’s much point talking about it				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

1.25	There are times when I keep quiet about my injury because: talking about it doesn’t help me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

S-DQ

Hagger & Riley (2010)

Reasons for sharing information with others

2.1	There are times when I talk to other people about my injury because: I want emotional support				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.2	There are times when I talk to other people about my injury because: they help me keep going when I feel like giving up				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.3	There are times when I talk to other people about my injury because: I don’t want to bottle up my feelings				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.4	There are times when I talk to other people about my injury because: talking to others helps me understand my difficulties better				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.5	There are times when I talk to other people about my injury because: I feel like I’m not facing my problems alone				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.6	There are times when I talk to other people about my injury because: I want more information about my problem				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.7	There are times when I talk to other people about my injury because: I’ve found that once they understand, people are generally helpful				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.8	There are times when I talk to other people about my injury because: I’m feeling low and need some emotional support				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.9	There are times when I talk to other people about my injury because: they help me sort my problems out				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.10	There are times when I talk to other people about my injury because: I feel better for getting things off my chest				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.11	There are times when I talk to other people about my injury because: It makes me feel better if they know why I’m like this				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

2.12	There are times when I talk to other people about my injury because: they might think I’m stupid if I don’t explain				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.13	There are times when I talk to other people about my injury because: I don’t want them thinking I’m strange or odd				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.14	There are times when I talk to other people about my injury because: I just feel I’ve got to explain myself to them				
	Definitely true	Probably true	Not Sure	Probably false	Definitely false

2.15	There are times when I talk to other people about my injury because: I don’t want them getting the wrong idea about me				
	Definitely true	Probably true	Not sure	Probably false	Definitely false

C-2: Enacted Social Support Questionnaire

Enacted Social Support Questionnaire (ESSQ)

Riley and Hagger (2010)

Please tell us who you live with

If you have no family please tick here ☐

If you have no contact with your family please tick here ☐

The following questions ask about the help and support you have actually received from other people in the last year. These questions are about people you do not live with. Please DO NOT include in your answers support that you get from the people you live with. We have provided some examples.

Practical help – for example, they have given you a lift somewhere maybe to an appointment or event; helped you with jobs around the house; looked after the house or a pet while you were away; got your shopping or collected something for you etc.

1	In the past year, how often have you received practical help from **family members (not including those you live with)**				
	most days	most weeks	once or twice a month	once or twice a year	never

2	In the past year, how often have you received practical help from **your friends**				
	most days	most weeks	once or twice a month	once or twice a year	never

3	In the past year, how often have you received practical help from **neighbours** or **acquaintances**				
	most days	most weeks	once or twice a month	once or twice a year	never

Advice or information – for example, they have offered you suggestions about what to do about a problem you had or a difficult situation you faced; helped you find out about or to understand something; helped you fill in a form or write a letter; shown you how to do something, like how to use a computer program or how to operate a video recorder or other appliance etc.

4	In the past year, how often have you received advice or information from **family members (not including those you live with)**				
	most days	most weeks	once or twice a month	once or twice a year	never

5	In the past year, how often have you received advice or information from your **friends**				
	most days	most weeks	once or twice a month	once or twice a year	never

6	In the past year, how often have you received advice or information from **neighbours** or **acquaintances**				
	most days	most weeks	once or twice a month	once or twice a year	never

Moral or emotional support - for example, they cheered you up when you were feeling down; they listened to you sympathetically when you were upset about something; helped you to settle in or adjust to changes in your life; encouraged you or motivated you when you needed it; helped you deal with challenges etc.

7	In the past year, how often have you received moral or emotional support from **family members (not including those you live with)**				
	most days	most weeks	once or twice a month	once or twice a year	never

8	In the past year, how often have you received moral or emotional support from **your friends**				
	most days	most weeks	once or twice a month	once or twice a year	never

9	In the past year, how often have you received moral or emotional support from **neighbours** or **acquaintances**				
	most days	most weeks	once or twice a month	once or twice a year	never

Socialising - for example, you've been to visit them or they've come to visit you; you've chatted together over the 'phone or the garden fence; they've had a drink or meal with you; you've gone out to a pub or restaurant together; you've gone with them to a sporting event, the cinema etc.

