



## A social identity approach to acquired brain injury (ABI)

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A Social Identity Approach to Acquired Brain Injury (ABI)



**UNIVERSITY *of* LIMERICK**

**OLLSCOIL LUIMNIGH**

**‘A Social Identity Approach to Acquired Brain Injury (ABI)’**

**R. Stephen Walsh**

**Degree of PhD in Psychology**

**University of Limerick**

**Supervised by Dr. Stephen Gallagher; Professor Orla Muldoon;**

**Submitted to the University of Limerick, December 2014**



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **List of papers**

Walsh, R. S., Fortune, D. G., Gallagher, S., & Muldoon, O. T. (2014). Acquired brain injury: combining social psychological and neuropsychological perspectives.

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Walsh, R.S., Muldoon, O.T., Gallagher, S., & Fortune, D.G., (in press) 'Affiliative and 'self as doer' identities: relationships between social identity, social support, and psychological well-being amongst survivors of acquired brain injury (ABI).' *Neuropsychological Rehabilitation*

Walsh, R.S., Gallagher, S., Fortune, D.G, & Muldoon, O.T., (submitted). 'An investigation of relationships between cause, disability, stigma, survivor identity and quality of life following Acquired Brain Injury (ABI)'.

Walsh, R.S., Muldoon, O.T., Fortune, D.G., & Gallagher, S. (submitted). 'A longitudinal study of relationships between self-categorization, consistency of identification and anxiety following acquired brain injury (ABI)'.

### **Conference presentations**

Walsh, R.S., Gallagher, S., Muldoon, O.T., Fortune, D.G., (2014, June) Active and affiliative identities: Investigating relationships between social identity, social support, anxiety and depression amongst survivors of brain injury. International Conference on Social Identity and Health, Ottawa.

Walsh, R.S., Fortune, D.G., Gallagher, S., Muldoon, O.T. (2014, May) Active and affiliative identities: A mediation model investigating relationships between identity,

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

social support, and psychological well-being amongst survivors of brain injury and the general International Brain Injury Association (IBIA) Conference, San Francisco.

Walsh, R.S., Gallagher, S., Muldoon, O.T., Fortune D.G., (2013, October) *Relationships between social identities, social support, anxiety and depression following ABI*, Annual Research Symposium, University Hospital Limerick

Walsh, R.S., Gallagher, S., Muldoon, O.T., Fortune, D.G., (2013, August) *Relationships between Social Identity, Social Support and psychological well-being following Acquired Brain Injury (ABI)*. BPS Social Section Conference, Exeter University.

Walsh, R.S., Fortune, D., Gallagher, S., Muldoon, O.T. (2013, May) *Looking to the 'social' in biopsychosocial: the Social Identity Approach as a vehicle for integration of social psychology and neuropsychology in the study of acquired brain injury (ABI)*. International Society for Theoretical Psychology (ISTP), Universidad Católica de Chile, Santiago, Chile.

Walsh, R.S., Gallagher, S., Muldoon, O., and Fortune D.G. (2012, August) *Combining Social Psychology & Neuropsychology in the study of ABI*. European Association of Social Psychology Summer School, University of Limerick.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Walsh, R.S., Gallagher, S., Muldoon, O. (2011, September). *Understanding identity through acquired brain injury*. British Psychological Society (Social Section) Conference, University of Cambridge.

### **Poster Presentations**

Walsh, R.S., Fortune, D.G., Gallagher, S., Muldoon, O.T. (2014, May) Different identities, different correlates: Stigmatized identity, survivor identity and depression following acquired brain injury. International Brain Injury Association (IBIA) Conference, San Francisco.

Walsh, R.S., Fortune D.G., Gallagher, S., and Muldoon, O., (2012, December) *Social Identity, Social Support and Quality of Life (QoL) following Acquired Brain Injury (ABI)* British Psychological Society (Division of Clinical Psychology) Conference, University of Oxford.

### **European Association of Social Psychology Summer school**

In August 2012 the two week EASP summer school was hosted at the University of Limerick. I was fortunate to be accepted and attended a workshop on social identity and health headed by Prof. Alex Haslam and Dr. Stephen Gallagher.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Abstract**

The central argument put forward in this thesis is that, in the context of acquired brain injury (ABI) social identity matters. The first article is a theoretical paper which reviews an emerging literature that is trying to draw together social psychology and neuropsychology in the study of ABI. This article argues that the social identity approach is an appropriate vehicle for such integration and introduces the concept of identity sub-types based on belonging and based on participation in activities. Social support is recognized as an important factor in rehabilitation following ABI. The second paper is an empirical study which employs the concepts of affiliative and self as doer identities to explore reciprocal relationships between social identity, social support, and emotional status following ABI. Results support a hypothesised model indicating that affiliative identities have a significant indirect relationship with emotional status via social support and self as doer identification. Evidence supports an ‘upward spiral’ between social identity and social support such that affiliative identity makes social support possible and social support drives self as doer identities. The third paper examines relationships between cause of ABI, level of disability, stigma, survivor identity, and quality of life amongst a group of ABI survivors. This study found that cause of injury and disability severity, had a significant mediated relationship with quality of life outcomes via stigma and survivor identity. The fourth paper, presenting the third and final study, was a longitudinal investigation that explored how the understandings that people have of themselves, as expressed in their affiliative and self as doer self-categorisations, impact anxiety. Anxiety is of particular importance following ABI because anxiety has been identified as a significant predictor of functional outcomes. Results indicate that, over time, identity continuity and multiplicity following ABI contribute to lower levels of anxiety. Social identities matter.

# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **Declaration**

The substance of this thesis is the original work of the author and due reference and acknowledgement has been made, where necessary, to the work of others. No part of this thesis has been submitted in candidature of any degree.

## **Statement of the candidate's contribution to co-authored papers**

The theoretical paper and three studies included in this thesis were written up in four papers for publication. As detailed below, the substantial contribution to the co-authored papers was made by the candidate. However, while the candidate is fully responsible for the work presented in this thesis, where the first person is used it is in the plural (i.e. 'we' rather than 'I') as in the original peer-reviewed articles to reflect the collaborative efforts guiding the research process. Since each manuscript is meant to stand alone, some information may be repeated.

### **Paper 1: Literature review – Chapter 2**

Walsh, R. S., Fortune, D. G., Gallagher, S., & Muldoon, O. T. (2014). Acquired brain injury: combining social psychological and neuropsychological perspectives. *Health Psychology Review*, 8(4), 458-72.

The first, theory paper was written by the candidate under the supervision of Professor Orla Muldoon and Doctor Stephen Gallagher. Professor Donal Fortune provided clinical neuropsychological feedback during the framing of arguments.

### **Paper 2: Study 1 – Chapter 3**

Walsh, R. S., Muldoon, O. T., Gallagher, S., & Fortune, D. G. (*in press*).

Affiliative and self as doer identities: relationships between social identity,



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

social support, and emotional status amongst survivors of acquired brain injury (ABI). *Neuropsychological Rehabilitation*.

The research presented in this study was designed by the candidate under the supervision of Professor Orla Muldoon and Doctor Stephen Gallagher.

Professor Donal Fortune advised regarding participant recruitment and offered guidance regarding ethical procedures within ABI Ireland. The data was collected by the candidate with the help of an ABI Ireland assistant psychologist (Jenny Grace). Statistical analysis, interpretation of results, framing of arguments and write up of the article was conducted by the candidate with supervisory support from Professor Orla Muldoon and Doctor Stephen Gallagher.

### **Paper 3: Study 2 – Chapter 4**

An investigation of relationships between cause, disability, stigma, survivor identity and quality of life following Acquired Brain Injury (ABI).

Manuscript submitted to Archives of Clinical Neuropsychology

The research presented in this study was designed by the candidate under the supervision of Professor Orla Muldoon and Doctor Stephen Gallagher.

Professor Donal Fortune advised regarding participant recruitment and offered guidance regarding ethical procedures within ABI Ireland. The data was collected by the candidate with the help of an ABI Ireland assistant psychologist (Jenny Grace). Statistical analysis, interpretation of results, framing of arguments and write up of the article was conducted by the candidate with supervisory support from Professor Orla Muldoon and Doctor Stephen Gallagher.

### **Paper 4: Study 3 – Chapter 5**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

A longitudinal study of relationships between self-categorization, continuity of self, and anxiety following Acquired Brain Injury (ABI). Manuscript submitted to Brain Injury

The research presented in this study was designed by the candidate under the supervision of Professor Orla Muldoon and Doctor Stephen Gallagher.

Professor Donal Fortune advised regarding participant recruitment and offered guidance regarding ethical procedures within ABI Ireland. The data was collected by the candidate with the help of an ABI Ireland assistant psychologist (Jenny Grace). Statistical analysis, interpretation of results, framing of arguments and write up of the article was conducted by the candidate with supervisory support from Professor Orla Muldoon and Doctor Stephen Gallagher.

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R. Stephen Walsh

(Candidate)

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Statement of the Supervisor's Contribution to Co-authored Papers**

As outlined in the candidate's statement above, the substantial contribution to the co-authored papers presented in this thesis was made by the candidate. This includes the review of the literature, study design, statistical analysis, and interpretation of the data, together with the write-up for publication. The supervisors contributed to the papers by advising on statistical analysis and interpretational issues, relevant literature and writing style. The theoretical framing in this thesis and the arrangement of the papers is the product of concerted discussion between the candidate and his supervisors.

Professor Orla Muldoon \_\_\_\_\_

Doctor Stephen Gallagher \_\_\_\_\_

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Acknowledgments**

Firstly I gratefully acknowledge the Irish Research Council for the funding I was awarded for my PhD and the Faculty of Education and Health Sciences for their scholarship funding prior to the IRC.

I would also like to express my deep gratitude to the clients and staff of ABI Ireland who have made this research possible, particularly Lucia, Dave and all linked to the Castleisland office.

I owe more than can be acknowledged to my supervisors Prof. Orla Muldoon and Dr. Stephen Gallagher for giving me the chance to undertake this research, and for the guidance, support and assistance I have received. Their doors were always open, they are both supervisory superstars and I appreciate it. I would also like to thank Prof. Donal Fortune who has been a mentor and a guide since my undergraduate studies.

Most importantly I must thank my family: Maria, Molly Heather and Freyja. I appreciate that you put up with me for all the years that this has taken and I cannot thank you enough for the countless days, weekends and evenings you left me the space to chase my questions and for the hours you have listened to my ramblings.

You are the best and this is as much yours as it is mine.

Last but not least, thank you to Mum, Dad, and my sister Zoe.

# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **List of Appendices**

Appendix 1. ABI and Identity Questionnaire

Appendix 2. HADS

Appendix 3. MPAI

Appendix 4. MOS Social Support Survey

Appendix 5. WHOQOL BREF

# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **Table of contents**

<b>List of Papers</b>	<b>i</b>
<b>Abstract</b>	<b>iv</b>
<b>Declaration</b>	<b>v</b>
<b>Acknowledgments</b>	<b>x</b>
<b>List of Appendices</b>	<b>xi</b>
<b>Chapter 1:</b> General Introduction	<b>1-11</b>
<b>Chapter 2:</b> Acquired brain injury: combining social psychological and neuropsychological perspectives.	<b>12-46</b>
<b>Chapter 3:</b> Affiliative and ‘self as doer’ identities: relationships between social identity, social support, and emotional status amongst survivors of acquired brain injury (ABI).	<b>47-81</b>
<b>Chapter 4:</b> An investigation of relationships between cause, disability, stigma, survivor identity and quality of life following Acquired Brain Injury (ABI)	<b>82-110</b>
<b>Chapter 5:</b> A longitudinal study of relationships between self-categorization, continuity of self, and anxiety following Acquired Brain Injury (ABI).	<b>111-135</b>
<b>Chapter 6:</b> General Conclusion	<b>136-148</b>
<b>Bibliography</b>	<b>149-168</b>
<b>Appendices</b>	<b>169-183</b>

## **A Social Identity Approach to Acquired Brain Injury (ABI)**



# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **CHAPTER 1**

### **General Introduction**

#### **Introduction**

The program of research presented in this thesis constitutes an article based PhD. Informed by the social identity approach (Haslam, Reicher, & Platow, 2011) the topic is the application of social psychology to the study of acquired brain injury (ABI). In a landmark paper that galvanized this PhD research, Haslam, Jetten, Postmes, and Haslam (2009) set out how groups impact the psychology of individuals through their capacity to be internalised as part of a person's social identity. The social identity approach advocated by Haslam et al. (2009) has echoes of Vygotskian theory which can usefully be understood as a theory of internalisation whereby 'interpsychological activity becomes intrapsychological activity' (Frawley, 1997, p.94). Vygotsky was also interested in the role played by participation in activities in the sociogenetic formation of self (Daniels, Cole, & Wertsch, 2007). It seems that from Vygotsky's point of view, belonging to groups frames individuals' activity and that belonging to groups and participating in activities are directly relevant to identity processes. This interpretation of Vygotskian thought raised a question in my mind as to whether there is a quantitative difference in identities founded on belonging and identities founded upon doing that a social identity approach would be equipped to address.

Haslam et al. (2009) outlined some central themes that have emerged from social identity research including social identity as a determinant of symptom appraisal and response; social identity as determinant of health-related norms and behaviour; social identity as a basis of social support; social identity as a coping

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

resource and social identity as a determinant of clinical outcomes. Haslam et al. (2009) pointed to the capacity for a social identity approach to enrich academic understanding in these areas and for the social identity approach to play a key role in shaping health-related policy and practice. The articles presented in this thesis strive to build on Haslam et al.'s line of thought by attending to distinct identity sub-types, including those pertaining to belonging and those pertaining to doing, and apply a social identity approach to the study of Acquired Brain Injury (ABI). The outputs from the body of research that make up this thesis include one theoretical paper and three empirical papers.

It is necessary at this point to provide some further, brief, historical context. The approach to brain injury developed by Luria and Vygotsky, in the early twentieth century casts a long shadow. The neuropsychology developed by Luria and Vygotsky was characterised by an insistence that psychological research should never be divorced from the 'real world' and a neuropsychology which recognized the social origins of higher psychological processes (Cole, Levitin, & Luria, 2006). This focus of Luria and Vygotsky on ecological validity was mirrored by the concern expressed by the seminal social identity theorist Tajfel (1981, p.18) who said that 'social psychology as we know it today is 'irrelevant' only to the extent it is a social science practiced in a social vacuum'. Tajfel's (1981) understanding that social psychology must have relevance beyond the narrow confines of the psychology lab remains fundamentally important 30 plus years on, and in conducting the research presented herein we attempt to emulate his approach and use social psychology to engage in a useful and practical way with the 'real worlds' of those ABI survivors who took part in it.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Social identity is an appropriate vehicle for this endeavour (Walsh, Fortune, Gallagher, & Muldoon, 2014).

Looking a little more closely to social identity it is noteworthy that concepts of identity are often promiscuously mingled (Daniels, Cole, & Wertsch, 2007) resulting in a significant lack of clarity. One source of particular confusion in the identity sphere is the concept of personality. Personality can be understood as a set of stable traits located within the core of each individual (Daniels et al., 2007) whereas identity can be understood as the product of self-interpretation processes which take place as the result of social interaction (Simon, 2004). Yeates, Gracey, and Collicutt McGrath (2008) applied a biopsychosocial approach to the deconstruction of 'personality change' after ABI and argue that the concept of 'personality' has been superseded by concepts of cognitive representations of 'self'.

The biopsychosocial approach originates in the theorising of Engel (1977). Engel's (1977) influential biopsychosocial model highlighted the importance of psychological and social factors to those living with illness and disease. Acknowledgement of social, contextual and cultural factors is central to the biopsychosocial approach and the challenge it presents to what Engels described as reductionist, dogmatic biomedical thought. This recognition of the importance of the social and the cultural is important because it speaks to the neuropsychology initiated by Luria and Vygotsky, just as it also speaks to the social psychology of Tajfel and Turner and it evidences a way of understanding clinical practice that is open to, and welcoming of, cross-disciplinary input. The biopsychosocial model offers an umbrella under which a social approach to neuropsychology, such as that originating in the seminal work of Luria and

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Vygotsky and more recently expressed by neuropsychological clinicians and researchers such as Haslam et al. (2008), Yeates, Gracey, Collicutt McGrath (2008), and Gracey and Ownsworth (2012), can integrate coherently with an applied approach to contemporary social psychology as articulated by Jetten, Haslam, and Haslam (2012). This is important because it facilitates a genuinely social analysis that begins with ‘the group in the individual’ rather than ‘the individual in the group’ (Reicher, Spears, & Haslam, 2010). Building on this social start point, the golden thread running through this thesis is that social identities matter and the social identity approach is a suitable vehicle for specification of ‘the social’ in a psychosocial perspective on ABI that may ultimately contribute to an overall biopsychosocial understanding.

The first theoretical paper (Walsh, Fortune, Gallagher, & Muldoon, 2014) reviews and contextualises an emerging literature which is trying to draw neuropsychology and social psychology together. This article presents a rationale for the integration of neuropsychology and social psychology and serves as an overall literature review.

The second article explores associations between affiliative identities, self as doer identities, social support and psychological well-being following ABI and builds on the notion that different identities may be important and distinct predictors of well-being after ABI. The existing social identity literature indicates a reciprocal relationship between social identity and social support such that each makes the other possible. In order to further interrogate this apparent reciprocity the second article, a cross-sectional study, applied a social identity analysis to a study of relationships between social identities, social support, and psychological well-being following ABI. In particular this study considered social identity in

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

terms of sub-types based on belonging (affiliative identity) and based on doing (self as doer identity). Analysis revealed that affiliative identities have a positive indirect effect on psychological well-being via social support and self as doer identity. These results support the idea of an ‘upward spiral’ (Haslam, O’Brien, Jetten, Vormedal, & Penna, 2005) where social identity is understood to drive social support and social support is understood to drive social identity. The findings add to the literature in that they illustrate the utility, at least in social approaches to neuropsychology, of considering social identity in terms of distinct sub-types based on belonging and based on meaningful activity.

Using measures of brain injury severity to predict the day to day difficulties that people will experience in the post-acute phase of recovery is extremely problematic (Entwistle & Newby, 2013). This issue of poor predictive efficacy points to the need for a holistic approach to ABI that attends to the social aspects of brain injury (Ben-Yishay & Diller, 2011). Building on this insight, the rationale for the third paper was that disability and cause of injury, because of what they mean to ABI survivors in the contexts of their social worlds, may be useful predictors of outcome. In particular, this study investigated the hypothesis that disability severity and cause of injury would both be related to quality of life and that these relationships would be mediated by stigma and survivor identities. This cross-sectional study found that disability predicted overall health satisfaction and that stigma associated with ABI mediated the relationship between disability and psychological quality of life, social relationships quality of life and environmental quality of life. In contrast, cause of injury was related to survivor identity and a significant mediated pathway was found between cause of injury and overall quality of life and psychological quality of life via survivor identity. These findings highlight the importance of social identities, in this

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

instance stigma and survivor identity, to quality of life following ABI. Findings also highlight the importance of attending to different identity types. Large and Marcussen (2000) argue that identities are crucial in predicting different forms of distress because concepts of identity emphasise subjective meaning. The results of this study are potentially useful because they contribute to an understanding of the role played by social identities in complex relationships between cause, disability and quality of life following ABI.

The fourth and final article is a longitudinal investigation of the relationship between strength of affiliative identification, self as doer identification and anxiety that takes into account the impact, over time, of consistency and change in self categorized identifications. To the best of our knowledge this study is the first to track these identities over time and to investigate longitudinally how these identities might impact well-being. Anxiety is of particular importance in the context of ABI because anxiety has been identified as a significant predictor of functional outcome (Ponsford, Draper, & Schonberger, 2008). Continuity of self has been linked to post ABI adjustment (Bowen, Yeates, & Palmer, 2010) and self discrepancy has been linked to anxiety. A moderated mediation analysis was conducted that found a significant mediated pathway between affiliative identification and anxiety via self as doer identification. This mediated pathway was found to be moderated by continuity of affiliative self categorization and variation in self as doer self categorization. These findings evidence the importance of identity continuity and multiplicity following ABI. Together these papers sought to produce knowledge relevant to the advancement of theory and practice which will be of interest, and more

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

importantly of use, to those engaged in the provision of neuropsychological rehabilitation.

## A Social Identity Approach to Acquired Brain Injury (ABI)

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## **A Social Identity Approach to Acquired Brain Injury (ABI)**

**CHAPTER 2**

**Paper 1**

**Acquired brain injury: combining social psychological and neuropsychological perspectives.**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Abstract**

This theoretical paper reviews an emerging literature which attempts to bring together an important area of social psychology and neuropsychology. The paper presents a rationale for the integration of the social identity and clinical neuropsychological approaches in the study of acquired brain injury (ABI). The paper begins by reviewing the social and neuropsychological perspectives of ABI. Subsequently, theoretical and empirical studies that demonstrate the social influences on neuropsychology and the inherently social nature of mind are considered. Neuropsychological understandings of social identities and their potential relationships to the variability in acquired brain injuries are also discussed. The values of these understandings to ABI rehabilitation are then examined. The paper concludes by suggesting an agenda for future research that integrates the social identity and neuropsychological paradigms so that psychology might grow in its store of applicable knowledge to enhance support and rehabilitation for those with ABI.

**Keywords:** acquired brain injury (ABI); social identity; neuropsychology; rehabilitation.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

ABI is currently the leading cause of death and disability in young adults. It is considered one of the most common neurological disorders (Howes, Benton, & Edwards, 2005) and, for the survivors of ABI it is widely regarded as a very debilitating condition (Jones, Jetten, Haslam, & Williams, 2011). It has been described as a silent epidemic (Jones et al., 2010). In the United States traumatic brain injury (TBI) is reported to be eight times more common than a combination of breast cancer, AIDS, spinal cord injury and multiple sclerosis (Kolb & Whishaw, 2009) and in the UK, Howes et al. (2005) report a male to female ratio of 2:1 in the incidence of TBI. These figures do not include injuries from strokes, infections and other sources. One estimated incidence of ABI is one per five hundred of population globally with occurrence most likely in children under four, adults under thirty and those over sixty five years of age (Jones ., 2010). This population profile means that, worldwide, there are a very large number of ABI survivors with a considerable life expectancy. The importance of the health and well-being of such a large number of people, with long lives ahead of them, is difficult to overstate in terms of the survivors themselves, their families, and the wider social and economic cost.

