Appendix

Part Two: Extended Appendices

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Appendix

INTRODUCTION (A1)

The purpose of this introduction is to expand on issues in the main manuscript that could not be included due to word count limitations. The manuscript is written towards a particular target audience, so certain concepts are explored more fully in this section including the definition and effects of a brain injury. Also the literature is explored in more detail here, looking at neuropsychological factors and coping, additional models of coping after brain injury and an expansion of the literature on social identity.

Acquired Brain Injury: definitions, causes and prevalence **(manuscript, p2)**

Acquired Brain Injury (ABI) can be defined as an insult or injury to the brain that has been sustained since birth; for example tumours, strokes, haemorrhages or a traumatic injury. The most common causes of ABI in adults are Traumatic Brain Injury (TBI) and stroke . TBI is often used interchangeably with ABI, although it is more specifically defined as “trauma caused to the brain by an external force impinging upon the head and brain” . For recruitment purposes, this study used people from the wider aetiology of ABI but draws evidence from both the ABI and TBI literature.

In estimating the prevalence of head injury, a recent UK study looked at attendance at emergency departments over six years. The study found an overall rate for head injuries of 453 per 100,000 of which moderate to severe head injuries were rated at 40 per

100,000. Males were more at risk than females and risk factors for moderate to severe injuries included living in an urban location and for children and adolescents.

The Effects of Acquired Brain Injury and Unmet needs **(manuscript, p2-3)**

The effects of ABI hinge upon a variety of factors: severity, age, site of injury and how the injury happened , however any brain injury is idiosyncratic and a uniformed recovery can not be expected . Most people make rapid physical progress within the first six months after their head injury , although some residual physical issues still remain . Subsequently, studies have focused more on the effects of a multitude of 'hidden disabilities' e.g. cognitive difficulties in memory, attention and executive functions and behavioural difficulties with motivation, fatigue and personality change . Frontal and temporal lobe structures are particularly vulnerable to damage from TBI . Frontal lobe functions are those required to initiate, plan, execute and monitor complex goal-directed activities and also play a role in inhibition and insight .

Morton and Wehman's review of the TBI literature identified four key themes, firstly that people who had experienced a TBI were at a high risk of a decrease in social support and friendships; they lacked the opportunity for establishing new social contacts and friends; there was a decrease in leisure activities for those with severe TBI; and anxiety and depression were found at high levels for prolonged

periods of time after the injury. The literature also highlights further related social difficulties, such as socio-emotional functioning and social communication , as well as loss of role .

As already discussed depression, anxiety and low self-esteem are common following ABI, even at five to seven year follow-ups . Rates of suicide among survivors are also higher than in the average population . In an analysis of mortality trends after ABI, Pentland et al. concluded that for premature deaths after a predominately mild injury, substance misuse and suicide were common. These and other studies suggest that this is a group of people with long term unmet psychosocial needs. This is also reflected in the evidence base from rehabilitation services which shows unmet need mainly in the cognitive and psychological domains .

Brown and Vandergoot compared individuals after TBI with people who had experienced spinal cord injury and those who had no disability. They looked at subjective quality of life and found that individuals in the TBI group had stronger unmet important needs than the other two groups. Also, reduced QOL in all domains except one (bodily pain), has been found in stroke populations compared with healthy controls .

Neuropsychological Factors Associated with Coping Strategies after ABI **(manuscript, p5)**

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Anson & Ponsford looked at the impact of neuropsychological functioning on coping style using only two measures in their small study of 33 participants. To measure memory they used the Rey Auditory Verbal Learning Test (RAVLT). Some studies (although not all) have shown correlations between the RAVLT and with psychological distress such as anxiety, depression and post traumatic stress . Therefore, caution should be exercised in interpreting the results in TBI populations, where psychological distress is known to be a common sequelae. For executive functioning they used the Six Elements subtest from the Behavioural Assessment of the Dysexecutive Syndrome . The Six Elements subtest is part of a wider test battery and looks at rule following, planning and organisation. Although they found no significant correlations, they were limited by using only two tests, trying to cover the whole range of cognitive functioning.

Krpan et al. used a much wider battery to look at executive functioning and coping, one year post injury with people mainly classified as having mild to moderate TBI. They included multiple tests that involved memory, perceptual shifting, attention, visual search, motor function and mental flexibility, abstract thinking and self-regulation. Again this was a small study using only 21 TBI participants, but they included a non-neurological control group. Interestingly, no relationships were found between coping and executive functioning in the control group even though there were

no statistical differences in reported coping style and few differences in executive functioning. However, in both studies , objective neuropsychological data were used to measure executive functioning, neither used any measure based on subjective experience of executive difficulties.

Models of Coping after ABI **(Manuscript, p6)**

There are three main models which place coping as a mediating variable for QOL outcomes. Godfrey et al. propose a Stress-Appraisal-Coping model (SAC) already discussed in the manuscript. Moore and Stambrook's conceptual model places cognitive moderators such as attributional style, locus of control and coping behaviours, as central mediators influencing psychosocial outcome. Other less important moderating factors, which they propose influence the adjustment process, are: education, personality, social network, financial, stigma and resources. In their revised model (p125) they place coping as the final common pathway leading to poor outcome after TBI. Although social factors are acknowledged by this model, they are largely ignored and ruled out as beyond intervention. This exclusion of an important factor that has been shown to play an important part in psychological outcome after ABI is disappointing.

Kendal and Terry present a complex model based on Lazarus and Folkman's cognitive-phenomenological theory of stress and

adjustment. They identify five antecedents (cognitive impairment, neurological factors, personal resources, environmental resources and situational factors) which impact upon psychosocial adjustment, all mediated by appraisal and coping processes. Social support is grouped with family style and financial status making up the environmental resources factor. Some support has been provided for relationships between demographic and cognitive variables with psychosocial adjustment, within the confines of this proposed model but not how factors such as social support might be mediated by appraisal and coping style.

Social Identity **(manuscript, p8)**

Recent studies from organisational and social psychology have looked at the part played by social identity and social support in the experience of stressful situations . Some authors are now considering how Social Identity Theory and the closely related Self-Categorisation Theory , could relate to research in the health domain. The cornerstone of these two theories is the assumption that “the self is intrinsically linked to the group” (Iyer, Jetten, Tsivrikos, in press, p2).

Social identity can be seen to affect a person’s reaction to stress in two ways . Firstly, the extent to which a social identity is salient determines whether or not a stressor is perceived as threatening, i.e. Folkman and Lazarus’ primary appraisal . Haslam et al. showed that

when presented with a stressful task, students were more likely to see it in a positive light when information was provided by an in-group rather than an out-group member.

The second way in which social identity can mediate stress reactions is during the secondary appraisal, providing a basis for members to receive and benefit from social support. Therefore, when acting in terms of a shared group membership, members can receive and benefit from the social support of their group.

Haslam, O'Brian, Jetten, Vormedal and Penna's Norwegian survey of people recovering from heart surgery included measures on social identification with family/friends, social support, self-esteem and satisfaction. They found that those with higher levels of identification with family/friends were less stressed, had higher self-esteem and were more satisfied. They also concluded that the impact of social identification on stress and life satisfaction was mediated by social support. However, some of the measures used were rather too simple to capture the complex processes involved; for instance, identification with family and friends was measured on a scale consisting of only two items. Similar studies by other authors have also provided support for this idea .

Abraido-Lanza & Revenson applied the social identity framework to understanding role-related stressors and psychological adjustment

in rheumatic diseases. They found that disruptions to important social identities (spouse, homemaker, parent and worker) are more psychologically disturbing. Rheumatic disease is also a chronic illness and thus we might expect to find similar effects of disrupted social identity in ABI patients. The deficits associated with ABI would be expected to intrude greatly on a number of different social identity roles, with a corresponding negative impact on psychological well-being.