10	In the past year, how often have you socialised with **family members (not including those you live with)**				
	most days	most weeks	once or twice a month	once or twice a year	never

11	In the past year, how often have you socialised with **your friends**				
	most days	most weeks	once or twice a month	once or twice a year	never

12	In the past year, how often have you socialised with **neighbours** or **acquaintances**				
	most days	most weeks	once or twice a month	once or twice a year	never

Section 4: additional information
(please mark the appropriate box)

4.1	Gender
Male	Female

4.2	Please would you tell us your age

4.3	Please would you tell us your status? Are you		
single	separated/divorced	married / have a partner	widowed

4.4	Please would you tell us how your brain injury occurred?		
Vehicle driver/passenger	Motorcycle	Fall	Assault
Vehicle pedestrian	Bicycle	Industrial Accident	Sports Injury
Brain Tumour	Aneurysm	Other please specify	

4.5	How obvious do you think your disabilities are to other people?	
All Hidden	Obvious to others	Have both hidden and obvious injuries

4.6	Please would you tell us which level of schooling you reached?	
Higher Education	Secondary Education	Primary School

4.7	Please will you indicate which of these apply to you now?	
Working full-time - Paid	Working part-time - Paid	I am not working or I am unable to work
Working full-time - Voluntary	Working part-time - Voluntary	

4.8	Please would you tell us which month and year your brain injury happened?
Month	Year

4.9	Please would you tell us what your occupation was at the time of your TBI?

Thank you for taking part

C-3: Rosenberg Self-Esteem Scale (RSE)

RSE Scale
Rosenberg, M. (1965)

Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle **Strongly Agree**. If you agree with the statement, circle **Agree**. If you disagree, circle **Disagree**. If you strongly disagree, circle **Strongly Disagree.**

1	On the whole I am satisfied with myself			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
2	At times, I think that I am no good at all			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
3	I feel that I have a number of good qualities			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
4	I am able to do things as well as most other people			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
5	I feel I do not have much to be proud of			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
6	I certainly feel useless at times			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
7	I feel that I am a person of worth, at least the equal of others			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
8	I wish I could have more respect for myself			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
9	All in all, I am inclined to feel that I am a failure			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**
10	I take a positive attitude toward myself			
	Strongly Agree	**Agree**	**Disagree**	**Strongly Disagree**

The original scale is available on http://www.bsos.umd.edu/socy/research/rosenberg.htm

C-4: Social Avoidance and Distress Scale (SAD)

The SAD scale by David Watson and Ronald Friend was used in this study.

If you wish to see the scale please refer to the following article, where it is available on page 450.

Watson, D., & Friend, R. (1969). Measurement of Social-Evaluative Anxiety. *Journal of Consulting and Clinical Psychology, 33*(4), 448-457.

C-5: The revised University of California Los Angeles Scale (UCLA)

The UCLA was used in this study with the kind permission of Professor Dan Russell.

If you wish to see the scale please refer to the following articles where it is available on page 475 and page 23 (for version 3):

Russell, D., Peplau, L. A., & Cutrona, C. E. (1980). The Revised UCLA Loneliness Scale: Concurrent and Discriminant Validity Evidence. *Journal of Personality and Social Psychology, 39*(3), 472 - 480.

Russell, D. W. (1996). UCLA Loneliness Scale (Version 3): Reliability, Validity, and Factor Structure. *Journal of Personality Assessment, 66* (1), 20 - 40.

C-6: Life Satisfaction Questionnaire (LiSat-11)

The LISAT-11 checklist was developed by Fugl-Meyer (2002) (English translation).

If you wish to see the scale please refer to the following article where it is available on page 245.

Fugl-Meyer, A. R., Melin, R., & Fugl-Meyer, K. S. (2002). Life satisfaction in 18 to 64 year old swedes: in relation to gender, age, partner and immigrant status. *Journal of Rehabilitation Medicine, 34*, 239 - 246.

C-7: The Community Integration Questionnaire (CIQ)

The CIQ was used in this study with the kind permission of Associate Professor Barry Willer.

If you wish to see the questionnaire please refer to the following article, where it is available on pages 86 to 87.

Willer, B., Rosenthal, M., Kreutzer, J. S., Gordon, W. A., & Rempel, R. (1993). Assessment of community integration following rehabilitation for traumatic brain injury. *Journal of Head Trauma Rehabilitation, Special* (2), 75 - 87.