A number of theoretical approaches for understanding ABI have been employed including social psychological and neuropsychological models. As they stand, however, on their own they are not sufficient. Habitual thinking within both social psychology and neuropsychology needs to be transcended. The traditional neurobiological approach needs to embrace a more complex understanding of social and contextual factors available via social psychology. Social psychological approaches to health and ABI need to integrate an

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

understanding of the heterogeneity of injuries and ill-health that populate even a single diagnosis.

Thus at present, there is no compelling model of ABI that specifies in a testable manner how knowledge from these two fields might be coherently integrated to improve outcomes following ABI. To this end, we review the emerging literature pertaining to ABI from both the social identity and neuropsychological perspectives. Here, we consider the potential benefits of attending to the impact of neurology on underlying brain injury for those interested in ABI rehabilitation, as well as those interested in how social psychological processes underpin health generally and ABI in particular. Drawing on contemporary understandings of ABI, we subsequently consider the literature emerging from contemporary clinical neuropsychology (e.g. Donald, 2001; Broks, 2003; Yeates, Gracey, & Collicutt McGrath, 2008; Bowen, Yeates, & Palmer, 2010; Damasio, 2010) that is cognisant of the influence of social factors on brain functioning. Here our emphasis is on the value to clinical neuropsychology of attending fully to the influence of social factors on health and well-being and also the value to social conceptualisations of health and well-being of attending to the influence of pertinent clinical neuropsychological factors. We conclude by suggesting that the integration of these two fields in a specified and testable manner is now opportune and to this end we offer some directions for future research.

### **1. Applying a Social Psychological Approach to Acquired Brain Injury**

Research has also adequately demonstrated that psychology plays a crucial role in the determination of health and disease (Aronson, Wilson, & Akert, 2010).

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Gallagher, Phillips, Ferraro, Drayson, and Carroll (2008), for example, found that social support is positively related to immunity. Social factors such as maintained group memberships following stroke have been shown to mediate clinical outcomes (Haslam et al., 2008). Social psychology is at the confluence of a number of disciplines including cognitive psychology, individual psychology, social anthropology, sociology and language (Hogg & Vaughan, 2008). This renders social psychology both intellectually stimulating and packed with practical potential for application to the study of conditions such as ABI which comprise social and biological components.

We posit then that social psychology, and the social identity approach in particular, is well placed to inform clinical neuropsychology. Consistent with this position, and in the context of ABI, neuropsychology seems unable to explain the gap between functional impairment and neurological injury such as that which presents in ABI survivors who can, for example, solve complex problems presented by people they know, but are unable to solve simple puzzles presented by strangers (Bowen et al., 2010). It seems clear, in such cases, that there are social factors at play.

Whilst there have been some attempts made through the biopsychosocial approach to explain the more general finding that level or nature of organic injury does not reliably predict nature or level of functional impairment or disability (e.g., Borrell-Carrio, Suchman, & Epstein, 2004; Main, Richards, & Fortune 2000), the biopsychosocial approach is individualistic (Lewis, 2007), underspecified as a model (Epstein & Borrell-Carrio, 2005) and associated with theoretical and epistemological tension when applied to ABI (Yeates, Gracey, & Collicutt-McGrath, 2008). Against these arguments, we suggest that it makes sense to consider neurobiology, psychological and social factors in the context of



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

ABI. Furthermore, utilising the social identity approach as a lens through which to examine ‘the social’ in biopsychosocial facilitates development of a theoretically coherent, clearly specified model which transcends cognitive individualism and is amenable to empirical testing. In effect, an integrative perspective, incorporating social identity and neuropsychology, facilitates the type of bridge building approach to theoretical development advocated by Abrams and Hogg (2004) that is required to progress knowledge in the study of ABI. It is the logical next step from the existing social identity literature.

### ***1.1 Applying a Social Identity Approach to Acquired Brain Injury***

In this paper we propose that a theory particularly well suited to our task is the social identity approach. The social identity approach is a psychological metatheory incorporating social identity theory (SIT) and self categorization theory (SCT) (Haslam, Reicher, & Platow, 2011). The social identity paradigm is conspicuous in social psychology because it embarks on analysis from a unique position. Rather than starting with ‘the individual in the group’ it proceeds from the understanding that one must begin with a consideration of how the group influences the individual (Reicher, Spears, & Haslam, 2010). Social identity was defined by Tajfel (1982) as an individual’s knowledge that they belong to certain social groups and that membership of these groups has emotional and value significance for them. It focuses on the ‘we’s’ people ascribe to and how when ‘we’ self-categorise as a group member ‘we’ interact with ‘others’. SCT has a focus on the shift behind people’s self categorization from idiosyncratic individuals to individuals as members of collective groups. It is interested in how we behave and how others behave towards us based on our group memberships or social identities.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

The term ‘identity’ has of course multiple meanings in psychology. Identity can be conceived of as comprising individual and collective (or personal and social) components. Drawing on the social identity approach and its associated ontological position, we argue that individual and collective identities are conceptualisations of the self that are inherently social (Simon, 2004). Identities and identification processes are active and dynamic. The subjective importance of these components to ourselves and others vary as a function of salience. An identity such as ‘brain injured’ might be particularly salient in the aftermath of the injury for those affected by a brain injury but may recede as they adjust to their injury and subsequent everyday life. However for families or friends of those affected, who may see behaviour entirely inconsistent with their previous perception of this person, the salience of the brain injury may increase.

Essentially then, the social identity position argues that identification processes arise as a consequence of both individual and collective factors. For example, a medic who acquires a brain injury may be treated differently as a ‘patient’ than those without such a medical background, particularly in health care settings. As our position argues that identity is regarded as the product of self-interpretation processes which occur as the result of social interaction, the differential interactions as a consequence of either injury identities or other prior identities such as occupational, gender or family identities are crucial to how individuals see themselves and cope in the aftermath of their injury. Essentially what may be considered a personal or individual identity in one context may manifest as a social or collective identity in another context. This is not seen as problematic within the social identity tradition because identity is regarded as a fluid and context dependent phenomenon. Reicher, Spears & Haslam (2010,

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

p.48) express the concept succinctly when they make the point that social identity needs to be understood as simultaneously individual and social.

Moreover, Haslam, Jetten, Postmes, and Haslam (2009) argue that because self-categorization and social identity processes structure social interaction they are central to the accumulation of health related social capital. As such, social identity has become a key approach for understanding both health and illness. Jetten, Haslam, and Haslam (2012) for example have usefully engaged with the topic of brain injury from a social identity perspective. Those social psychological studies in this area (e.g. Haslam et al., 2008; Jones et al., 2010) consider ABI as a unitary phenomenon. Our argument here is that this issue of injury type is crucial. Injuries that produce deficits which interfere with processing of social cues for example are likely to produce more difficult social interactions. Social interactions, which we posit may be linked to injury type and severity, are argued at a theoretical level to be a cornerstone upon which social identity processes and associated collective identities are built.

In order to explain the variability between functional impairment and associated injury, a social identity perspective then is a logical proposition. Haslam et al. (2009) argue that there are five processes, or pathways, through which 'the social' can influence health. Drawing again on the social identity paradigm, they argue that individuals' constructions of themselves within social contexts can be determinants of symptom appraisal and response, health related norms and behaviours, and clinical outcomes. For example, Levine and Reicher (1996) found that female sports science students perceived a knee injury as more serious than a facial rash when their sports science identity was salient and vice versa when their gender identity was salient. Lennon, Gallois, Owen, and McDermott (2005) applied the social identity approach to an investigation of

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

young women's health behaviour. They found that during their early high school years, young women saw smoking as the norm in the 'cool' group. Taking up smoking was seen as the way into this group. Conversely, Lennon et al. report young mothers and young pregnant women as quitting in order to be a 'good mother', a group for whom the norm is not to smoke.

In terms of clinical outcomes, Cole, Kemney, and Taylor (1997) researched the progression of HIV amongst gay men. They found that gay men who could not maintain particular social identities, and were sensitive to rejection based on their inability to maintain those identities, experienced a significantly faster progression of the disease compared to those rejection-sensitive gay men who were able to conceal their homosexual identity. Haslam et al. (2009) also identified social identity as a basis for social support and as a coping resource. A sense of shared social identity underpins the ability of group members to buffer themselves from the negative consequences of their circumstances. For example, in a study of patients recovering from heart surgery, Haslam, O'Brien, Jetten, Vormedal, and Penna (2005) found that social identification with friends and family was a predictor of positive outcomes regarding stress, self esteem and life satisfaction.

## **2. Applying a Neurobiological Approach to understanding Identity Processes in ABI**

Neuropsychology is the study of the relationship between brain and behaviour (Andrewes, 2001). It has been strongly influenced by the 'brain hypothesis', the idea that the brain is the source of behaviour (Kolb & Whishaw, 2009). It has also been strongly influenced by cognitive psychology (Andrewes, 2001), a perspective which focuses on processes internal to the individual (Billig,

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

2003). It regards the brain as the basis of mind, and in turn behaviour (Kolb & Whishaw, 2009). It has been argued to be inward looking (e.g. Bowen et al., 2010, p.304).

The neuropsychological perspective is strong regarding the identification of deficits. It often happens that people with closed - head brain injuries have significant cognitive deficits, yet have little or no evidence of cerebral damage visible on their neuroimaging. In such cases neuropsychological testing can offer the only path to documenting the nature and extent of cognitive disturbance affecting a person (Kolb & Whishaw, 2009). However, it is noteworthy that standardised neuropsychological tests are perceived by some in neuropsychological rehabilitation as limited because they may not reflect functional improvement in a patient (Benson & Pavol, 2007) and of course performance on cognitive tasks may also be affected by a number of social and contextual factors.

In their fMRI study, Volz, Kessler, and von Cramon (2009) explored how social identity, which they defined as the self concept derived by an individual from perceived memberships in significant social groups, was implemented at a cerebral level. They report that the social self is constituted by the same mechanisms as the personal self and they associate these mechanisms with the medial prefrontal cortex (MPFC). The question we raise is what happens when the biological substrate of social identity suffers insult? Volz et al. (2009) propose that our 'selves' extend psychologically beyond our physical bodies and involve belonging to other individuals, 'the in-group', and differentiating oneself from 'the out-group'. What happens when the cognitive resources necessary for these self categorization processes are compromised by brain damage?

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

In a recent study, Jones et al. (2010) systematically examined, from a social identity perspective, the relationship between injury severity, personal changes, social network changes and well-being amongst a group of people recovering from head injury. They found, somewhat counter intuitively, that more severe head injuries were associated with increased levels of life satisfaction. By way of explanation they proposed that this was because more severe head injuries tended to be linked with significant 'identity work' by injured people. This was in turn seen as resulting in the strengthening of their personal identities and social networks post injury.