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METHOD (B1)

This section provides more detail about the participants.

Participants

Acquired Brain Injury Group. Participants from this group all attended one of the Headway Devon day centres. Members are invited to take part in a range of activities including vocational, educational and creative activities as well as social/group activities.

Comparison Group. Originally, the participants in the comparison group were to be matched to the ABI group using the criterion of: time since injury, age and gender. This was not possible in the final study because of a two-month delay waiting for research approval. This cut data collection time significantly, which was already pressured due to the constraints of doctoral research. Additionally, the participant pool from the Pain Management service was smaller and of a different clinical population than had originally been expected.

It was also originally proposed that the participants in the comparison group would have received traumatic orthopaedic injuries. This group has been used in TBI studies as an appropriate comparison group because of the comparable traumatic nature of the injury . However, the participants who responded from the Pain Management service did not all fit into this category (see Table 1 in

manuscript, p15). Subsequently, the comparison group was renamed as a “chronic pain group” to reflect this change in demographics. Chronic pain groups are also comparable to ABI in terms of chronicity, functional loss and associated handicap, socio-economic factors and effects on mood and well-being . A chronic pain group has also been used as a suitable comparison for ABI in a recently published study .

METHOD (B2)

This section details the choice of measures used in the study, including previous use of the measures, reliability, validity and scoring. It also includes Principal Component Analysis results for the coping measure and information about the Glasgow Coma Scale.

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Measures - Neuropsychological

Participants in the ABI group underwent a small battery of neuropsychological measures. The reason for this was twofold. Firstly, the individual test scores provide important descriptive information about the ABI group. Secondly, the individual test scores and mean z-score[C2, p111] would be used in the analysis of the relationship between cognitive functioning and coping style. The tests were chosen to gain important data but within a limited time scale to reduce fatigue for participants and enabling enough data to be collected to make the study viable (see Table 6).

Controlled Oral Word Association Test . Participants had one minute to name as many words as they could, beginning with a certain letter (F, A, and S). This is a short test which provides a good insight into various cognitive functions (see Table 6). Detailed administration and scoring guidelines were taken from Spreen and Strauss . The test is reported to have high reliability (.65-.88) and validity .

The Trail Making Test B [B3, p85]. Participants are asked to draw lines to alternatively connect numbers and letters in their respective sequence. The test is timed and measured in the number of seconds taken for the task. The test has shown to have both high reliability (.66-.86) and validity in neurological groups and to be highly

sensitive to brain damage . Detailed administration and scoring guidelines were taken from Spreen and Strauss .

Logical Memory 1 and 2 [B3, p85] from the Wechsler Memory Scale III Abbreviated .Two different stories are read to the participant and immediately after hearing each story they are asked to recall it from memory (immediate) and then again 25 minutes later (delayed). Participants are scored on the accuracy of their recall. The WMS-III-abbreviated subtests have good reliability (Logical Memory 1 = .88, Logical Memory 2 = .79) and good test-retest reliability (.76 - .80) and have been tested using people with a range of neurological disorders including TBI .

DEX Questionnaire [B3, p84] from the Behavioural Assessment of the Dysexecutive System . Items are rated on a 5-point scale from Never, to Very often. One version of the questionnaire was completed by the ABI participant and one by a partner, relative or carer. The discrepancy score was used as a measure of insight, an important factor to consider, because insight is often affected by brain injury . The DEX also gives an indication of self-/other-reported executive functioning .

Appendix

Table 6. Summary of common cognitive deficits after ABI and how the neuropsychological measures addressed them

Common cognitive deficits after ABI	References	Measures used			
		COWA T	Trails B	Logical Mem 1	Logical Mem 2
Attention deficits and distractibility		✓	✓	✓	✓
Slowed cognitive processing and behavioural responding		✓	✓		
Impaired learning & retrieval of new information		✓ (short-term memory)		✓ Immediate Memory	✓ Delayed Memory
Deficits in auditory or visual processing		✓ Verbal	✓ Visual	✓ Verbal	✓ Verbal
Frontal lobe signs (initiation, planning/organisation, motor programming etc.)		✓	✓		

Measures - Psychosocial

Brief COPE [B3, p86] . It has been used in both stroke and TBI populations and internal consistency has been reported between α =.50-.90 . Principal Component Analysis was used with varimax rotation on the data from the 14 subscales. Initially a four factor solution was computed however exploration of the factor loadings and examination of the scree plot suggested using three factors which were labelled as maladaptive (α = .59 for the ABI group and α = .82 for the chronic pain group), problem focused (α = .71 for the

ABI group and α = .64 for the chronic pain group) and support seeking (α = .70 for the ABI group and α = .71 for the chronic pain group) (see Table 7). The three factors accounted for 53.47% of the variance and were generally consistent with Cook and Heppner's coping factors; problem-engagement, social/emotional-orientated and avoidance-orientated coping. However, this study included humour and religion as they had adequate loadings on factors which were above .4.

Table 7. Rotated component matrix for three factor solution

Brief COPE subscales (items making up subscales in brackets)	**Factor 1** *"Maladaptive"*	**Factor 2** *"Problem-focused"*	**Factor 3** *"Support-seeking"*
Self-distraction (1,19)		**.60**	
Active coping (2,7)			**.63**
Denial (3,8)	**.68**		
Substance use (4,11)	**.43**		
Using emotional support (5,15)			**.80**
Use of instrumental support (10,23)			**.81**
Use of behavioural disengagement (6,16)	**.76**		
Venting (9,21)	**.49**		.41
Positive reframing (12,17)		**.79**	
Planning (14,25)		**.71**	
Humour (18,28)		**.42**	
Acceptance (20, 24)		**.69**	
Religion (22,27)		.41	**.51**
Self-blame (13,26)	**.81**		
Variance Explained	24.65%	17.46%	11.36%

Factor loadings ≥.40 suppressed. **Bold** denotes items loading onto each factor.

Exeter Identity Transition Scales [B3, p88] . This social identity measure is currently in development at the University of Exeter and has been used with participants after stroke . It is split into two parts: the first asks participants to name the groups (up to six) that they considered themselves members of before and after their injury/onset of pain. Part two, contains 15 items which are then summed to produce the following subscales (min = 3, max =21): *multiple group memberships before injury* (items A1-3); *multiple group support before injury* (items A4-6); *maintenance of group membership post injury* (items B1-3); *new group membership post injury* (items B4-6)**;** *maintenance of support systems post injury* (items B7-9). The higher scores denote a higher amount of group memberships/group support pre and post injury. Haslam et al. (in press) report good internal consistency for the following scales: multiple group memberships before stroke (α= .89) multiple group support before stroke (α= .93), maintenance of group membership after stroke (α= .94) and new group memberships (α= .85).

WHOQOL-BREF [B3, p94] . This is the shortened version of the World Health Organisation Quality of Life assessment (WHOQOl-100). The WHOQOL-BREF has shown good to excellent internal consistency, test-retest reliability, discriminant validity and construct validity in healthy populations and other patient groups . It has also shown very good internal consistency (0.75 similar to 0.89) and test-retest

validity (0.74 similar to 0.95) in a TBI population . There is a continued debate around use of appropriate measures of QOL in brain injury populations . However, the WHOQOL-100/BREF has been suggested by Bullinger and The TBI consensus group (2002) as an important tool to consider and use in future research because of its comparability across countries and different health conditions.