Appendix Table C-1

Table C-1: Spearman’s rho correlations (two tailed tests) for all questionnaires/sub-scales used in the third study

Spearman's rho correlation coefficients		ESSQ Modified	RSE Total	SAD Total	LISAT Total	UCLA - Loneliness Scores	CIQ Total	CIQ his	CIQ sis	CIQ prod
N-DQ$_1$	Corr. Coeff.	.128	-.250	.266	-.072	.415	.053	.118	-.153	.178
	Sig. (2-tailed)	.308	.044	.032	.568	.001	.673	.348	.224	.157
N-DQ$_2$	Corr. Coeff.	.053	-.402	.388	-.288	.297	-.031	.000	-.076	.055
	Sig. (2-tailed)	.674	.001	.001	.020	.016	.809	.999	.550	.663
N-DQ$_3$	Corr. Coeff.	-.013	-.360	.315	-.146	.325	.030	.173	-.135	.029
	Sig. (2-tailed)	.921	.003	.011	.247	.008	.815	.167	.283	.818
N-DQ$_4$	Corr. Coeff.	-.060	-.349	.231	-.180	.277	.032	.086	.005	-.040
	Sig. (2-tailed)	.638	.004	.064	.152	.025	.801	.494	.967	.754
N-DQ Total	Corr. Coeff.	.076	-.357	.345	-.128	.380	.064	.157	-.095	.090
	Sig. (2-tailed)	.550	.003	.005	.308	.002	.615	.212	.453	.474
S-DQ$_1$	Corr. Coeff.	.140	-.220	.113	.030	.033	-.068	-.090	-.023	.086
	Sig. (2-tailed)	.265	.078	.369	.815	.794	.590	.474	.857	.495
S-DQ$_2$	Corr. Coeff.	.055	-.013	.060	.044	-.050	-.034	-.116	.058	.026
	Sig. (2-tailed)	.662	.919	.638	.728	.694	.788	.358	.647	.839
S-DQ Total	Corr. Coeff.	.095	-.069	.099	.049	-.013	-.056	-.123	.031	.055
	Sig. (2-tailed)	.450	.586	.432	.700	.920	.660	.330	.803	.665

Appendix Table C-2

Table C-2: Demographic data and sub-scales used in study 3 - Spearman's rho (2-tailed) and Mann-Whitney U tests

Spearman's rho correlation coefficient		N-DQ1	N-DQ2	N-DQ3	N-DQ4	N-DQ Total	S-DQ1	S-DQ2	S-DQ Total	ESSQ Total	RSE Total	SAD Total	LISAT Total	UCLA Total	CIQ Total	CIQ his	CIQ sis	CIQ prod
4.1: Gender	Please see Table C-6 and C-7 below																	
4.2: Age	Corr. Coeff.	-.055	-.070	-.074	.048	-.074	.061	-.021	.009	-.223	-.051	.182	-.018	.033	-.241	.022	-.134	-.333
	Sig. (2-t)	.666	.577	.556	.707	.560	.630	.867	.941	.074	.687	.147	.887	.792	.053	.860	.286	.007
4.5: Overt/covert disability	Corr. Coeff.	.026	-.009	-.059	-.182	-.056	.028	.077	.056	-.188	.122	-.012	.058	.036	-.026	.068	-.089	-.061
	Sig. (2-t)	.835	.944	.643	.148	.660	.826	.542	.655	.134	.333	.927	.646	.778	.836	.591	.481	.632
4.6: Education	Corr. Coeff.	.038	.141	.090	.064	.104	-.020	-.023	-.003	.114	.089	-.035	.097	-.141	-.015	-.001	.001	-.057
	Sig. (2-t)	.763	.263	.473	.613	.408	.875	.854	.979	.368	.482	.783	.442	.263	.906	.995	.995	.653
4.8a Time since your ABI	Corr. Coeff.	-.250	.217	.114	-.023	-.019	-.191	-.060	-.114	-.043	-.162	.200	-.133	.117	.006	.045	.076	-.081
	Sig. (2-t)	.045	.083	.364	.858	.883	.128	.636	.366	.733	.197	.111	.290	.353	.965	.720	.549	.523
4.8b Month of accident	Corr. Coeff.	.117	.076	-.101	.170	.084	.133	-.002	.040	-.001	-.023	-.040	.103	-.117	-.001	.056	-.056	.038
	Sig. (2-t)	.352	.547	.422	.177	.507	.291	.988	.752	.995	.859	.749	.412	.354	.995	.656	.656	.766
4.9: Employment at time of ABI	Corr. Coeff.	.066	.089	-.118	.080	-.007	-.027	-.004	-.035	.065	-.112	.123	-.157	-.047	-.143	-.321	.053	.142
	Sig. (2-t)	.604	.482	.350	.527	.954	.830	.973	.784	.609	.374	.330	.212	.708	.254	.009	.674	.258
Mann-Whitney U Tests (Mn = mean)																		
4.3: Marital Status	Significant difference between Marital status and life satisfaction: Single (Mn=20.48, N=26) and Married/Partner (Mn=29.25, N=22), U = 181.50, Z = -2.166, p = .03, r = .313 (medium effect size). Those in a relationship report greater life satisfaction than those who are single.																	
4.4: How your ABI occurred	Significant difference between TBI due to a fall and a vehicle accident: Vehicle (Mn=12.07, N=15) and Fall (Mn=5.8, N=5), U = 14, Z=-2.061, p=.042, r =.461 (medium effect size). Participants whose TBI was due to a fall show lower self-esteem than those whose TBI was due to a vehicle accident. Significant difference between TBI due to a brain tumour (post operative) and a vehicle accident: Vehicle (Mn=16.67, N=15) and brain tumour (post op) (Mn=9.18, N=11), U = 35, Z=-2.473, p=.013, r =.485 (medium effect size). Participants whose TBI was due to problems from post surgical brain tumour show lower self-esteem than those whose TBI was due to a vehicle accident.																	
4.7: Current occupation	Significant difference in self-esteem for those in employment and those who are not. Not working (Mn 30.45, N=56) and working part time voluntary (Mn=46.88, N=8), U = 109, Z=-2.34, p=.019, r = .029 (medium effect size). Those doing voluntary work have a higher level of self-esteem than participants who are not employed. Significant difference in productivity scores supports the previous finding. Those not working (Mn 29.94, N=56) and those in part time voluntary work (Mn=50.44, N=8), U=80.5, Z=-3.036, p=.002, r = .379 (medium effect size). Those who undertake voluntary work report being more productive / active than those who describe themselves as not employed.																	