It seems clear that the social identity approach, as exemplified by Jones et al. (2010) is being usefully applied to the investigation of ABI. However, there appears to be a gap in the approach. In treating ABI as unitary, it is overlooking biologically based differences. Evidence from neuropsychology demonstrates that ABI is not unitary; rather it indicates that injury location is crucial, and in particular disruption in the connections between networks of areas working together. For example, if we consider one area of the underneath of the frontal lobe – the Orbitomedial frontal cortex - there is a well found demarcation of function such that if a person sustains an injury to the surface of this area, the difficulty will emerge as problems in identifying particular smells or odours. By contrast, if the injury is adjacent or more to the medial wall of this area (and we are still talking about a relatively small area on the underneath of the brain at the front), their memory for the story of their lives (their autobiographical memory) is likely to be impaired – a significantly more socially devastating outcome arising from in this case, disruption to connections from this area to the Hippocampus and medial cortical regions (Zald & Andreotti, 2010). These differences in impairment, mediated by lesion location and disruption in the networks of areas

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

working together have real implications for survivors of ABI and the differences in impairment have real implications regarding survivors' functioning in social contexts. Evidence of different outcomes, contingent on differing social interactions and the transformation in social and group life associated with particular lesions or deficits in those with ABI would be strong evidence for social cure or cause for recovery from ABI.

Fisher, Shamay-Tsoory, Eran, and Aharon-Peretz (2011) report how 'MS', a twenty nine year old Israeli graduate student lost large parts of her ventromedial prefrontal cortex (vmPFC) and orbitofrontal cortex (OFC) in a terrorist attack. Following her injuries, 'MS' experienced depression, social isolation and lost most of her friends. Her family commented on her change from a quiet, pleasant daughter and student (role identities) to a rude, disinhibited and unstoppably talkative person. The traditional neuropsychological perspective, taking into consideration the nature and extent of 'MS's' lesions, would predict precisely such sequelae. Lesion location impacts social functioning. Underlying neurology is fundamental to understanding ABI. It must be attended to by the social identity approach.

Fisher et al. (2011) proceed to report that seven years after their original assessment, neuropsychologists returned to undertake follow up assessments with 'MS'. By that time 'MS' was married and working for a government agency. She reported a good marital relationship marked by anxiety for her partner's well-being, as well as having good family and social contacts. Given the nature of her injury (large lesion to vmPFC and OFC) this was, from a neuropsychological perspective, quite unusual. With the notable exception of the Iowa Gambling Task (an assessment of decision making and risk), 'MS's' performance on neuropsychological tests designed to measure prefrontal damage was mostly

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

normal – she did remarkably better on tests that she had previously been impaired on. When the neuropsychologists who conducted the follow up tests came to do so, they assumed that their patient would do poorly on them. Instead they found improvement. Fisher et al. (2011) point out that the subtle deficits found in the follow up did not fit the theoretical sequelae of ‘MS’s’ lesions. They suggest possible explanations for her improvement might include a high cognitive reserve, the specific characteristics of her injury, plasticity and compensation strategies. These potential explanations illustrate a major weakness of the traditional neuropsychological perspective – an over reliance on individualism may neglect the significance of social factors as important vehicles of change.

In contrast to the internal explanations put forward by Fisher et al. (2011), from a social identity perspective, analysis must begin with the group in the individual (Reicher et al., 2010). The identities people hold are a product of the groups they belong to and individual behaviour is a function of their identities. Ponsford, Draper, and Schonberger (2008) in their article regarding the long-term aftermath of TBI link emotional status, familial support and functional outcomes. The social identity approach, via concepts including self stereotyping, identity salience, fit and social influence offers a framework whereby the needs and supports that stand behind people’s behaviour, well-being and outcomes might be analysed. Applied to the case of ‘MS’, a social identity analysis which recognizes that people organize and understand their worlds in manners reflective of their group memberships (Haslam & Ellemers, 2011) appears promising. Fisher et al. refer to several of ‘MS’s’ roles including, daughter and woman. Daughter is a role loaded with expectations (Chodrow, 1978). Fisher et al. implicitly recognize this when they note that the high standards of academic achievement attained by ‘MS’s’ mother might lie behind her appraisal of apathy in ‘MS’. Gender is



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

considered an important issue in social psychology (e.g. Hollway, 2007) and it is recognized as being under-researched in the context of brain injury (Howes et al., 2005). Stereotyping, in the social identity approach, is about what the appropriate and relevant behaviours are in a given context (Spears, 2011). The anxiety ‘MS’ expresses for the well-being of her husband seems to confound the theoretical sequelae flowing from a neuropsychological analysis of her lesion. Might self-stereotyping as a wife account for the concern expressed by ‘MS’ for her husband’s well-being? Does ‘MS’s’ gendered identity as a woman allow her access emotional support which, for social identity reasons, is less freely available to those young males who are more often the victims of ABI? Does ‘MS’s’ gender identity, in a sense, facilitate access to ‘free therapy’ from her social networks? Fisher et al. (2011) garner much of their data regarding ‘MS’ from her mother and the mother/daughter relationship appears, from the information in their article, to be a pivotal one. Klein, Spears, and Reicher (2007) state that an identity requires practical expression in order to be sustainable and that identity generally also requires acknowledgement by others in order to be viable. Experience of identity loss is understood to be of major importance in rehabilitation following ABI (Nochi, 1997; Nochi, 1998). On the evidence contained in the Fisher et al. article it would appear that identities relating to her gender and role as daughter may have been a factor in ‘MS’s’ recovery. The social identity approach offers a vehicle which can be used to understand instances where identity expression in behaviour is affected by available audiences, and further, it can be used to understand how such identity performances can feed into and inform social identity itself (e.g. Klein et al., 2007). The shift we propose, in analysis and emphasis, is from a thing, ‘MS’s’ lesion, to a process – her identity. One is not independent of the other, but both

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

must be considered in order to understand the psychology behind her remarkable recovery.

### **3. The Theoretical Value of a Dual Approach**

Since the Second World War the study of cognition has been dominated by three models: the social thinker as a consistency seeker; as a naive scientist; and as a cognitive miser (Haslam, 2004). This individualism has been heavily absorbed across psychology and neuroscience (e.g. Ito, 2010; Todorov, Harris, & Fiske, 2006) giving rise to constructions of individuals as information processors (Yeates et al., 2007). The individualistic, neuropsychological view is that all behaviour including language and reasoning can be accounted for by brain function (e.g. Kolb & Whishaw, 2009, p.37). In opposition to this stands the social identity approach which regards humans as irreducibly cultural beings. There is a theoretically interesting conflict regarding ontology behind this divergence of views. Zerubavel and Smith (2010) argue that it is necessary to transcend this individualism and consider significant group memberships in order to understand the psychological self.

Their argument is consistent with the historic views of Vygotsky and Luria, and also in line with the social identity approach which takes the position that only by beginning with an analysis of the group in the individual is it possible to understand the individual in the group (Reicher et al., 2010). The historical approaches of Vygotsky and Luria offer a start point from which a contemporary integration that is epistemologically, ontologically, and methodologically coherent might proceed. Hollway (2007, p.201) argues that the problem of binaries constitutes a widespread difficulty in Western thought and that binaries present a problem of particular salience for social psychology because the discipline is

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

defined by dualism – the study of individuals in social contexts. The argument expressed by Hollway has crossover to the historical thinking of Luria who in his autobiography (Cole, Levitin, & Luria, 2010) recounts how, in the early twentieth century, “the naturalists and the mentalists had artificially dismembered psychology” (Cole et al., 2010, p.41). Luria also outlines Vygotsky’s realization that understanding human psychology requires recognition of a bi-directional process between individual and social world which rested on an acceptance of the material basis of consciousness (Frawley, 1997, p.6). Vygotsky’s theorizing built on a concept of internalization whereby intra-individual psychology flows from a connection of the external with the internal (Frawley, 1997, p.33). This Vygotskian ontology facilitates transcendence of the type of dualism identified by Hollway (2007) and it also anticipates the social identity approach as outlined by Reicher, Spears, & Haslam, (2010) which recognizes that analysis must begin with the group in the individual rather than the individual in the group. It also evidences a precedent for an approach to neuropsychology that is intrinsically social. ‘Back to the future’ if you will.

Similarly, Bateson (2010) argues that the study of human cognition requires progression beyond debate cantering on distinctions between ‘innate’ or ‘acquired’ processes. In Bateson’s view, positioning human behaviour as belonging wholly to one or another category is insufficient. Moreover, he argues that the simplification achieved by separating complex phenomena pertaining to human nature into dichotomous categories is unhelpful. Neuropsychology, in addressing ABI, needs to move beyond the brain and consider the social aspects of mind. Similarly, social psychology in seeking to understand recovery in survivors of ABI needs to consider the biological underpinnings and consequences of brain injury.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Theoretically then, research in this area has the potential to inform our conception of mind. ‘Mind’ can be conceptualised as both intrinsically biological and intrinsically social. Using ABI as a location for research allows us to consider the relationship between our neurology and our social selves and in particular affords the opportunity to consider potential reciprocal relationships between our social and biological selves. The innovative field of social cognitive neuroscience evidences an emerging recognition that cognition and social interaction are bound up with each other at a fundamental level (Semin & Echterhoff, 2011) and that these socio-cognitive processes are related to the function of underlying cortical structures (Amodio & Frith, 2006).

### **4. The Value of a Dual Approach for ABI Rehabilitation**

Whilst these theoretical issues are fascinating, in the context of ABI the debates are of crucial practical significance. Whilst it is doubtless a challenge to bring these two fields together, the potential pay-offs of integrating the two perspectives in a testable model are substantial. In practical terms, enhanced understanding, treatment and rehabilitation of those with ABI is a plausible possibility. From both theoretical and practical points of view then, the reciprocal interplay between identity and ABI becomes particularly important. Traditional neuropsychological theory places stable personality traits within the biology of each individual (Yeats et al., 2008). It regards rehabilitation following ABI as being about coming to terms with permanent change. It is a “clinical dead end” (Yeats et al., 2008, p.568).

In contrast, a social identity approach posits identity as actively generated in contexts, an emergent property of social interaction (Levine, 1999). Applied to post ABI rehabilitation, the implications of the traditional neuropsychological

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

perspective stand in stark contrast to the implications of the social identity approach. From a traditional neurological standpoint, rehabilitation centres on adjusting to irrevocable neurological change. Against this, from a social identity point of view, identity is an emergent property, people can adapt, scaffolding can be provided and rehabilitation can extend beyond coming to terms with impairment extending even to the notion of growth (Ownsworth & Fleming, 2011).