The WHOQOL-BREF produces a profile with four domain scores, specifically: physical (Q3,4,10,15~18); psychological (Q5~7, 11,19,26); social (Q20~22); and environmental (Q8,9,12~14, 23~25). Domain scores were calculated by multiplying the mean of all facet scores included in each domain by a factor of 4 and then transforming them into a 0-100 scale (as detailed by the WHOQOL-BREF manual) with higher scores denoting higher QOL. A mean overall QOL was also computed in this current study using the domain scores .

The Satisfaction With Life Scale[B3, p93]

The total score of the SWLS is calculated by summing the individual responses to the five items (range 5-35). Scores between 5-9 denote people that are extremely dissatisfied with their life; 10-14 are substantially dissatisfied; 15-19 shows slightly below average dissatisfaction; 20-24 is an average score; 25-29 represents a high score and 30-35 represent people who are highly satisfied with their life. It has been shown to have internal consistency of .87 , test-

retest reliabilities of .84 and .54 (two and four-month intervals respectively) and has been used within TBI studies .

Hospital Depression and Anxiety Scale[B3, p92] .

This measure has been used in various clinical populations including stroke, TBI and chronic pain . It has been shown to have good internal consistency for both depression and anxiety subscales (.82 and .83 respectively) . Depression and anxiety are common psychological sequelae of TBI so it was important to include a measure of current mood .

Glasgow Coma Scale Score

The severity of a head injury is usually measured by several methods: the period of time between receiving a head injury and regaining continuous day-to-day memory for events (posttraumatic amnesia, PTA); the depth of unconsciousness, as measured by the Glasgow Coma Scale ; and the length of unconsciousness. Table 8 details the most widely accepted classification of injury, the Glasgow Coma Scale , which is used in current clinical practice as a reliable indicator of global outcome.

Table 8. Severity of head injury using Glasgow Coma Scale (GCS), length of unconsciousness and Post Traumatic Amnesia (PTA)

Severity	GCS Score	Length of	Length of

		unconsciousness	**PTA**
Mild	13-15	<15 mins	< 1 hour
Moderate	9-12	15 min-6 hours	1-24 hours
Severe	3-8	> 6 hours	1-7 days
Very Severe	N/a	N/a	1-4 weeks
Extremely Severe	N/a	N/a	> 4 weeks

METHOD (B3)

Test Materials Used

Background/Demographic Questionnaires:

Neuropsychological measures/questionnaire (ABI only)

*Psychosocial Questionnaires** 86

Appendix

***NOTE:** Space does not permit the enclosure of copies of all versions of the measures used. Enclosed in this Appendix are the ABI versions. In three measures, the wording was changed according to participant group. A note of each of the changes has been made below. However, copies of the excluded measures can be provided on request. Also please note that the wording represents that fact that we were expecting a traumatic orthopaedic sample rather than a chronic pain group.

Dysexecutive Questionnaire (DEX) from Behavioural Assessment of the Dysexecutive
Self-rated version included. Independent-rated version (not included) asks the same questions from a third person perspective.

Brief COPE
The words 'Head Injury' are replaced by 'Orthopaedic Problem' in the version for participants in the chronic pain group

Exeter Identity Transition Scales (EXITS)
The word 'injury' is replaced by 'orthopaedic problem' in the version for participants in the chronic pain group

BRIEF BACKGROUND QUESTIONNAIRE (Head Injury)

1. Gender: Male / Female

2. Age:

3. Where are you living now? (please circle)

Alone	With partner	With family

4. What is your current marital/relationship status?

Married	With partner	Single

5. When did you complete your education?

At age 16	
At 18 ('A' levels)	
At degree level	
Higher degree level	

6. What is your ethnic group?

Appendix

A. White	B. Mixed	C. Asian or Asian British	D. Black or Black British	E. Chinese or other ethnic group
☐ British	☐ White and Black Caribbean	☐ Indian	☐ Caribbean	☐Chinese
☐ Irish	☐ White and Black African	☐ Pakistani	☐ African	☐ Other
☐ Other	☐ White and Asian	☐ Bangladeshi	☐ Any other Black background	
	☐ Any other mixed background	☐ Any other Asian background		

Employment Status

1. What was your job before your head injury?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state your job title (if applicable):

_____

2. What is your current job?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state your job title (if applicable):

_____

Information about your head injury

Please turn over……..

1. How did you get your head injury?

Road traffic accident	Fall	Assault	Sports injury	Other

2. When was it? _____

Please briefly describe what happened:

3. Were you knocked unconscious?

Yes	No

4. How long for?		Less than 30 minutes
		30 minutes – 6 hours
		More than 6 hours

5. Did you have to spend time in hospital?	Yes	No
If yes, how long for?		
Inpatient stay: Outpatient Rehabilitation:		
6. Have you had epilepsy since your head injury?	Yes	No
7. Did you have any other injuries?	Yes	No
If 'yes' please describe them here:		

8. Have you had any other head injuries or strokes where you were unconscious?	Yes	No
If 'yes' please briefly describe them and include how long you were unconscious:		

Thank You

BRIEF BACKGROUND QUESTIONNAIRE (Head InjurySignificant Other)

1. Gender: Male / Female **2.** Age:

3. What is your relationship to your spouse/partner? (please circle)

Husband	Wife	Partner	Other (please state)

4 Are you living with your partner/spouse at the moment?	Yes	No
5 Were you living together ***before*** their head injury?	Yes	No
6 How long have been with your spouse/partner?		

Appendix

Education & Employment Status

1 When did your spouse/partner complete their education?

At age 16	
At 18 'A' levels	
At degree level	
Higher degree	

2. What was your spouse/partner's job before their head injury?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state their job title (if applicable):

_____

3. What is your spouse/partner's current job?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state their job title (if applicable):

_____

Information about the head injury

1. How did your spouse/partner get their head injury?

Road traffic accident	Fall	Assault	Sports injury	Other

2. When was it? _____

Please turn over….

Please briefly describe what happened:

3. Was your spouse/partner unconscious?

Yes	No

4. How long for?		Less than 30 minutes
		30 minutes – 6 hours
		More than 6 hours

5. Did they have to spend time in hospital?	Yes	No
If yes, how long for?		
Inpatient stay: Outpatient Rehabilitation:		
6. Has your spouse/partner had epilepsy since their head injury?	Yes	No
7. Did they have any other injuries?	Yes	No
If 'yes' please describe them here:		
8. Has your spouse/partner had any other head injuries or strokes where they were unconscious?	Yes	No
If 'yes' please describe them here:		

9. Have ***you*** ever been unconscious through a head injury?	Yes	No
If 'yes' please briefly describe what happened and include how long you were unconscious:		

Thank You

BRIEF BACKGROUND QUESTIONNAIRE (Orthopaedic Group)

1. Gender: Male / Female

2. Age:

3. Where are you living now? (please circle)

Alone	With partner	With family

4. What is your current marital/relationship status?

Married	With partner	Single

5. When did you complete your education?

At age 16	
At 18 ('A' levels)	
At degree level	
Higher degree level	

6. What is your ethnic group?

A. White
☐ British
☐ Irish
☐ Other

B. Mixed
☐ White and Black Caribbean
☐ White and Black African
☐ White and Asian
☐ Any other mixed background

C. Asian or Asian British
☐ Indian
☐ Pakistani
☐ Bangladeshi
☐ Any other Asian background

D. Black or Black British
☐ Caribbean
☐ African
☐ Any other Black background

E. Chinese or other ethnic group
☐Chinese
☐ Other

Employment Status

1. What was your job before the onset of your orthopaedic pain problem?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state your job title (if applicable):

_____

2. What is your current job?

Unemployed	Voluntary (unpaid)	Part-time paid work	Full-time paid work	Student	Retired

Please state your job title (if applicable):

_____

Please turn over……..