Appendix Table C-3

Table C-3: Spearman’s rho (2-tailed) Correlation Matrix for N-DQ and S-DQ (two-tailed tests)

Correlation Matrix – significant relationships show that factor analysis may reveal one or more factors

Spearman's rho n = 65		N-DQ2	N-DQ3	N-DQ4	N-DQ. Total	SDQ1	S-DQ2	S-DQ Total
N-DQ1	Correlation Coefficient	.511**	.581**	.421**	.813**	.565**	.408**	.517**
	Sig. (2-tailed)	.001	.001	.001	.001	.001	.001	.001
N-DQ2	Correlation Coefficient		.662**	.576**	.788**	.376**	.389**	.432**
	Sig. (2-tailed)		.001	.001	.001	.002	.001	.001
N-DQ3	Correlation Coefficient			.631**	.863**	.314*	.175	.269*
	Sig. (2-tailed)			.001	.001	.011	.163	.031
N-DQ4	Correlation Coefficient				.751**	.234	-.023	.096
	Sig. (2-tailed)				.001	.061	.853	.445
N-DQ.	Correlation Coefficient					.464**	.311*	.420**
	Sig. (2-tailed)					.001	.012	.001
SDQ1	Correlation Coefficient						.659**	.848**
	Sig. (2-tailed)						.001	.001
S-DQ2	Correlation Coefficient							.951**
	Sig. (2-tailed)							.001

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table C-4: Eigenvalues and loadings for ESSQ items N=65 using FA

Total Variance Explained

Component	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings a
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	4.935	41.122	41.122	4.935	41.122	41.122	4.351
2	2.134	17.786	58.908	2.134	17.786	58.908	2.861
3	1.287	10.725	69.633	1.287	10.725	69.633	2.469
12	.116	.967	100.000				

Extraction Method: Principal Axis Factoring.

a. When components are correlated, sums of squared loadings cannot be added to obtain a total variance.

Table C-5: Eigenvalues and loadings for non-disclosure and self-disclosure items N=120 using principal axis factoring as a comparison

Total Variance Explained

Factor	Initial Eigenvalues			Extraction Sums of Squared Loadings			Rotation Sums of Squared Loadings a
	Total	% of Variance	Cumulative %	Total	% of Variance	Cumulative %	Total
1	10.677	26.692	26.692	10.061	25.152	25.152	8.612
2	5.243	13.108	39.800	4.621	11.552	36.704	7.248
3	1.958	4.895	44.695				
4	1.837	4.593	49.287				
5	1.605	4.012	53.299				
40	.104	.259	100.000				

Extraction Method: Principal Axis Factoring.

a. When factors are correlated, sums of squared loadings cannot be added to obtain a total variance.