So alongside the bi-directional view of mind, is the re-emergence in contemporary psychology that social factors shape and alter neurobiology over the lifespan. Giarnos et al. (2007) for example built on animal research which indicates that structural change in the anterior cingulate cortex (ACC), the hippocampus and the amygdala are associated with chronic social stressors. They found that chronic life stressors predicted decreased hippocampal volume amongst a sample of healthy older women. Giarnos et al. (2007) also report that early childhood stressors, for example witnessing domestic violence, predicted decreased ACC volume. Clearly such neurobiological changes are outside of the awareness of many of those affected. Their practical significance relates to the ability of the mind to adapt and indeed develop subsequent to these changes.

Rehabilitation following ABI is about enabling people to be all that they can in terms of psychological, social, leisure, vocational and everyday functioning (Wilson, 2009). In practical terms, neuropsychological rehabilitation rests on theoretical models. Assessments, treatments and measurements of rehabilitation efficacy flow from these models (Wilson & Gracey, 2009). Bowen et al. (2010) argue for the necessity of integrating the biological with the social in effective psychological therapy following ABI. Indeed, their discussion is an example of a trend amongst neuropsychological rehabilitation clinicians to ‘dip’ in and out of

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

perspectives on the basis of what works. This does not necessarily correspond with what is theoretically coherent. In their case, Bowen et al. (2010) move between neuropsychology and psychotherapy in the form of family and relational therapy. Considering that Bowen et al. (2010) were looking to psychotherapeutic approaches, it is perhaps unsurprising that they report integration of the biological and the social as seeming to demand a constant pendulum between ontologies, epistemologies and methodologies. An adequate model requires the incorporation of both the social and the biological. It demands a concept of mind which is not limited to processes internal to the biology of each individual. The model must recognize that mind is neither entirely internal nor entirely external, but rather emerges from reciprocal processes of interaction between both. The innovation presented here is not to seek integration of social psychology and neuropsychology, as that is a process already underway. Rather, the innovation lies in the articulation of how the social identity approach may be an appropriate vehicle for that integration and how this might offer insights to both neuropsychological and social psychological traditions as well as offering important lessons for rehabilitative practice.

### **5. An Agenda for Future Research**

It seems clear that the most prominent weakness of the dominant perspective in contemporary neuropsychology is its under attention to social factors. A model is required with the capacity to explain the bi-directional interaction between biology and society in the context of ABI. Zerubavel and Smith (2010) argue against the view that psychology and neuroscience are moving towards an explanation of cognition in terms of intrapersonal processes. They claim that while such a view of cognition remains dominant in the West, it is

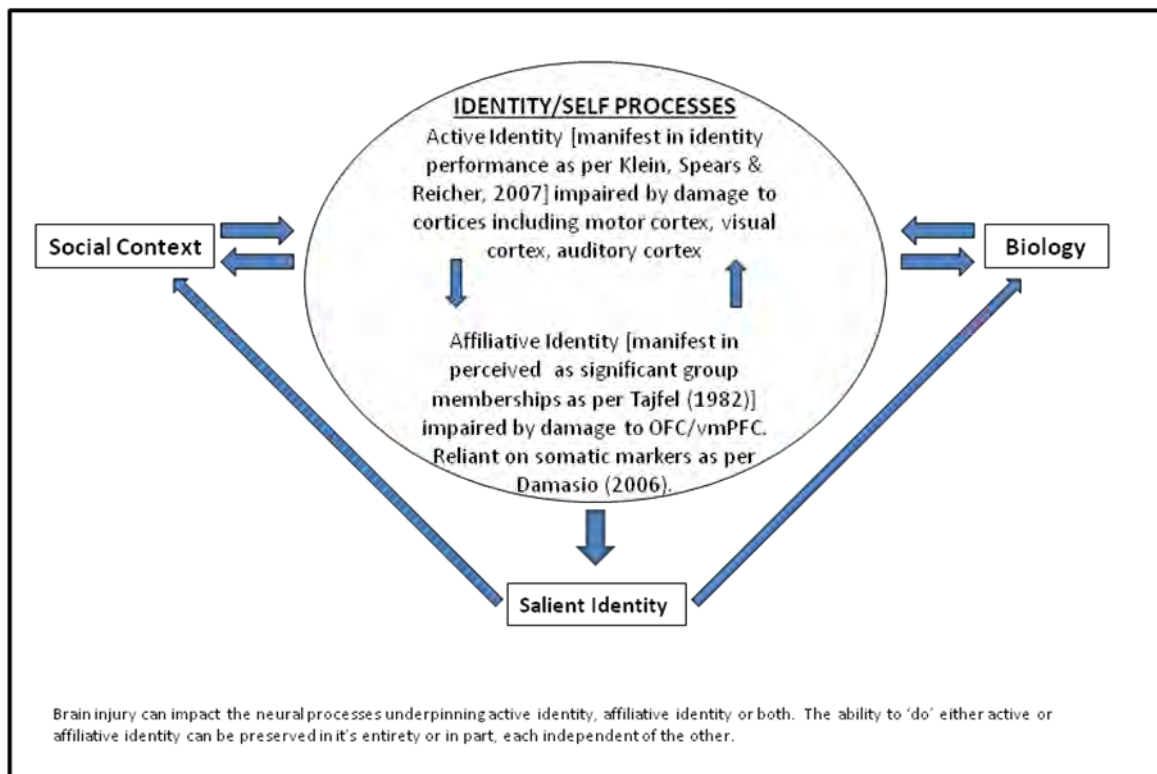
## **A Social Identity Approach to Acquired Brain Injury (ABI)**

rejected by modern scholarship. They argue that it is necessary to cross conceptual and methodological levels in order to understand cognition. In order to understand the psychology of human health and well-being in the context of ABI, it is necessary to develop an integrative model.

Within the social identity approach, Simon (2004, p.9) advances the view that multiple possible identities emerge from interaction between brain and environment. He uses the idea of identity in a broad sense to cover phenomena and processes discussed elsewhere under the heading ‘self’ (Simon, 2004, p.2). His approach has been adopted here. Simon also opines (Simon, 2004, p.52-53) that there is no compelling reason to think that individual or collective identities are founded on different types of self aspects. The important point, according to Simon, is that identities can be experienced as socially shared or social categorical and provide a foundation for collective identity under the appropriate social conditions. This is another area where neuropsychology can mesh with the social identity approach. Libby (2008) suggests that activation in cortical midline structures (CMS) constitute a marker, a neural signature, of the current self. In doing so, she explicitly links self to social context (Libby, 2008, p.193). In their fMRI studies, Volz et al. (2009); Yaoi, Osaka, and Osaka (2009) suggest that the medial prefrontal cortex (mPFC) is integral to self. Similar to Simon (2004), Volz et al. (2009) argue that both personal and social selves operate on the same neural machinery and they further suggest that it is important to examine when and how these identities influence and shape each other.

Figure 1 outlines our model of identity/self processes and ABI. The model proposes that active and affiliative self processes emerge from interaction between social and neurobiological factors. Following Vygotskian theorizing (Frawley, 1997),

## A Social Identity Approach to Acquired Brain Injury (ABI)



**Figure 1. Identity/Self Processes and ABI**

the model recognizes that identity is the product of internalization processes whose genesis lies in the social world. Social context is regarded as preceding identity processes, though these processes are dynamic and cyclical. Individuals do not emerge in a biological state of wholeness into social situations. Rather, the import of neurobiology is that it facilitates identity processes, and its responsiveness and plasticity influences the emergent self. For example, active identity (or the performance of identity as per Klein, Spears, and Reicher, 2007), rests on widely distributed neural systems and networks that include motor, visual and auditory cortices. Neurobiology also underpins the ability to affiliate to others in a range of social groups in a meaningful way. This is achieved via our social contexts and a system of somatic markers centred, most likely, in the prefrontal cortices and receiving input from deeper regions of the brain (Damasio, 2006).



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Tajfel (1982) defined social identities as those identities in which we invested emotional and value significance. It is therefore crucial to consider what happens when the networks of associated brain regions that facilitate identity processes suffer insult and the neural machinery that underpins emotional and social skills is compromised. Uddin, Iacoboni, Lange, and Keenan (2007) link identity with cortical midline structures (CMS) and a right lateralized frontoparietal network that overlaps with mirror neuron areas. What happens to identity when these areas suffer insult? It would also be fascinating to explore what (if any) neurobiology stands behind the five processes via which Haslam et al. (2009) argue social identity mediates the relationship to health. What happens when, following ABI, people no longer have the cognitive resources to ‘do’ self-categorization? Haslam, Jetten, O’Brien, and Jacobs (2004) tell us that a basis of social support is self categorization. It seems plausible to predict that those who cannot self-categorize as brain injured (as for example in anosognosia where survivors are unaware of their own deficits) should have more dysfunctional social interactions resulting in diminished health and well-being. If social identity is a key resource which feeds into clinical outcomes, those who retain memberships of valued social groups should achieve more positive clinical outcomes compared to those who assume or ascribe to a less valued or stigmatized identity.

The integrated social identity model of stress (ISIS; Haslam, 2004) also offers direction for the study of health and ABI. ISIS differs from individualistic analyses of stress because it regards groups as central to the experience and perception of stress. Groups are seen to buffer stress, and identities are central to the appraisal, meaning and experience of it. (Muldoon, Schmid, & Downes, 2009). According to the ISIS model, in order to understand stress, it is necessary

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

to move beyond individualistic analysis and incorporate social dimensions.

Central to the primary and secondary appraisal of stressors is the issue of perceived control (Lazarus & Folkman, 1984). Those with injuries perceived as arising from causes outside of their own actions (for example a cyclist hit by a car) are likely to appraise their injury in very different way from those perceived as being affected as a consequence of their own actions (for example an intoxicated motorist involved in an accident). Studies that attend to the impact of these social aspects of stress and their impact on stress appraisal, social support and clinical outcomes might be achieved using existing methodology.

Social identity continuity, as manifest in maintained group memberships, has been shown to predict well-being after stroke (Haslam et al., 2008). As with stress, identities are central to the experience of ABI. For example, Jones et al. (2010) found that the relationship between severity of brain injury and effects on life satisfaction were buffered by the strengths of identities and social networks following injury. However, the impact of the ‘identity as a person who has sustained a brain injury’ was not considered in this study and the potential for this to impact on rehabilitation and progression post injury in addition to the nature of the injury itself is an important avenue of future research. In particular, we believe that injuries associated with visible symptoms (e.g. hemi-paralysis) or stigma (e.g. that associated with injury from violence) are likely to have the strongest meta stereotyping effects for the brain injured and as a consequence the strongest impact on health and well-being. It is worth examining these predictions empirically, as any consequences of these social identity processes on clinical outcome are amenable to intervention.

The social identity approach regards identity as a process (Simon, 2004), and a generative one at that (Levine, 1999). This conceptualisation is shared by

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

the emerging field of cultural neuroscience. There, Kitayama and Park (2010) argue that the brain processes from which the self emerges are socially and culturally grounded. They argue that while the computer metaphor has been incredibly useful to psychology it is time to move beyond the concept of a bounded computational mind. Integration of the social identity approach and neuropsychology in the area of ABI has the potential to push clinical and theoretical boundaries.