Appendix

Information about your orthopaedic pain problem

1. Please briefly describe the nature of your orthopaedic pain problem:

2. What was the cause of your orthopaedic pain problem?

Road traffic accident	Fall	Assault	Sports injury	Lifting injury	Unknown	Other (please state)

3. When was it? _____

If you can't remember exactly then please give approximate date

Please briefly describe what happened:

4. Did you have to spend time in hospital? Yes / No

If yes, how long for?

Inpatient stay: Outpatient Rehabilitation:

5. Did you lose consciousness when the injury occurred? Yes / No

If 'yes' please briefly describe what happened and include how long you were unconscious:

6. Have you **ever** been unconscious through a head injury? Yes / No

If 'yes' please briefly describe what happened and include how long you were unconscious:

Appendix

Thank You

Dysexecutive Questionnaire (DEX)

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Examples sheet with Trails B sample and Logical Memory 1 & 2 Stories

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Appendix

Brief COPE

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Appendix

Brief COPE

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See: Carver, C. S. (1997). You want to measure coping but your protocol's too long: Consider the brief COPE. *International Journal of Behavioral Medicine, 4,* 92-100.

Appendix

EXITS – Part 1

Appendix

EXITS – Part 1

Part A: Before your injury_____

Please answer the following questions about the groups you belonged to **before** your injury.

1. Before my injury I was a member of lots of different groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

2. Before my injury I was active in lots of different groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

3. Before my injury I had friends who were in lots of different groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

4. Before my injury I received support from members of lots of different groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

5. Before my injury I got practical help from members of lots of different groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

6. Before my injury members of lots of different groups helped me deal with my problems.

do not agree at all 1 2 3 4 5 6 7 agree completely

Part B: After your injury_____

Please answer the following questions about the groups you have belonged to **after** your injury.

1. After my injury, I still belong to the same group(s) that I was in before my injury.

do not agree at all 1 2 3 4 5 6 7 agree completely

2. After my injury, I am still active in the same group(s) that I was active in before my injury.

do not agree at all 1 2 3 4 5 6 7 agree completely

3. After my injury, I still have friends in the same group(s) that I was in before my injury.

do not agree at all 1 2 3 4 5 6 7 agree completely

4. After my injury, I have joined one or more new groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

5. After my injury, I am active in one or more new groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

6. After my injury, I have become friends with people in one or more new groups.

do not agree at all 1 2 3 4 5 6 7 agree completely

7. After my injury, I still receive support from the same group(s) that I was in before my injury.

do not agree at all 1 2 3 4 5 6 7 agree completely

8. After my injury, I still get practical help from the same group(s) that I was in before my injury.

do not agree at all 1 2 3 4 5 6 7 agree completely

9. After my injury, members of the same group(s) that I was in before my injury still help me deal with my problems.

do not agree at all 1 2 3 4 5 6 7 agree completely

Thank you very much for taking part!

Hospital Anxiety and Depression Scale

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Appendix

Satisfaction With Life Scale

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See: Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The Satisfaction With Life Scale. *Journal of Personality Assessment, 49,* 71-75.

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WHOQOL-BREF

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WHOQOL-BREF

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Example Communication Aid (for Brief COPE)

1 = I haven't been doing this at all

2 = I've been doing this a little bit

3 = I've been doing this a medium amount

4 = I've been doing this a lot

METHOD (B4)

Recruitment Procedures

Different recruitment procedures were used in this study, the details of which are below.

Acquired Brain Injury Group. Participants in this group were accessed via the charity Headway Devon and attended one of five day centres across Devon. The managers in each centre were briefed

on the research by Headway Devon and the researcher; including the inclusion/exclusion criteria (see manuscript, p13). From this, a list of potential participants was drawn up for each centre; who were approached by the managers to see if they would be interested in finding out more about the study.

The researcher met with interested people individually, to give a full description of the study using the information sheet[D3, p134]. Due to the potentially vulnerable nature of these participants, care was taken to check for levels of understanding, in line with the Mental Capacity Act 2005.

If people were interested in taking part, and the researcher was satisfied with levels of understanding, written consent [D3, p137] was obtained in compliance with the Mental Capacity Act 2005. A date and time was then arranged to start completing the research materials[B3]. If this was not on the same day or the participant had trouble remembering the details of the study, the procedures above were revisited.

Data collection for participants with ABI, took between one and a half and four hours (with breaks) per person depending on cognitive abilities. Subsequently, data collection for this group took place over 30 days (centres were open from 10am-4pm).

Appendix

Significant Other for ABI Participants. Once the ABI participants had taken part in the study, they nominated a person who knew them well, usually a partner (n = 15) or family member (n = 8) but for a minority this was a Headway member of staff (n = 7). This person filled in additional information on their behalf including a demographic information form and the DEX questionnaire. The nature of what was being sent was fully discussed with the head injured participant before research pack was sent out[B3; D2, p131; D3, p133]. Of 30 packs sent out, 25 were received. If packs were not received, permission was sought for Headway staff to provide the information instead.

Chronic Pain Group. Participants in this group were accessed via the Superintendent Physiotherapist with the Pain Management Team at the Royal Devon and Exeter Hospital. Ethical Approval was granted by Somerset Research Ethics Committee and Research approval by the Royal Devon and Exeter NHS Foundation Trust[D1, p120,123]. Invitation letters [D2, p128] were sent out from the Superintendent Physiotherapist to people who had received the service and fitted the inclusion criteria (see manuscript, p 14). Those who gave consent to be contacted by sending back a tear off slip providing their contact details, were sent a research pack[B3; D2, p129; D3, p133].

Appendix

METHOD (B5)

This section contains a priori power calculations and a discussion about post hoc power calculations for this study. It also contains the rationale for including additional hypotheses not originally included in the research proposal.

Power Analyses

Statistical power is the probability of avoiding a Type 2 error . It depends on several factors including the type of test, the effect size, the design, the alpha level set, whether the test is one- or two-tailed and the relative size of the samples .

In order to determine the required sample size, power calculations were completed for each hypothesis at the design stage. As there are no relevant studies stating effect size in the literature, power was calculated using tables . Power of 0.8 (or 80%) is recommended as an acceptable level .

A Priori Power Calculations

> *Hypothesis 1a. There will be a difference between the ABI group and the chronic pain group on group maintenance and new group membership post injury/onset.*

For a between subjects design and a two-tailed t-test, with 80% power, using a standard .05 alpha level and a medium effect size

(d=0.5) , the total number of participants needed was calculated to be just over 60 in each group[1] .

Hypotheses 1b-d. Multiple regressions were planned to address Hypotheses 1b-d. The literature on calculating sample size in regression analyses was conflicting and advice was sought from supervisors at the university and from statisticians at a local Research and Development and Support Unit. The consensus at the time of the design stage was as Van Belle suggests; for power analysis using multiple regression, you should 'obtain at least ten subjects for every variable investigated' (p87). This was also echoed in a recent study on TBI and QOL "to ensure adequate power and to minimize the potential for overfitting the model…a conservative n-to-k (cases to variables) ratio of at least 10:1 [was used]" (p893). Therefore, the number of participants needed was calculated using these criteria (see Table 9).

Table 9. **A priori power analysis for hypotheses 1b-d, detailing number of participants needed**

Hypothesis	Outcome Variables	Predictors Variables	Total number of participants needed
1b *Hypothesis 1b. There will be an association between the overall level of cognitive functioning in the ABI group and maintenance of group membership.*	Maintenance of groups	1. Coping – maladaptive, problem-focused, support-seeking 2. Severity of injury (overall cog functioning) 3. Time since injury 4. Multiple group membership pre 5. Age 6. Gender	60

[1] At the design stage, the researcher's inexperience with power calculations, led them to mistakenly believe that this number (n=60) represented the total number of participants needed; not, as is correct, total per group (therefore N=120). Unfortunately, this was not picked up by the marking process and so the planned number of 60 participants went uncorrected. Otherwise the study would not have been viable in the time scale planned. This was an important learning point.