Appendix Table C- 6

Table C-6: Results of Mann-Whitney test for gender and additional questionnaires (N=65) (two-tailed)

Questionnaire		Mean Rank	Median	M-W U	Z	Exact sig. p	Effect size r
UCLA	Male (50)	32.10	23.5	330.00	-.702	.464	-.08
	Female (15)	36.00	27				
SAD	Male (50)	30.10	33	230.00	-2.265	.023	-.28
	Female (15)	42.67	36				
CIQ	Male (50)	33.79	14	335.50	-.617	.544	-.28
	Female (15)	30.37	13				
LiSat-11	Male (50)	33.50	41	350.00	-.390	.703	-.05
	Female (15)	31.33	37				
RSE	Male (50)	35.91	19	229.50	-2.271	.022	-.28
	Female (15)	23.30	15				
ESSQ	Male (50)	32.76	20	363.00	-.187	.852	-.02
	Female (15)	33.80	21				

Females score significantly higher for social avoidance and distress than males

Males score significantly higher for self-esteem than females

Table C-7: Results of Mann-Whitney test for gender and non-disclosure and disclosure questionnaires (N=65)

Questionnaire		Mean Rank	Median	M-W U	Z	Exact sig. p	Effect size r
N-DQ1	Male (50)	29.38	23	194.00	-2.82	.004	-.35
	Female (15)	45.07	32				
N-DQ2	Male (50)	29.57	9	203.50	-2.68	.006	-.33
	Female (15)	44.43	14				
N-DQ3	Male (50)	30.37	13	243.50	-2.05	.040	-.25
	Female (15)	41.77	17				
N-DQ4	Male (50)	30.18	13.5	234.00	-2.20	.027	-.27
	Female (15)	42.40	19				
N-DQ Total	Male (50)	29.23	58	186.50	-2.94	.003	-.37
	Female (15)	45.57	81				
S-DQ1	Male (50)	29.18	15.5	184.00	-2.98	.002	-.37
	Female (15)	45.73	23				
S-DQ2	Male (50)	29.48	32	199.00	-2.74	.005	-.34
	Female (15)	44.73	44				
S-DQ Total	Male (50)	29.08	48	179.00	-3.05	.002	-.38
	Female (15)	46.07	64				

Effect sizes are given in Table 6-15

Females score significantly higher for disclosure and concealment than males

Appendix Table C-8

Table C-8: Spearman’s rho correlations for 7 variables in mediation analysis (N=65)

Spearman's rho Correlations to support mediation analysis

N = 65		S-DQ Total	ESSQ Total	SAD Total	UCLA Loneliness Score	CIQ Total	LISAT Total
N-DQ Total	Correlation Coefficient	.420**	-.001	.345**	.380**	.064	-.128
	Sig. (2-tailed)	.001	.992	.005	.002	.615	.308
S-DQ Total	Correlation Coefficient		.177	.099	-.013	-.056	.049
	Sig. (2-tailed)		.157	.432	.920	.660	.700
ESSQ Total	Correlation Coefficient			-.383**	-.384**	.070	.302*
	Sig. (2-tailed)			.002	.002	.581	.014
SAD Total	Correlation Coefficient				.500**	-.260*	-.349**
	Sig. (2-tailed)				.001	.037	.004
UCLA – Loneliness Score	Correlation Coefficient					-.097	-.483**
	Sig. (2-tailed)					.442	.001
CIQ Total	Correlation Coefficient						.241
	Sig. (2-tailed)						.053

**. Correlation is significant at the 0.01 level (2-tailed).

*. Correlation is significant at the 0.05 level (2-tailed).

Table C-9: Critical values for 12 path analyses investigating possible mediation

AMOS 7.0 (bootstrapped) – Standardized Indirect Effects (SIE) of mediation for N-DQ and S-DQ with ESSQ, UCLA and SAD and CIQ and LISat-11 for individual evaluations

Variables			SIE	Confidence Intervals bias corrected (BC)		p two tailed	Bootstrap Standard Error (SIE SE)
predictor	mediator	outcome		Lower	Upper		
N-DQ	ESSQ m	CIQ	.004	-.021	.072	.473	.020
		LiSat-11	.013	-.027	.085	.384	.027
	SAD	CIQ	-.086	-.270	.006	.065	.067
		LiSat-11	**-.128**	**-.282**	**-.031**	**.006**	**.062**
	UCLA	CIQ	-.024	-.184	.081	.590	.065
		LiSat-11	**-.174**	**-.332**	**-.061**	**.001**	**.069**
S-DQ	ESSQ m	CIQ	.009	-.020	.090	.399	.024
		LiSat-11	.021	-.012	.112	.223	.028
	SAD	CIQ	-.030	-.123	.013	.143	.032
		LiSat-11	-.061	-.176	.031	.188	.053
	UCLA	CIQ	.002	-.022	.066	.507	.020
		LiSat-11	.020	-.112	.163	.764	.069

Table C-9 shows figures obtained for each of the 12 mediation analyses, figures change slightly when the variables making up a specific model are combined because of the interaction between the variables, they support the findings in Table 6-17 and Figure 6-4

Comparison of models

Several models were compared to see if the findings were supported.