Our intrinsically social view of mind offers a neuropsychological start point which affords itself for integration with the social identity approach. Such an integrated perspective would complement the necessarily pragmatic approach of neuropsychological rehabilitation clinicians who are required to consider both biological and social factors in an attempt to not only “fix what’s wrong, but also to build what’s strong” (Duckworth, Steen, & Seligman, 2005, p.631). Bowen et al. (2010) caution against prioritization of survivors and their damaged brains relative to their partners and families. They suggest that such an approach draws attention away from how issues such as depression and adjustment are shared within a couple following ABI. Furthermore, Bowen et al. (2010) note that neglecting the social aspect of ABI can unwittingly add to the range of challenges faced by survivors and their families. In a broad statement of position, they propose that in order to understand what is happening in the brain, neuropsychology must look outwards to relationships and context. In conceiving of mind as inherently social, and identity as a process, the minority neuropsychological tradition is in tune with the clinical pragmatism necessary in neuropsychological rehabilitation. The argument advanced by the present paper is that an integration of the social identity approach with clinical neuropsychology has the potential to close this gap between what ‘works’ and what is theoretically

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

coherent in psychological rehabilitation following ABI. We look forward to the future with optimism.

## A Social Identity Approach to Acquired Brain Injury (ABI)

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## **A Social Identity Approach to Acquired Brain Injury (ABI)**

**CHAPTER 3**

**Paper 2**

**Affiliative and ‘self as doer’ identities: relationships between social identity, social support, and psychological well-being amongst survivors of acquired brain injury (ABI).**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Abstract**

Social support is an important factor in rehabilitation following Acquired Brain Injury (ABI). Research indicates that social identity makes social support possible and that social identity is made possible by social support. In order to further investigate the reciprocity between social identity and social support, the present research applied the concepts of affiliative and ‘self as doer’ identities to an analysis of relationships between social identity, social support, and emotional status amongst a cohort of 53 adult survivors of ABI engaged in post-acute community neurorehabilitation. Path analysis was used to test a hypothesised mediated model whereby affiliative identities have a significant indirect relationship with emotional status via social support and self as doer identification. Results support the hypothesised model. Evidence supports an ‘upward spiral’ between social identity and social support such that affiliative identity makes social support possible and social support drives ‘self as doer’ identity. Our discussion emphasises the importance of identity characteristics to social support, and to emotional status, for those living with ABI.

**Key Words:** Brain Injury; Social Identity; Social Support; Depression; Anxiety



# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **Introduction**

As a result of acquired brain injury (ABI) identity often becomes derailed and identity loss following ABI is commonplace (Brooks, 2003; Nochi 1998). However lost identity is not the full story. In the life-course of ABI survivors selves are reconstructed post injury and the self narrative continues (Douglas, 2013). There is a growing recognition of the importance of social factors to individual well-being following brain injury. One such factor is social identity (Haslam et al., 2008). Another is social support (Douglas, 2013). The purpose of the present study was to investigate and attempt to progress understanding of reciprocal processes between social identity, social support and emotional status amongst a cohort of individuals who have survived ABI.

Identity can be understood as that active and dynamic understanding of self which people derive from interactions between themselves and their environments (Simon, 2004, p.45). Tajfel (1982) defined social identity as the sense of self deriving from significant group memberships. The sense of self we develop from membership of social groups, from our families and work colleagues for example, is crucial in the context of a stressor like ABI because as Turner (1982, p.21) argued “social identity makes group behaviour possible”. Social identity provides a basis for mutual social influence (Turner, 1991) and shared social identity facilitates a range of positive social interactions and various other acts of solidarity (Haslam, Jetten, Postmes, & Haslam, 2009). Research shows that difficulties around identity such as self-discrepancy are associated with poor adjustment following ABI (e.g. Cantor et al., 2005). In contrast, continuity of identity following ABI may positively impact well-being because it allows

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

survivors to maintain a consistent self-narrative (Sani, Bowe, & Herrera, 2008) tethering survivors to their pasts and facilitating functioning in the present (Jones, Jetten, Haslam, & Williams, 2012). Consistent with this understanding Haslam et al. (2008) found that identity continuity across time predicts the degree to which individuals adjust following stroke.

In a landmark paper, Haslam, Jetten, Postmes, and Haslam (2009) identified the investigation of relationships between social identities, health and well-being as an important applied field of inquiry for contemporary social psychology. The idea of ‘social cure’ was further developed by Jetten, Haslam, and Haslam (2012) who advocated the social identity approach as a perspective particularly well suited to application in the study of associations between social relationships, group memberships, health and well-being; and people living with ABI are no exception (e.g. Douglas, 2012). In the aftermath of ABI individuals often experience stress and identity loss (Nochi 1998), a likely consequence of failing to meet the obligations and expectations associated with their previous social and professional roles (Ponsford, 2013). Moreover, given that individuals with ABI experience identity loss, research showing that they frequently report fewer social interactions, low social support and poor emotional status is hardly surprising (Dahlberg et al., 2006). It is also worth noting that the positive influence of social support for the emotional status of people with brain injury is well-documented (e.g. Douglas, 2012), implying that research examining the social identity factors associated with social support are clearly warranted.

Social support is a term with diverse meanings, and consequently, it is a term frequently subjected to criticism regarding how it might best be defined and measured (Uchino, 2004). In an influential review, Cohen and Wills (1985)

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

proposed that a distinction be drawn between structural and functional social support. Structural social support pertains to that social support resulting from social ties such as marital status and number of relationships. Functional social support looks to the degree that interpersonal relationships such as provision of affection, generating feelings of belongingness, or provision of material aid, generate social support (Cohen, 1988).

A second important distinction regarding social support is that between main effects and buffering effects. The main effect model suggests that social resources have a beneficial effect regardless of whether or not people are under stress. In contrast, the buffering model proposes that social support is only related to well-being for those under stress (Cohen, 1988). In an extensive review of the literature Thoits (1995) reported that although structural measures of social support relate positively to well-being, they do not buffer the effects of chronic or stressful life events. A large body of evidence suggests that actually received social support and perceived social support are only mildly related (Kaul & Lakey, 2003). Furthermore, evidence indicates that received social support is less consequential in terms of health and well-being than perceived social support (Sani, 2012). Hence, the research reported herein focuses on the aspect of perceived functional social support.

Despite recognition of the importance of social identity and social support for psychological well-being in ABI survivors, at present, the precise natures of these relationships remain unclear. It is widely accepted that social identity, the sense of self deriving from significant group memberships (Tajfel, 1978; Tajfel & Turner, 1979), makes social support possible but it has also been reported that social support enables social identity. Haslam, O'Brien, Jetten, Vormedal, and

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Penna (2005) found that social support mediated the relationship between social identification and psychological well-being in groups experiencing extreme stress, implying that these two processes are working together to improve well-being. Jetten, Haslam, Iyer, and Haslam (2010, p.6) emphasised the distinction between social identity and social support and outlined the relationship between them as one where social identity 'makes social support possible'. For example, research has found that a sense of shared social identity with similar others (ingroup members) enhanced the effectiveness of social support information to reduce stress reactions compared to those without this shared social identity (outgroup members) (Gallagher, Meaney, & Muldoon, 2013; Haslam et al., 2005). In the context of ABI, survivors who appear to redefine themselves and develop new identities are more likely to develop new social relationships and have better adjustment compared to those who struggle with their identities (Ellis-Hill & Horn, 2000). These studies suggest that social identities facilitate social support.

In contrast to the finding that social identity makes social support possible, Gleibs, Haslam, Haslam and Jones (2011) found that social support contributes to the construction of social identity. This is consistent with Haslam et al. (2005, p.367) who suggested an 'upward spiral' involving social identity and social support whereby social support also increases social identification. Furthermore, recently Wakefield and colleagues found that social identity was made possible through social support groups for people with multiple sclerosis. Moreover, a shared sense of identity with support group members was associated with improved psychological well-being (Wakefield, Bickley, & Sani, 2013). Taken together then, these findings suggest that the two variables act reciprocally- social identity driving social support and social support driving social identity.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

One possible explanation as to how social support and social identity might work reciprocally may lie in the nature of the social identity under consideration. It might be that not all social identities are the same and that interrogating different types of identity could facilitate progression towards understanding of this apparent reciprocity between social identity and social support. Billig (1995) identified a banal aspect of social identity whereby identity is often unexpressed and unrecognized but nevertheless present and available for mobilisation if and when required. These ‘background’ identities hinge on feelings of belongingness. They are the groups to which we affiliate, the groups we feel we belong to that are understood as making us who we are. Family and nation are perhaps two obvious examples. These types of belonging identities are referred to herein as affiliative identities. Affiliative identities are generally, as Stevenson and Muldoon (2010, p.584) point out in the context of Billig’s banal identity, ‘the assumed backdrop to everyday life...often unexpressed but always ready to be mobilised’. Indeed, for much of the time it is conceivable that the families, nations and groups that we affiliate to do not even register in our conscious awareness. But they are there, just beneath the surface, ready to become activated as soon as triggered by social or contextual factors. One such potential trigger is stress, another is ill health. Both triggers come together in ABI.

Turning next to a second type of social identity, and in accordance with social identity theorising, Deaux, Reid, Mizrahi, and Ethier (1995) state that membership of social groups provides individuals with an important basis for self-definition. This observation has also been made in the literature of other disciplines including that of social neuroscience where the self is understood as a

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

conduit through which ‘who we are’ is constructed via ‘the social groups we are immersed in’ (Lieberman, 2013, p.191). In concluding that social identities are heterogeneous rather than homogenous, one of the distinctions drawn by Deaux et al. (1995) is that between identities founded upon relationships and identities associated with occupation. The second type of social identity considered here has been described by Houser-Marko and Sheldon (2006) as ‘the self as doer’ construct. This construct comprises identities that are actively constructed in everyday ways and which are actively claimed (Stevenson & Muldoon, 2010). Ashmore, Deaux, and McLauhlin-Volpe (2004) distinguish between ascribed identities, such as gender, and achieved identities, such as occupation. Ascribed identities include those types of affiliative identities detailed in the previous paragraph whereas achieved identities include those ‘self as doer’ type identities identified by Houser-Marko and Sheldon. This constructive component of identity is strategically deployed in the manner suggested by self-categorization theory (Reicher & Hopkins, 2004). It is a work in progress, a project ongoing in the sphere of conscious awareness and day to day discourse. Activity is the fulcrum of ‘self as doer’ identities. As such, activity carries with it the potential for considerable utility in the setting of neuropsychological rehabilitation. Taking part in facilitated and supported activities (for example men’s sheds and painting groups) might provide a basis for identity construction amongst a cohort for whom identity loss is recognized as commonplace. Wilson, Gracey, Malley, Bateman, and Evans (2009), refer to meaningful functional activity as those activities which provide the basis for social participation. Meaning making is central to this aspect. It is clear that from several theoretical points of view, ranging from the social constructionist (e.g. Butler, 2003) to the neuropsychological (Wilson et al., 2009), to the social identity approach (Klein,

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Spears, & Reicher, 2007), to occupational therapy (Hammell, 2004; Wilcock, 1998) that identity is presented as intimately intertwined with activity or ‘doing’. Some identities require performance, Klein et al., (2007) for example, stated that in order to be sustainable identities must be capable of expression. They also stated that identities generally require recognition by others in order to be viable. Self as doer identities hinge on performance.