1c *There will be a relationship between maintenance of group membership post injury/onset and using specific coping strategies (maladaptive, problem-focused, support-seeking)*	Coping: maladaptive, problem-focused, support-seeking	1. Maintenance of group membership 2. Severity of injury (overall cog functioning) 3. Time since injury 4. Multiple group membership pre 5. Group (ABI/Con) 6. Gender	60
1d *Maintenance of group membership post injury/onset will be associated with overall quality of life (WHOQL-BREF), life satisfaction (SWLS) and mood (HADS) in both groups*	QOL, life satisfaction mood	1. Multiple groups pre 2. Maintenance of groups 3. Group (ABI/CP) 4. Age 5. Time since injury 6. Severity of injury (mild, mod, sev)	60

Post Hoc Power Calculations

When exploring the data prior to main analysis it became apparent that the data for the EXITS measure did not fit with the assumptions needed for parametric analysis[C1, p106]. Therefore, multiple regressions were no longer suitable for testing the hypotheses. For Hypothesis 1a, the non-parametric equivalent of the t-test, the Mann-Whitney test was substituted to explore the hypothesis. For Hypotheses 1b-d, Spearman's correlations still allowed the original hypotheses to be explored.

It is recognised by the researcher that post hoc power calculations are desirable to compute the actual power of the study using participant numbers and effects sizes from the collected data. However, with non-parametric tests, literature searches and investigations failed to find post hoc power calculation equations.

Perhaps this is because as Field states that you cannot calculate power for non-parametric tests because it is linked to the Type 1 error rate which is based on normal distributions (p.534).

Hypotheses 2 and 3. These were not originally primary hypotheses for this study, so power calculations were not performed at the design stage (see below).

Rationale for Introducing Secondary Hypotheses

Due to the concerns regarding the EXITS measure and the subsequent disappointing primary results [C1, p108] it was decided that it would be interesting to expand the hypotheses in two areas. As can be seen from the introduction, coping style has been associated with QOL life, life satisfaction and mood in ABI groups. The researchers wanted to explore whether this trend could also be seen in this study's data, which could provide more support for the current evidence base.

Hypothesis 2a: Adaptive coping strategies (support-seeking and problem-focused coping) will be positively associated with improved psychological outcome in quality of life (WHOQOL-BREF), life satisfaction (SWLS) and mood (HADS) in both groups.

Hypothesis 2b: Maladaptive coping strategies will be negatively associated with poorer psychological outcome in quality of life

(WHOQOL-BREF), life satisfaction (SWLS) and mood (HADS) in both groups.

Also, evident from the literature was the discrepancy between findings regarding the impact of neuropsychological variables on coping. Therefore, it was decided that it would be interesting to include an exploratory hypothesis about neuropsychological variables and coping.

Hypothesis 3: There will be a relationship between neuropsychological variables (overall cognitive functioning; executive functioning; memory; self/other reported executive functioning; and insight) and using specific coping styles in the ABI group.

Using Bonferroni corrections in the results section helped to reduce the likelihood of Type 1 errors due to multiple comparisons.

RESULTS (C1)

Data Analysis and Screening

Prior to data analysis the data were examined for accuracy of data entry, missing values and fit between their distributions and the assumptions of parametric analysis. Accuracy of input was checked using frequency and descriptive tables, histograms and box plots, specifically looking for out of range values, implausible means and univariate outliers. No outliers were found.

Five chronic pain cases within the EXITS measure reported that they did not belong to any groups, pre or post onset of pain, and therefore these cases were removed from analyses involving this measure. For all other psychosocial measures, excluding the EXITS, the missing data was identified (4 data points). As there were so few missing values, they were replaced with the average score for that variable . There was no more than one missing data point per variable.

The data were checked against the assumptions for parametric tests:

- The data are normally distributed

- The data have homogeneity of variance
- Data were measured at least at the interval data
- Data were gathered independently

This included an examination of histograms, calculation of the Kolmogorov-Smirnov statistic and calculations of skewness and kurtosis . Z-scores were created for kurtosis and skewness figures (e.g. zskewness = skewness value – 0/SE skewness) to check for p values indicating that significant violations had occurred . Specifically, for skewness and kurtosis, z-scores $\geq$1.96 = p$\leq$.05 and $\geq$2.58 = p$\leq$.01 . Analysis revealed that the majority of the variables did fit with the assumptions for the use of parametric tests. However, some data did not fit the above criteria, specifically the EXITS measure, some neuropsychological variables and the maladaptive coping scale (see Table 10).

Table 10. Shows skewness, kurtosis and Kolmogorov-Smirnov statistics for data that violated parametric assumptions.

	Skewness (z-score)	**Kurtosis** (z-score)	**Kolmogorov-Smirnov**
Multiple group support pre (EXITS)			
ABI	.34 (z = .80)	-1.14 (z = -1.37)	.13 (p = .18)
Chronic Pain†	.66 (z = 1.42)	-.52 (z = .58)	.21** (p = .008)
Maintenance of group memberships post (EXITS)			
ABI	1.03* (z = 2.41)	.27 (z = .32)	.19** (p = .006)
Chronic Pain†	.64 (z =	-1.15 (z =	.17 (p = .06)

	1.38)	1.27)	
New group memberships post (EXITS)			
ABI	-1.15** (z = -2.69)	1.30 (z = 1.56)	1.55 (p = .07)
Chronic Pain†	1.12* (z = 2.41)	-.31 (z = -.34)	.28** (p = .000)
Maintenance of group support post (EXITS)			
ABI	.46 (z = 1.08)	-1.23 (z = -1.48)	1.56 (p= .06)
Chronic Pain†	.84 (z = 1.81)	-.59 (-.65)	.21** (p = .005)
Maladaptive Coping (Brief COPE)			
ABI	1.11** (z = 2.60)	.78 (z = .94)	.14 (p = .14)
Chronic Pain	1.03* (z = 2.41)	.40 (z = .48)	.17* (p = .024)
DEX-other *(ABI only)*	1.10** (z = 2.58)	.96 (z =1.15)	.50 (p =.10)
Mean memory score (scaled scores) *(ABI only)*	-.34 (z = -.80)	-1.06 (z = -1.27)	.19** (p =.008)
Insight (DEX discrepancy score) *(ABI only)*	.96* (z = 2.25)	-.10 (z = -.12)	.18* (p =.02)

*z-score ≥1.96 = p≤.05 ** z-score ≥2.58 = p≤.01 † with five cases deleted.

Log, square root and reciprocal transformations of the data were attempted, however these did not affect the non-normal distribution for the large majority of skewed data. It was decided to leave the data as it was and to use non-parametric analysis where applicable (indicated in the manuscript). This decision was taken because: transformations did not work for all variables; and transformed data

meant that a different construct was addressed to the one originally measured, making them unhelpful for interpretation especially when the measures concerned have been widely used .

EXITS Measure

During the data collection, concerns arose about the validity of the EXITS measure when used with this population. During data collection for the ABI participants, the use of a face-to-face semi-structured interview was needed to help them understand and respond to the questions. This was how the measure had been successfully used in previous studies . The main problem noted was that people found the idea of social identity difficult to conceptualise and often just listed a number of hobbies including solitary activities. With face-to-face contact it was easy for the researcher to clarify, however this was not the case for the data collected via the postal questionnaires that went to the chronic pain group. Subsequently, a number of questionnaires came back with large amounts of missing data (n=5) and also people noted groups which appeared to represent hobbies (e.g. reading) rather than groups of people (e.g. book club). This led to concerns about the validity of using the EXITS as a postal measure which was fed back to the developers of the measure.