Table C-10: Critical values for mediation analysis for Figures C-2 (N-DQ) and C-3 (S-DQ)

AMOS 7.0 (bootstrapped) – Standardized Indirect Effects (SIE) of mediation for N-DQ and S-DQ with ESSQ, UCLA and SAD and CIQ and LISat-11 - models

Variables			SIE	Confidence Intervals bias corrected (BC)		p two tailed	Bootstrap Standard Error (SIE SE)
predictor	mediator	outcome		Lower	Upper		
N-DQ	ESSQ m **SAD** **UCLA**	CIQ	-.060	-.213	.065	.360	.071
		LiSat-11	**-.254**	**-.411**	**-.090**	**.003**	**.084**
S-DQ	ESSQ m SAD UCLA	CIQ	-.045	-.148	.038	.272	.047
		LiSat-11	-.019	-.163	.128	.760	.075

Comparison of models

Several models were compared to see if the findings were supported.

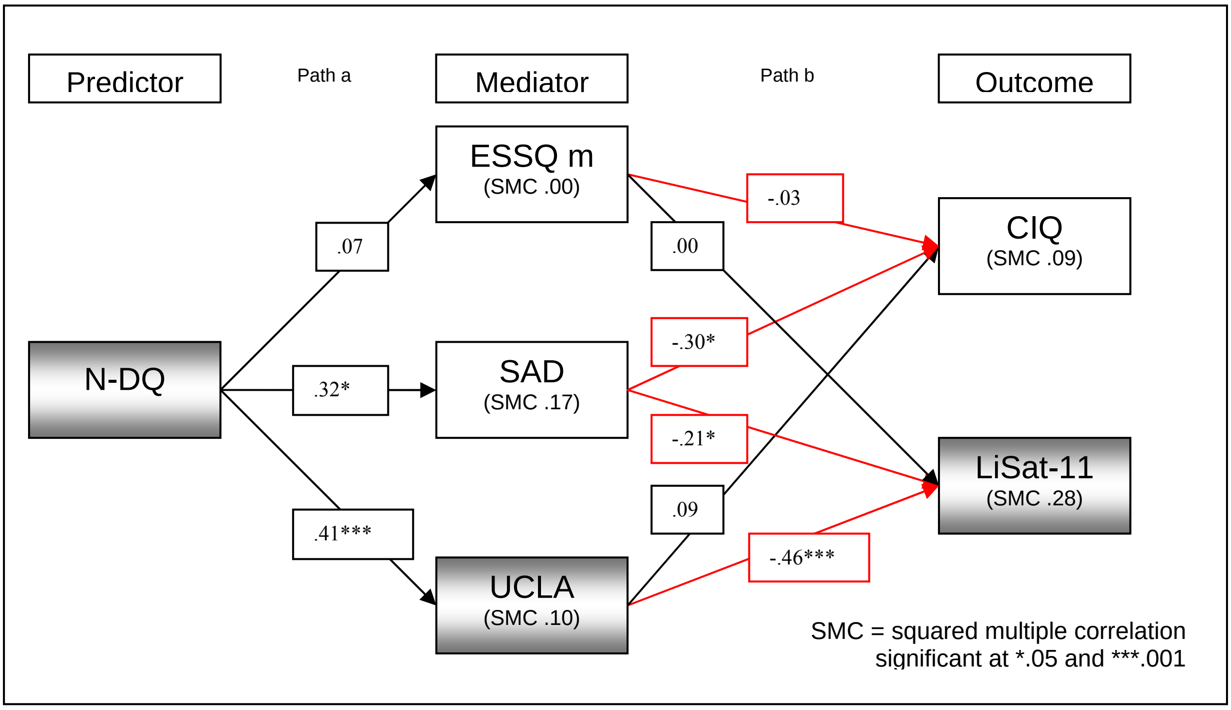

Figure C-1: N-DQ associations with mediators ESSQ m, SAD and UCLA to outcomes CIQ