Gracey et al. (2008) suggest that in the specific context of emotional adjustment following ABI concentrating on questions relating to those activities that hold meaning for individuals might be helpful. This raises the question, in the context of ABI, do affiliative and self as doer identities have the same potential with regards to emotional status?

We set out to test a hypothetical model which suggests that affiliative identities generate social support which facilitates participation in activities that provide a basis for self as doer identities which in turn impact positively upon emotional status by carrying out path analysis. Following the guidance of Hayes (2013) we also investigate an alternative model to determine whether self as doer identities drive social support and in turn affiliative identities. This approach (i.e. testing alternative models) cannot establish with absolute certainty the direction of causal flow but it can help establish an argument against a competing causal order as a plausible account thereby ruling out this possibility as an alternative explanation.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Method**

#### **Participants.**

Fifty-three adult survivors (39 men and 14 women) of brain injury, engaged in post-acute community neurorehabilitation with a national brain injury service provider in Ireland, took part in this study. Average age was 44 years ( $SD=12.32$ ). The youngest participant was 20 years and the oldest was 65 years. Average time since injury was 7 years ( $SD=7.54$ ). 22 participants had an ABI as a result of stroke. The other 31 participants had an ABI as a result of road traffic accidents ( $n=15$ ), falls ( $n=7$ ), tumour ( $n=4$ ), assault ( $n=2$ ), hypoxia ( $n=2$ ) and unknown ( $n=1$ ). Glasgow Coma Scale (GCS) scores were only available for 25 of the 53 participants. GCS scores indicated that 6 of these participants had mild injuries (GCS scores of 13 to 15), 2 had moderate to severe injuries (GCS scores of 9 to 12) and 17 had severe injuries (GCS scores less than 8). Because of the low proportion, low numbers, and uneven distribution of GCS scores severity was not included in further analysis. Inclusion criteria were: people currently accessing services from the national service provider; aged 18 to 65; English as a first language. Exclusion criteria were: people with a level of aphasia or comprehension difficulties that would prevent the successful completion of questionnaires; the presence of a major medical illness unconnected to the ABI (e.g., Dementia). All participants gave informed consent and the study was approved prior to data collection by the local relevant research ethics committee.

#### **Measures.**



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### ***Affiliative Identity; Self as doer identity.***

Ashmore, Deaux, and McLaughlin-Volpe (2004) emphasise the importance of self categorization and suggest that researchers should allow respondents the opportunity to answer open ended questions regarding group memberships. The approach advocated by Ashmore et al. (2004, p.86) also allows researchers ensure that participants are referring to the phenomenologically ‘correct’ social category in their responses. As such, self categorized affiliative identity was established with the question ‘Which group of people you belong to is most important to who you are?’ Self-categorized self as doer identity was accessed via the question ‘Which of the things you do is most important to who you are?’

Identity strength was then established using items from Leach et al.’s (2008) valid and reliable multicomponent model of ingroup identification. An advantage of this model is that it facilitates both unidimensional and fine grained analysis of ingroup identification (Leach et al., 2008). The identity measure employed comprised a 13 item questionnaire measuring group level self investment (solidarity; satisfaction and centrality) and group level self definition (individual self stereotyping; ingroup homogeneity). In a slight alteration from the original 14 item questionnaire, the original question 7, ‘Being [in-group] gives me a good feeling’, was omitted because it closely resembled the included item ‘It is pleasant to be [in-group]’ and had the potential to cause confusion with ABI participants. Individual item scores were obtained using a 7 point Likert scale (1= Agree; 7 = Disagree) as per Leach, Rodriguez Mosquera, Vliek, and Hirt (2010) and in line with Leach et al. (2008) the five subscales of the multicomponent model of in-group identification were summed to provide a measure of identity strength. This procedure was applied to both self as doer and affiliative identity. The identity

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

questionnaire first measured self as doer identity and then affiliative identity.

Sample items include 'I feel a bond with...'; 'I often think about the fact that I am...'. Cronbach's  $\alpha$  for self as doer identity = .85; Cronbach's  $\alpha$  for affiliative identity = .83. Identity scores were reversed in order that higher scores would equate to stronger identity.

### ***Social support***

Social support was measured using the Medical Outcomes Study social support survey (Sherbourne & Stewart, 1991). This 19 item scale measures perceived functional social support and includes measures of emotional/informational support (e.g. someone to listen to you when you need to talk); tangible support (e.g., someone to help you if you were confined to bed), affectionate support (e.g., someone who hugs you); and positive social interaction (e.g., someone to get together with for relaxation). The questionnaire has a 5-point Likert-type format with higher scores indicating higher social support and lower scores indicating an absence of perceived social support. The total score allows construction of an overall functional support index. The authors report that the scale is suitable for application in the context of chronic conditions. The authors further report that the support measures included in the survey are distinct from structural measures of social support (e.g. marital status, number of close friends) and also from health related measures (Sherbourne & Stewart, 1991). Cronbach's  $\alpha$  for this measure was .96.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### ***Emotional status***

Emotional status was measured using the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). The scale contains 14 four-point items, from 0 (not present) to 3 (considerable), with seven assessing largely the anhedonic rather the somatic aspects of depression (e.g., “I have lost interest in my appearance”) and seven assessing anxiety (e.g., “I feel tense or wound up”). This scale was designed in the setting of a general medical hospital outpatient clinic. The validity of HADS has since been confirmed by many studies and it has been shown to be an instrument suited to broad application (Snaith, 2003). Following Fortune, Smith & Garvey (2005) the anxiety and depression subscales of HADS were summed to create a total emotional status variable. Cronbach’s  $\alpha$  for HADS = .83. For the purpose of analysis, the total HADS scores were reversed in order that higher scores would equate to positive emotional status.

### **Design/Procedure**

This study had a cross sectional and correlational design. Participants were approached via their rehabilitation workers and each gave informed consent. Assessments took place at a time and location suitable to the participant; some assessments were conducted at the participant’s own home, others at offices provided by the service provider. One participant did not complete the affiliative identity component of the questionnaire, and another did not complete the self as doer identity component of the questionnaire. One client declined to participate

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

and five clients who agreed to participate were unable, on the day, to engage sufficiently to allow them to do so. Four participants had expressive aphasia so drawing with the use of a portable blackboard was used in conjunction with pointing to facilitate effective communication.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Statistical analyses**

All data were entered into SPSS for analysis. Checks were conducted for skewness and kurtosis; these indicated that the main study variables were normally distributed and thus parametric tests were used for correlation analysis. Initially analyses tested for bivariate correlations between self as doer and affiliative identities, social support, emotional status, age, gender and cause of injury in order to identify variables suitable for inclusion in the model. Commensurate with the guidance offered by Hayes (2009) bootstrapping to 5000 was conducted and the data tested for indirect effects. To this end, path analysis was conducted using PROCESS Model 6 (Hayes, 2013). This analysis was then repeated controlling for gender and cause of injury. In this model, the mediators are tested in a causal chain. Path analysis tested the chain suggested in the introduction i.e. affiliative identity → social support → self as doer identity → emotional status.

Following the suggestion of Hayes (2013) in order to investigate (and rule out) the possibility that an alternative causal explanation might 'fit' the data a self as doer identity → social support → affiliative identity → emotional status model was also tested.

## A Social Identity Approach to Acquired Brain Injury (ABI)

### Results

Table one illustrates the means and standard deviations of all measures employed.

Table 1. *Mean scores and standard deviations, all measures, ABI population.*

	N	Minimum	Maximum	Mean	Standard deviation
Self as doer	52	44	91	76	12.37
Affiliative Identity	52	57	91	83	9.11
Emotional Status	53	11	42	31	7.18
Social support	53	29	95	76	17.98

*Note, possible ranges: affiliative id 3-21; self as doer id 3-21; Psych. w.b. 0 – 42; social support 19-95*

### **Associations between social identities, social support anxiety and emotional status**

Preliminary analysis showed that active identity was positively correlated with both emotional status and social support, whereas affiliative identity was positively correlated only with social support. Gender had a significant correlation with active identity such that men had stronger active identities than women and affiliative identity correlated with cause such that stroke survivors had stronger affiliative identities than other injury types. Correlations between measures (Pearson's  $r$ ) are presented in Table 2.

## A Social Identity Approach to Acquired Brain Injury (ABI)

Table 2.

*Bivariate Correlations between measures (Pearson's  $r$ ).*

	Aff. Identity	Emot. Status	Social Support	Age	Gender	Cause
'Self as doer'	.54**	.41**	.63**	.18	.32*	.19
Affiliative Identity		.11	.59**	.16	-.08	.29*
Emotional Status			.35**	.06	-.22	.08

### Mediating relationships between social identities, social support, and emotional status

It was predicted that the relationship between affiliative identity and emotional status would be mediated by social support and self as doer identity. This hypothesis was supported. The indirect effect of affiliative identity on emotional status via social support and self as doer identity as mediators was:  $B=.29$ ;  $SE = .10$ ; 95% CI [.12, .49]. The standardised indirect effect was:  $\beta = .37$ ;  $SE = .12$ ; 95%CI [.16, .63]<sup>1</sup>. A model was also tested which included gender and cause of injury as covariates (these correlated with active and affiliative identities respectively in the preliminary analysis). Standardised effect sizes are not available in Process models which control for covariates but, controlling for gender and cause of injury, the unstandardised indirect effect of affiliative identity

<sup>1</sup> Looking to anxiety and depression as distinct outcomes: The total indirect effect of affiliative identity on anxiety via social support and self as doer identity as mediators was  $B=-.63$ ;  $SE = .20$ ; 95% CI [-1.19;-.35]. The total indirect effect of affiliative identity on depression via social support and self as doer identity as mediators was  $B=-.32$ ;  $SE = .19$ ; 95% CI [-.74;-.00].

## A Social Identity Approach to Acquired Brain Injury (ABI)

on emotional status via social support and self as doer identity was  $B = .27$ ,  $SE = .10$ ; 95% C.I. [.10, .51]. These findings can be understood in terms of affiliative identities generating higher perceived functional social support and functional social support facilitating participation in activities that become internalised as self as doer identities which in turn generate emotional status. There was no significant direct effect of affiliative identity on emotional status:  $B = -.21$ ;  $SE = .13$ ; 95% CI [-.47; .05].