As already discussed, the majority of the EXITS data violated non-parametric assumptions adding further concern. However the alpha

levels for the scales were high (α = .80 to .94) and comparable with a previously published study , so it was decided to continue to use the measure but to exercise caution when interpreting the results.

Analytic Strategy.

For hypotheses involving the social identity measure (EXITS), multiple regressions were planned prior to data collection. However, because the data violated parametric assumptions, Spearman's Rho correlations were judged to be the most appropriate way of testing the original hypotheses and considering sample size.

Multiple Significance Testing

Using multiple comparisons within a single analysis increases the chance of committing a Type 1 error, this risk was reduced by using the Bonferroni correction. Each test conducted took the set alpha level (0.05) and divided this by the number of tests conducted. This creates significant reductions in the alpha level and can increase the likelihood of Type 2 errors. There is continued debate around whether the Bonferroni correction or alternatives should be used or not, especially with small sample sizes and in exploratory studies . In this study, the Bonferroni correction was used because of the reliance on multiple correlations and the popular current use in published studies of a similar nature . Both unadjusted and adjusted p-values have been reported where possible, so those results which may have just failed to reach the adjusted significance are apparent.

RESULTS (C2)

The following section includes further detail about the results of the neuropsychological tests untaken by the ABI group including data on percentile ranks. Additionally, it provides more detail about the creation of mean z-scores.

Cognitive Functioning in ABI group

Overall Cognitive Functioning. The scores for the neuropsychological tests show that the majority of ABI participants are scoring in the impaired or low ranges of the neuropsychological tests compared to test norms (see Table 11)

COWAT. Scores were adjusted for age and years of education .

Trails Part B. Scores were adjusted for age . It is important to note that some participants could not attempt the Trails B task as they lacked the motor skills to do so, e.g. paralysis of their writing hand or inability to hold a pencil (n = 7).

Appendix

Logical Memory 1 and 2. Scores were converted into scaled scores and also converted into percentile ranks in the table below for comparison with other measures.

Procedure for allocation of mean overall cognitive scores for ABI participants

A large number of individuals were scoring below the range of published norms tables and in a range expected with people with moderate to severe head injuries. Therefore, it was decided to compare participants on cognitive functioning in relation to other ABI participants in this study. As such, ABI participants were allocated a mean overall cognitive score on the basis on their scores on the cognitive assessments given as an indication of severity of cognitive functioning (Trails B, COWAT, Logical Memory 1 & 2).

The raw scores on the neuropsychological tasks were made comparable by transforming them into standardised z-scores (z score = raw test score-mean test score/SD). The z-scores from the four neuropsychological tests were then averaged to create a single composite z-score for severity of injury.

For the cases where Trails B (n=7) was not completed, the average of the remaining three z-scores was used. The data was checked to make sure that not completing the Trails B task did not disadvantage overall z-scores for those participants. This was done by ranking all

participants with and without their Trails B score included and visually checking the data.

Before calculating the z-score for the Trails B task, scores needed to be transformed to match the direction of the other test scores. The scoring for Trails B meant that the higher raw score (seconds to complete the task), the more impaired a participant was. This was inversely proportionate to the other neuropsychological scores and needed to be adjusted before a composite z-score for all tasks could be obtained.

The cut-off score of 300secs was used to transform the raw scores into reversed scores (i.e. 300s = 0; 299s = 1). For example, if a participant scored 94secs on the Trails B their adjusted number would be 206 (300s - 94 = 206). Now higher scores on the Trails indicated better performance in accordance with the other measures.

Table 11. Summary of percentile ranks on neuropsychological tests for ABI group

Test	Percentile Rank % of ABI group scoring in this range (n)								
	<10th	**10th**	**20th**	**30th**	**40th**	**50th**	**60th**	**70th**	**80th**
COWAT	40 (12)	26.7 (8)	13.3 (4)	13.3 (4)	-	6.7 (2)	-	-	-
Trails B	*	*	≤ 20th	-	-	-	3.3 (1)	3.3 (1)	3.3 (1)

Appendix

				66.7					
				(20)					
Logical Memory 1	43.3 (13)	3.3 (1)		10 (3)	23.3 (7)	10 (3)	3.3 (1)	-	6.7 (2)
Logical Memory 2	37.9 (11)	6.9 (2)	6.9 (2)	27.6 (8)	10.3 (3)	10.3 (3)	-	-	-

* adjusted scoring started at 20th percentile .

RESULTS (C3)

This section provides more detail on comparisons between the ABI and chronic pain groups that could not be included in the main manuscript.

Comparison Between Groups

Comparison between groups for demographic information. Prior to the main data analyses, the ABI and chronic pain groups were compared against demographic variables. Independent t-tests showed no significant differences between the chronic pain and ABI groups for age ($t(58)= 0.64$, $p = .52$), years of education ($t(58) = -1.57$, $p = .12$) or time since injury/onset of pain ($t(58) = .76$, $p = .45$).

However, there was a significant association between gender and group $\chi^2(1) = 5.41$, $p = .038$. This finding is representative of what one would expect in these clinical populations. Data for traumatic brain injuries suggest that men sustain injuries about twice as

frequently as women , whereas in chronic pain conditions women are more likely to report problems .

Comparisons between groups on variables measured. On average the ABI group reported better physical quality of life (M = 52.14, SE = 2.99) than the chronic pain group (M = 42.62, SE = 3.06).This difference was significant $t(58) = 2.23$, p= .03 and represented a small sized effect r = .28. However, this was not significant at the more conservative adjusted alpha level.

Adjusted alpha levels. The adjusted alpha level for the above comparisons, was set at 0.0025 (0.05/20). This number was calculated using the total number of variables that were compared between the two groups in the study, including demographic variables (n=20).

Appendix

RESULTS (C4)

There were some important results that were non-significant using the adjusted alpha, therefore not as relevant for the main text but are important to consider to avoid making a Type 2 error; these are discussed here. The impact of demographic variables on coping is also explored in more detail.

Main Results

Demographic Variables and Coping. Although not conclusive, some demographic variables have been shown to influence coping styles (main manuscript, p5). Therefore it was decided to analyse the relationships between age, gender, time since injury and years of education with coping style, so that the impact of demographic variables could be considered when analysing the other variables (see Table 12). None of the relationships found remained significant at the adjusted alpha level (ABI = .0027; CP = .0041)

Table 12. Pearson's and Spearman's correlations showing the relationships between demographic variables and coping style

	Group	Maladaptive		Support-seeking		Problem-focused	
Age	ABI [a]	-.16 [ρ]	p=.41	-.15 [r]	p=.43	.14 [r]	p=.48
	CP [b]	-.16 [ρ]	p=.40	.004 [r]	p=.98	-.21 [r]	p=.27

Gender (male=1, female=2)	ABI [a]	.27 [ρ]	p=.15	.05 [ρ]	p=.80	-.09 [ρ]	p=.64
	CP [b]	-.50** [ρ]	p=.005	.20 [ρ]	p=.29	.09 [ρ]	p=.63
Time since injury	ABI [a]	-.10 [ρ]	p=.60	-.28 [ρ]	p=.13	.25 [ρ]	p=.19
Years of education	ABI [a]	.10 [ρ]	p=.62	.12 [ρ]	p=.54	.38* [ρ]	p=.04
	CP [b]	-.40* [ρ]	p=.03	.06 [ρ]	p=.76	-.17 [ρ]	p=.36

[a] adjusted alpha set at .0027(.05/18) [b] adjusted alpha set at .0041 (.05/12)
* p<.05 **p<.01 *** **significant at adjusted alpha levels.**
[ρ] = Spearman's correlation [r] = Pearson's correlation

Coping and Quality of Life, Life Satisfaction and Mood. Using Bonferroni corrections significantly reduces the alpha levels and can increase the likelihood of Type 2 errors **[C1, p109]**. As can be seen in the main results section (see Table 4, p27), there are a number of hypotheses that do not meet the more stringent adjusted alpha levels, but would be considered significant at the standard levels (p<.05 and p<.01). It is especially important to avoid making a Type 2 error considering that this study already has limited power influenced by small sample size and type of analysis. It is important to draw out these results because they may still be factors to consider in further confirmatory studies. Therefore, the following results reported are significant at p<.05 or p<.01 but not significant at the adjusted alpha levels (ABI = .0027 .05/18; CP = .0041). Significant results already reported in the manuscript will not be reported again here.