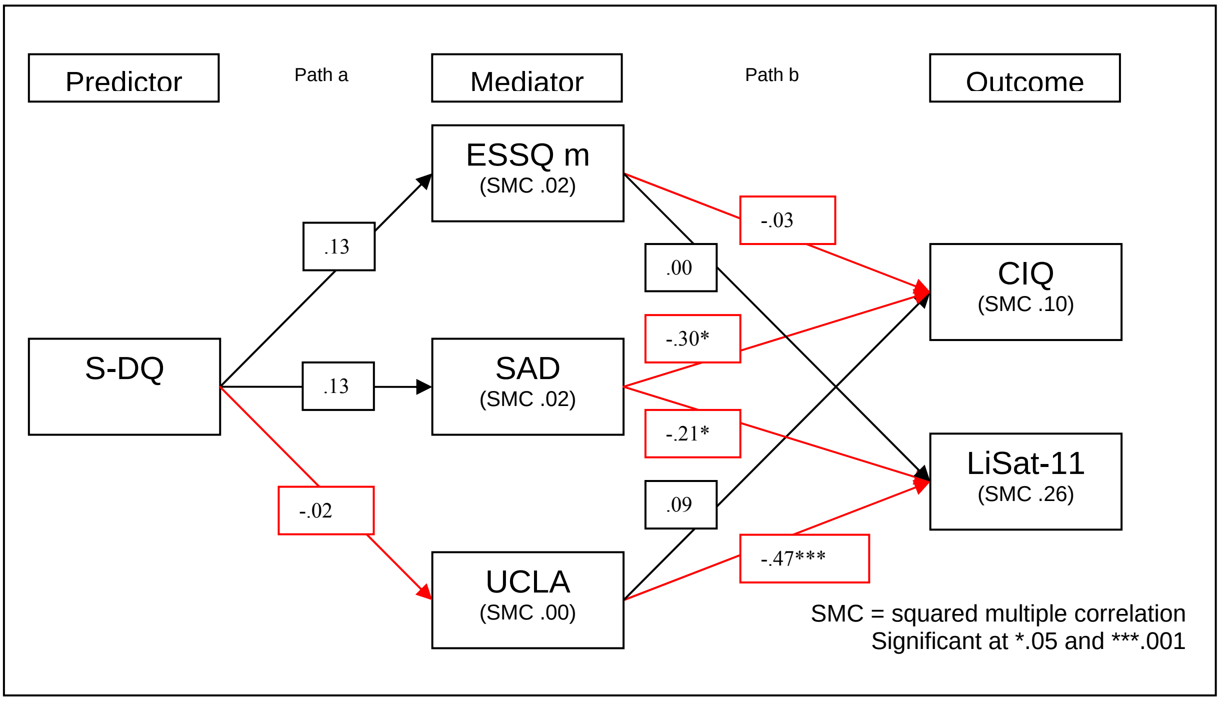

Figure C-2: S-DQ associations with mediators ESSQ m, SAD and UCLA to outcomes CIQ and LiSat-11. Red arrows show negative relationships were observed and black arrows positive relationships

When the analysis is carried out as a mediation model for S-DQ a relationship is observed between S-DQ to UCLA and CIQ.

Table C-11: Single t-test for RSE, SAD and UCLA

Single t-test[a] for SAD, UCLA and RSE

Outcome		x1	x2	Pooled SD	df	t	Significance (2-tailed)	Effect Size (d)
1	SAD Male	34.88	11.70	5.79	160.00	23.39	.00	4.00
2	SAD Female	39.87	12.20	6.68	204.00	15.37	.00	4.14
3	UCLA Male	39.52	37.06	11.18	150.00	1.27	.21	.22
4	UCLA Female	41.53	36.06	10.18	141.00	1.96	.05	.54
5	RSE vs. Study 1	12.14	4.10	3.71	149.00	13.09	.00	2.17
6	RSE vs. Study 2	12.14	21.86	6.30	85.00	-6.19	.00	-1.54
7	RSE vs. Study 3	12.14	21.46	5.80	104.00	-7.98	.00	-1.61

a. Limited to first 100 cases.

Table C-12: Single t-test for the CIQ

Single t-test[a] for CIQ

Outcome		x1	x2	Pooled SD	df	t	Significance (2-tailed)	Effect Size (d)
5	Home Integration Study 3 vs. ABI Male	4.78	5.15	2.80	143.00	-.75	.45	-.13
6	Home Integration Study 3 vs. ABI Female	4.47	6.61	2.32	81.00	-3.19	.00	-.92
13	Social Integration Study 3 vs. Male	7.18	9.23	2.04	143.00	-5.71	.00	-1.00
14	Social Integration Study 3 vs. Female	6.87	9.29	1.90	81.00	-4.42	.00	-1.27
19	Productivity Study 3 vs ABI Male	2.60	5.27	1.70	143.00	-8.91	.00	-1.57
20	Productivity Study 3 vs. ABI Female	2.60	5.18	2.10	81.00	-4.26	.00	-1.23
27	OVERALL CIQ Study 3 vs.ABI Male	14.56	19.52	4.51	143.00	-6.25	.00	-1.10
28	OVERALL CIQ Study 3 vs. ABI Female	13.93	21.12	2.70	81.00	-9.21	.00	-2.66

a. Limited to first 100 cases.

Comparison of the effect sizes in Tables C-11 to C-13 to Cohen’s values of .1 (small effect), .3 (medium effect) and .5 (large effect), reveals some very large effects

Appendix Table C-13

Table C-13: Single t-test for the LiSat-11

Single T-test[a] Life Satisfaction LiSat-11

Outcome		x1	x2	Pooled SD	df	t	Significance (2-tailed)	Effect Size (d)
1	Life as a whole vs Control	4.25	4.70	1.34	79.00	-1.19	.24	-.34
2	Life as a whole vs. Group 1	4.25	4.60	1.24	115.00	-1.51	.13	-.28
3	Life as a whole vs. Group 2	4.25	3.60	1.46	79.00	1.58	.12	.45
4	Vocation vs Control	1.46	4.90	1.92	79.00	-6.34	.00	-1.79
5	Vocation vs Group 1	1.46	4.10	1.71	115.00	-8.20	.00	-1.54
6	Vocation vs Group 2	1.46	3.20	2.01	79.00	-3.07	.00	-.87
7	Financial vs. Control	3.88	4.20	1.41	79.00	-.80	.42	-.23
8	Financial vs. Group 1	3.88	4.00	1.47	115.00	-.43	.66	-.08
9	Financial vs. Group 2	3.88	3.60	1.50	79.00	.66	.51	.19
10	Leisure vs Control	4.11	4.90	1.34	79.00	-2.09	.04	-.59
11	Leisure vs Group 1	4.11	4.30	1.29	115.00	-.79	.43	-.15
12	Leisure vs Group 2	4.11	3.10	1.50	79.00	2.39	.02	.68
13	Friends vs Control	4.15	5.00	1.41	79.00	-2.13	.04	-.60
14	Friends vs Group 1	4.15	4.60	1.32	115.00	-1.82	.07	-.34
15	Friends vs Group 2	4.15	4.10	1.51	79.00	.12	.91	.03
16	Sexual Life vs Control	2.37	4.60	1.57	79.00	-5.04	.00	-1.42
17	Sexual Life vs Group 1	2.37	4.10	1.53	115.00	-6.01	.00	-1.13
18	Sexual Life vs Group 2	2.37	3.70	1.64	79.00	-2.86	.01	-.81
19	ADL vs Control	5.26	5.60	.94	79.00	-1.27	.21	-.36
20	ADL vs Group 1	5.26	5.30	.94	115.00	-.23	.82	-.04
21	ADL vs Group 2	5.26	5.40	.92	79.00	-.54	.59	-.15
22	Family Life vs Control	4.31	5.20	1.71	79.00	-1.84	.07	-.52
23	Family Life vs Group 1	4.31	4.80	1.64	115.00	-1.59	.11	-.30
24	Family Life vs Group 2	4.31	3.90	1.80	79.00	.81	.42	.23
25	Relationship with Partner vs Control	1.95	5.00	2.34	79.00	-4.61	.00	-1.30
26	Relationship with Partner vs Group 1	1.95	4.80	2.13	115.00	-7.12	.00	-1.34
27	Relationship with Partner vs Group 2	1.95	4.00	2.41	79.00	-3.01	.00	-.85
28	Physical Health vs Control	3.94	5.30	1.41	79.00	-3.41	.00	-.96
29	Physical Health vs Group 1	3.94	4.80	1.36	115.00	-3.38	.00	-.63
30	Physical Health vs Group 2	3.94	3.70	1.56	79.00	.54	.59	.15
31	Psychological Health vs Control	3.62	5.10	1.38	79.00	-3.81	.00	-1.08
32	Psychological Health vs Group 1	3.62	4.80	1.37	115.00	-4.59	.00	-.86
33	Psychological Health vs Group 2	3.62	3.90	1.47	79.00	-.67	.50	-.19

a. Limited to first 100 cases.

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