Hypothesis 2a: Support-seeking and problem-focused coping strategies will be positively associated with improved psychological outcome in quality of life, life satisfaction and mood in both groups.

Support-seeking was negatively correlated with anxiety scores (r = -.37, p = .02) and depression scores (r = -.41, p = .01) in the chronic pain group only. Therefore the use of more support seeking-strategies, were correlated with better mood in the chronic pain group. Additionally, there was a positive relationship between increased use of support-seeking strategies and improved psychological QOL in the chronic pain group (r = .45, p = .007) and increased use of support-seeking strategies and improved social QOL (r = .48, p = .004) and improved life satisfaction (r = .31, p= .05) in the ABI group

Problem-focused coping was negatively correlated with depression in the chronic pain group (r = -.32, p = .04) but positively correlated with psychological QOL in the ABI group (r = .34, p = .03). So there was a relationship between the increased use of problem-focused coping and lower levels of depression in the chronic pain group. There was also a relationship between the increased use of problem-focused coping and improved psychological QOL life scores in the ABI group.

Hypothesis 2b: Maladaptive coping strategies will be negatively associated with quality of life, life satisfaction and mood in both groups.

Appendix

In the ABI group, maladaptive coping was negatively correlated with psychological QOL (r_s = -.50, p = .003), environmental QOL (r_s = -.38 , p =.02) and life satisfaction (r_s = -.40, p = .01) and positively correlated with higher depression scores (r_s = .35, p = .03). In the chronic pain group, maladaptive coping was negatively correlated with psychological QOL (r_s = -.38, p = .02).

To summarise, there was a relationship between increased use of maladaptive coping and poorer scores on environmental and psychological QOL, life satisfaction and depression in the ABI group, whereas in the chronic pain group, there was a relationship between increased use of maladaptive coping and only poorer scores on the psychological domain of QOL.

Appendix

ADDITIONAL PROJECT DOCUMENTATION (D2)

Invitation Letters to Participate in Study

Royal Devon and Exeter NHS
NHS Foundation Trust

Royal Devon and Exeter
Hospital (Wonford)
Barrack Road
Exeter
EX2 5DW

Tel: 01392 411611

Pain Management Team

Direct dial: 01392 403536
Direct fax: 01392 402576

Date:

Dear

We have been asked by a Trainee Clinical Psychologist, Georgina Gray, to assist in her research for her doctorate degree.

Georgina is interested in the types of social groups that people belong to and whether this affects how people cope and how they feel after chronic health problems. The project would involve filling out some questionnaires, which ask about social groups, coping strategies and quality of life.

Georgina would like to contact people who have been seen in our Pain Management Service, so we are initially contacting you on her behalf. If you are prepared to consider taking part and have no objection to Georgina contacting you, then please complete the tear-off slip below and return it in the enclosed pre-paid envelope as soon as you can. Georgina will then send you out an information pack for you to consider. If you do not wish Georgina to contact you please ignore this letter.

Yours sincerely,

Jonathan Blood-Smyth BSc (Hons.) MCSP, SRP
Superintendent Physiotherapist

.....✂.....

Appendix

I ..... agree to Georgina Gray contacting me to possibly participate in her research for her doctorate degree.

Name.....(please print)

Address.....

Version 1.1
11th July 2007

SCHOOL OF PSYCHOLOGY
DOCTORATE IN CLINICAL AND COMMUNITY PSYCHOLOGY
Washington Singer Laboratories
Perry Road
Exeter
UK EX4 4QG

Telephone +44 (0)1392 264695/262459
Fax +44 (0)1392 264623
Web
www.exeter.ac.uk/psychology

Dear

Re. Participation in a Research Study

Study title: "The impact of social identity and coping on quality of life after acquired brain injury (compared to people with orthopaedic problems)"

I am contacting people between 18-64 years old who have experienced orthopaedic problems and been seen at the Royal Devon and Exeter Hospital. This is why I am writing to you.

The purpose of this study is to find out whether there are any changes in the types of social groups that people belong to (social identity) and whether this affects how people cope and how they feel after an injury. Specifically, I am interested in two groups of people; those who have experienced a head injury and those who have experienced orthopaedic problems (chronic pain of Musculoskeletal origin) not involving the head.

To be able to take part you must:

1. Not have had a head injury (causing a loss of consciousness) at anytime.
2. Give your consent to take part
3. Be able to read and write in English

Inside this pack you will find everything you need to participate in this project. The information sheet (blue sheet) is enclosed explains the project in detail and tells you what it involves. Please read this carefully before you decide whether to take part or not.

If you would like to take part, please:

1. Read and sign the consent form (green sheet)
2. Complete the questionnaires as best you can. Try to answer all of the questions and be sure to turn the pages over.
3. Send the completed questionnaires and the consent form back to me in the **FREEPOST** envelope provided as soon as you are able. Keep the information sheet for your records.

If you are unable to take part or do not want to take part, you do not need to do anything and you will not be contacted again.

This study is part of my doctorate qualification in Clinical and Community Psychology.

If you have any questions or concerns about the project, please feel free to contact me on 01392 264695 and leave a message for me, giving a time when I am likely to be able to speak to you. I will call you back as soon as I am able.

Thank you for your time and for considering taking part in the project.

Yours sincerely,

Georgina Gray (Trainee Clinical and Community Psychologist)

Appendix

Version 3 8th July 2007

SCHOOL OF PSYCHOLOGY
DOCTORATE IN

CLINICAL

AND COMMUNITY PSYCHOLOGY
Washington Singer Laboratories
Perry Road
Exeter
UK EX4 4QG

Telephone +44 (0)1392 264695/262459
Fax +44 (0)1392 264623
Web www.exeter.ac.uk/psychology

Dear

Re. Participation in a Research Study

Study title: "The impact of social identity and coping on quality of life after acquired brain injury"

I am conducting the above study as part of my doctorate qualification in Clinical and Community Psychology.

The purpose of this study is to find out whether there are any changes in the types of social groups that people belong to (social identity) and whether this affects how people cope and how they feel after a head injury.

For this study I need to gather information from adults who have experienced a head injury and Headway Devon has allowed me to access people through their centres across Devon. has consented to take part in this study and I have been to the Headway centre and completed some questionnaires with him/her already. To help me with the research it is also important to have a small amount

of information from someone who knows him/her well. He/she has suggested that you would be the best person and that is why I am contacting you.

Inside this pack you will find everything you need to participate in this project. The information sheet is enclosed explains the project in detail and tells you what it involves. Please read this carefully before you decide whether to take part or not.

If you would like to take part, please:

1. Read and sign the consent form
2. Complete the questionnaires as best you can. Try to answer all of the questions and be sure to turn the pages over.
3. Send the completed questionnaires and the consent form back to me in the **FREEPOST** envelope provided as soon as you are able. Keep the information sheet for your records.

If you are unable to take part or do not want to take part, you do not need to do anything and you will not be contacted again.

If you have any questions or concerns about the project, please feel free to contact me on 01392 264695 and leave a message for me, giving a time when I am likely to be able to speak to you. I will call you back as soon as I am able.

Thank you for your time and for considering taking part in the project.

Yours sincerely,

Georgina Gray (Trainee Clinical and Community Psychologist)

Appendix

Version 1 15th July 2007

ADDITIONAL PROJECT DOCUMENTATION (D3)

Project information sheet and consent form

Project Information Sheet

Example Information Sheet for ABI Group 134

Consent Form

Example Consent Form for ABI Group 137

NOTE: The information sheets and consent forms for the significant other group and chronic pain group are not included due to word count limitations. The information sheets are very similar, with wording changes to make the information relevant to each group. The consent forms are identical, except for the exclusion of point 5. These are available on request.

Appendix

SCHOOL OF PSYCHOLOGY
Doctorate in Clinical and Community Psychology, Washington singer Laboratories, Perry Road, Exeter, EX4 4QG.
Tel: 01392 264695 Fax: 01392 264623

INFORMATION ABOUT THE RESEARCH

Head Injury Group

Study Title:
The impact of social identity and coping on quality of life after acquired brain injury.

Name of Researcher: Georgina Gray

I would like to invite you to take part in this research study. Before you decide, it is important that I explain why the research is being done and what it would involve for you.

Please read the following information carefully and talk to other people about it if you want to. If you would like further information please contact Georgina Gray (contact details on page 2).

What is the purpose of this study?

Experiencing a traumatic brain injury can affect people in many different ways and it may result in changes to their life.

The purpose of this study is to find out whether there are any changes in the types of social groups that people belong to (social identity) and whether this affects how people cope and how they feel after head injury.

It is hoped that the results can be used to help us understand the consequences of head injury in more detail and inform services about how they can further support people with a head injury.

Why I would like you to take part?

For this study I need to gather information from adults who have experienced a head injury. Your name was given to me by [Centre Manager] from Headway because [s/he] thought you might be interested in taking part.

To do this I need some information from people with head injuries. I also need a small amount of similar information from their partners or significant others. The information from your partner/significant other helps me to get another view about changes in you since your injury which is also important after anyone experiences a head injury.

What will happen if I take part?

Please Turn Over …

If you agree to take part, I will arrange a time and date to come and see you in a private room at the [Headway Centre]. We will decide together how to structure the interview around your needs, for example how long to meet for and when to take breaks. However, it is important to complete all the questionnaires on the same day if possible.

During the interview you will be asked to complete a number of different questionnaires and measures. Some can be completed by you and some I will complete with you. We can talk about what level of support you might need in completing the questionnaires so it suits you.

I will be present at all times to help you with any queries about what you have to do.

If you agree to take part I will also ask your permission to access your medical records. This will be done by a practicing Clinical Neuropsychologist (Phil Yates) involved in this study. He will only access the information which refers to the level of head injury you

received. This should have been recorded by doctors at the time of your head injury and is called a Glasgow Coma Score.

This score is important to this study because it helps us understand the severity of your injury and allows us to make comparisons between people who have experience mild, moderate and severe injuries.

I will also ask you to complete a few short tests of thinking that will help to give us a better picture of your current level of difficulties. These are tests that assess different aspects of brain function for example memory and attention.

Who is conducting the study?

Researchers: Georgina Gray, Trainee Clinical Psychologist (01392 264695)
Dr. Rachel Baron, Research Tutor (01392 264695)
Dr. Huw Williams, Clinical Neuropsychologist (01392 264695)
Dr. Phil Yates, Clinical Neuropsychologist (01392 264695)

Address: University of Exeter
School of Psychology
Washington Singer Laboratories
Perry Road
Exeter EX4 4QG

Potential risks and ethical considerations.

The major disadvantage in taking part in this study is the time needed to complete all the questionnaires. There are no known risks in taking part in this study. We are not knowingly asking you any upsetting questions, however, if you become concerned or distressed by any of the issues covered we can take a break at any time or you can contact Dr Huw Williams (details above).
We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with brain injuries.

Please Turn Over …

The research is part of a Doctorate degree in Clinical and Community Psychology at the University of Exeter and as such it has been checked and approved by Local NHS Research Ethics Committees.

Confidentiality

The information that you provide during the study will be kept strictly confidential. Your data will be stored securely on computer and in a locked filing cabinet. Only myself and my research tutors named above

will have access to the data that you supply. All the information you supply has a code and not your name so you will remain anonymous.

In some rare occasions not all the data collected will be used in the final results, this could be for a number of different reasons. However it will be treated with the same confidentiality as described above.

Your name and any other identifying information will not be used when writing up the research for publication or presentation.

What will happen to the results of the study?

The findings of the study will be made available to anyone who takes part and shared with the services directly involved. The researcher will also write up the study as part of her degree requirements and would also like to publish the work in an academic journal.

Do I have to take part?

It is up to you to decide. You do not have to take part in the study. If you decide to take part then please sign the attached consent form and return it in the envelope provided.

You are free to withdraw at any time, without giving a reason. If you decide not to take part, or you decide to withdraw at any time your decision will not affect your rights or the care you receive.

Please keep this information sheet for your records.

How do I find out more?

If you would like to find out more about the study or have any questions, please feel free to contact Georgina Gray (details above).

Thank you for your time,
Georgina Gray (Trainee Clinical and Community Psychologist)

Version 3.2 1st June 2007

SCHOOL OF PSYCHOLOGY

Consent Form to Participate in a Research Study – Head Injury
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Project Title:

Appendix

The impact of social identity and coping on quality of life after acquired brain injury.

Name of Researcher:
Georgina Gray, DClinPsy Student, School of Psychology, University of Exeter

Thank you for agreeing to take part in this study. Please read the statements below and place your initials in the boxes to confirm that you agree to take part. Please return 1 copy of this form to the researcher.

Please initial/tick boxes

1. I confirm that I have read and understood 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 that I am free to withdraw at any time without giving any reason. If I withdraw from the study my rights and care will not be affected. ☐
3. I understand that the information I provide will be stored securely on a computer and in locked filing cabinets. Only the researcher and research supervisors will have access to the information. ☐
4. I agree to take part in the above study. ☐
5. I agree to the researcher obtaining only my GCS score from my medical records ☐

I would like to receive a written summary of the results. YES / NO

_____ _____ _____

Name of Participant (*please print clearly*) Date Signature

1 copy for the participant; 1 copy for the researcher

Version 2.4 1st June 2007

DISSEMINATION STATEMENT (E1)

Information for Participants

As part of the consent form each participant will be asked to indicate whether they would like to receive a brief written summary of

results. Participants who respond ‘yes’ to this question, will receive a brief summary in a relevant and accessible format. For the chronic pain group, this information will be sent out via the post with a contact phone number for any questions. For the ABI group, a summary sheet will be produced, as well a verbal presentation of the results to participants at each Headway centre. Significant others for the ABI participants will receive a written summary. Every effort will be made to ensure that all medical and psychological terminology is explained.

Information for Services and Service Providers

Interested professionals from the various services that took part in recruiting for this study will be invited to receive feedback in the form of a summary document and a short presentation. These include Headway Devon staff and the Pain Management Service at the RD&E Hospital.

Wider Dissemination

The findings from this study will be submitted for publication in Neuropsychological Rehabilitation. The researcher will also give a 20 minute research presentation to peers and course staff. An abstract has also been accepted for a presentation at the International Neuropsychological Society’s fifth Satellite Symposium on Neuropsychological Rehabilitation on the 7thand 8th July 2008.

Appendix