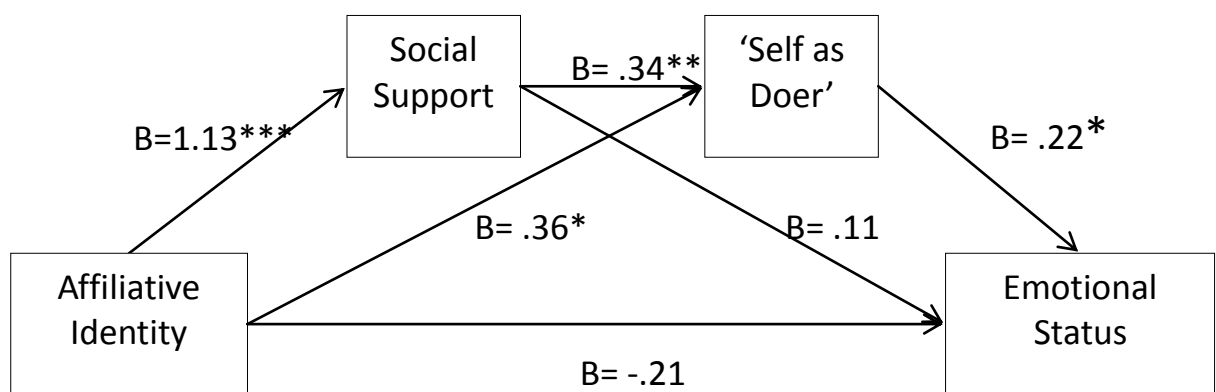


Figure 1. Path analysis for affiliative identity to emotional status via social support and self as doer identity.  $B = .29$ ;  $SE = .10$ ; 95% CI [.12, .49].

Note: \*  $p < .05$ ; \*\*  $p < .01$ ; \*\*\*  $p < .001$ :

The model of an alternative causal explanation, i.e. that self as doer identity had a significant indirect relationship with emotional status via social support and affiliative identity as mediators was also tested. This model was not significant.  $B = .02$ ;  $SE = .07$ ; 95% CI [-.12, .15]. In other words there was no significant relationship between self as doer identity and emotional status mediated by social support and affiliative identity.



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Discussion**

The results of this study suggest that in the context of ABI, affiliative identity is a significant driver of well-being via social support and self as doer identity. Our preliminary investigations examined whether affiliative and self as doer identities correlated differently with perceptions of social support and positive psychological wellbeing. Results indicate that for those survivors of ABI who took part in this study, these different types of identities had different effects. Affiliative identity was positively correlated with social support but not correlated with emotional status. In contrast, self as doer identity was positively correlated with emotional status in addition to being positively correlated with social support. This supports the approach advocated by Wilson, Gracey, Malley, Bateman, and Evans (2009) and suggests that meaningful activities that facilitate identity construction are of importance in terms of individual post ABI adjustment.

According to the literature, social identity both makes social support possible (Jetten, Haslam, Iyer, & Haslam, 2010) and is made possible by social support (Gleibs, Haslam, Haslam, & Jones 2011). To the best of our knowledge this study is the first to investigate whether the reciprocity between social identity and social support is explicable via consideration of different types of social identities. This research investigated how, in the context of ABI, the relationship between social identity and social support is such that each drives the other with regard to emotional status. The results of the path analysis suggest that examining identity in terms of affiliative and self as doer identity types offers a route to understanding the reciprocal relationship between social identity and social support described in the existing literature. Evidence suggests that affiliative

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

identity, a feeling of belonging, makes social support possible and that, in turn, social support enables self as doer identification. This evidence of reciprocity between social identity and social support is wholly consistent with self categorisation theory as set out by Turner and Oakes (1986) who in arguing for an interactionist social psychology clearly recognized and acknowledged such reciprocal interactions. This finding is also in line with the proposition put forward by Haslam, O'Brien, Jetten, Vormedal, and Penna (2005, p.367) who said that self categorization principles 'suggest that social identification has the potential to create an 'upward spiral' whereby identification increases social support and emotional status, which in turn increase social identification'.

Our finding that social support and self as doer identities mediate the relationship between affiliative identity and emotional status lends support to the view that social identities are heterogeneous (Deaux et al., 1995). It seems that belonging to groups (affiliative identity) fosters perceptions of social support and that perceiving social support facilitates participation in activities which become internalised as social identities (self as doer identity) which in turn impact positively on psychological well-being. Our results suggest that looking to one type of social identity alone may not tell the whole story regarding relationships between social identity, social support and emotional status following brain injury. The significance of identity arising from belonging, of affiliative identity, seems to rest in a wider causal chain that includes perceived social support and self as doer identities. Affiliative identity, identity built on belonging, seems to be necessary, but not sufficient, for positive emotional status following ABI. Engagement with meaningful activities that can become internalised as identities seems to be required. Results of this study support and clarify the existing social

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

identity literature pertaining to relationships between social identity, social support and emotional status. Evidence backs the view that the relationship between social identity and social support is such that each makes the other possible. Application of the concepts of self as doer and affiliative identity facilitates understanding of the processes through which this reciprocal interaction between social identity and social support takes place.

It seems that social identity resources are mobilised to safeguard or regain emotional status when it is threatened by circumstance. There are important practical considerations flowing from these findings, not least is the requirement for a programme of research which must focus on further uncovering processes of reciprocity (Turner & Oakes, 1986). In contrast to the social identity approach which understands individuality as a social property (Turner & Oakes, 1986), there remain perspectives in psychology which accept the concept of personality change and regard an important aspect of neuropsychological rehabilitation as being about coming to terms with irreversibly altered personality. Yeates, Gracey, and Collicutt McGrath, 2008 (p.568) refer to this type of individualistic perspective as a 'clinical dead end'. However, the evidence provided that self as doer identities can be driven by social support, challenges deterministic and individualistic understandings. It offers support instead for an interactionist approach. The evidence presented further affirms the utility of social approaches to neuropsychology such as applied by Yeates et al. (2008); Wilson, Gracey, Malley, Bateman, and Evans (2009); and Bowen, Yeates, and Palmer (2010). Our findings support the view that who it is that people understand and experience themselves to be, who they 'are', is a partly at least a function of external, social factors.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

These findings also support the type of relational approach advocated by Bowen, Yeates, and Palmer (2010) and by Ylvisaker, McPherson, Kayes, and Pellett (2008) in terms of metaphoric identity mapping. This type of ‘social neuropsychology’ (Haslam et al., 2008) has the potential for considerable utility in applied neuropsychological rehabilitation. Another important and practical consequence of the findings presented in this study is that they might contribute to a shift in understanding of social participation. Instead of regarding social participation as a desired outcome, as has traditionally been the case, social participation could instead be understood as a rehabilitation input that might usefully be targeted for intervention. As such, meaningful social activities might be structured for individuals in such a way that they contribute to developmental trajectory that is continuously fed through social experience (Gracey & Ownsworth, 2012). Cantor et al. (2005) suggested that better understanding of factors related to post ABI affective disorders is essential to the development of appropriate interventions to address these disorders. It is our hope that the distinction between the identity sub-types of affiliative and self as doer identities that was drawn in the present study might contribute towards such an understanding and perhaps even offer a basis for practical interventions that contribute towards individual recovery and adaption.

### ***Limitations***

This study was a correlational study and it must be acknowledged that a correlational design precludes a definitive causal interpretation of the relationships between affiliative identity, self as doer identity, social support, anxiety and depression. Hayes (2013) refers to the issue of causality as the cinnamon bun of social science – a sticky and messy concept. Hayes cautions that

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

statistical causality is a concept that unravels in an endless philosophical spiral of reductionism and recommends a more pragmatic approach. Hayes suggests that social scientists do the best they can with the statistical tools and data available to them. Therefore PROCESS Model 6 (Hayes, 2013) was employed in this study. This model was designed to establish the order of serial mediators in a causal pathway between predictor and outcome variables. While it is the case that this model does not definitively establish causation according to its author it does facilitate informed consideration and engagement with the contemplation of causal pathways between the variables being investigated.

There are other limitations to this study. In short, the findings should be regarded as preliminary due to sampling, measurement and design considerations. The sample size was relatively small and it is possible that cultural context and other factors might limit the generalisability of the findings. On this point, it would be interesting to investigate whether there would be a difference in these processes between cultures where cultural interdependence is favoured and western 'independent' cultures where 'doing' is regarded as important. It is also arguable that a longitudinal study would provide more compelling support for the finding presented here. In terms of measurement, while the authors approached the data informed by a social identity perspective and attempted to measure the strength of the single affiliative and self as doer identity which participants considered most important to 'what made them who they are' it needs to be recognized that identities are fluid and dynamic and may vary as a function of importance and salience at different times. As such, firm conclusions about the direction or causality of relationships should not be drawn at this point. Furthermore, the study did not include a 'stressed' non-ABI group which might

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

establish whether this data speaks to a broader model or is specific to the somewhat unique example of altered identity following ABI.

### **Conclusion**

Research of identity processes amongst survivors of ABI is interesting because it allows a measure of access to processes that can be understood as being, to some degree, interrupted and thus laid bare. It has been suggested that the interruption of higher psychological functions can serve as a path for their analysis (Cole, Levitin, & Luria, 2006). Contemporary neuropsychological researchers including Yeates, Gracey, and Collicutt McGrath, (2008) advocate social approaches to neuropsychology. Given the sample size and other limitations outlined previously the results presented herein constitute a level of qualified support for such approaches. The value of distinguishing between affiliative identity and self as doer identity is apparent on two levels: the theoretical and the applied. On a theoretical level, distinguishing between affiliative and self as doer identities and their associated pathways with regard to emotional status provided empirical results which support an argument for reciprocal interaction, and an argument against individualism in neuropsychological rehabilitation. On a practical level, the distinction between affiliative and self as doer identities would seem to offer the promise of utility in the applied context of ABI and it seems reasonable to suggest that the distinction may also offer the potential for practical application in a wider context.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

This report re-emphasises the importance of social support to emotional status. It also provides evidence supporting the idea of an upward spiral of reciprocity between social identities and social support as they relate to emotional status amongst those living with ABI. Self as doer and affiliative identities seem key to understanding this reciprocity and were demonstrated to be useful concepts for application in attempting to understand this 'upward spiral' because they were shown to work in different ways amongst people who have survived ABI. We believe that the social identity approach holds the key to explaining at least some of the complexity attaching to the reciprocal processes taking place between identity, social support and emotional status following ABI, but much remains to be done. A logical next step in this enterprise will be to incorporate analysis of neurological factors associated with ABI in an investigation of emotional status. We submit that the concepts of self as doer and affiliative identities offer a start point for the investigation of identity processes emerging from reciprocal interaction between social and biological factors following ABI and perhaps in the context of other chronic or extreme stressors.

## A Social Identity Approach to Acquired Brain Injury (ABI)

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## A Social Identity Approach to Acquired Brain Injury (ABI)

### Appendix 1:

Affiliative and 'self as doer' identities elicited from participants

#### Affiliative Identities:

ABI Ireland	1
Men's shed	1
Bridge club	1
Brothers (6boys)	1
Community centre	1
Dancing group	1
Extended family	1
Family	27
Football club	1
Friends	7
Girlfriend/family	1
Humankind	1
My marriage	1
My family	2
My kids	1
My partner	1
Not part of any group	1
People in bookies	1
Swimming group	1
Wheelchair assoc.	1
Total	53

#### 'Self as doer' identities:

Art	1
Baking	1
Being a good friend	1
Being a mother	1
Bird breeding	1
Building	1
Child care	1
Choir singing	1
Coffee with friends	1
Computers	1
Cooking and baking	1
DJing	1
Dressing/clothes	1
Farming	3
Fitness	1
Fixing / being handy	1
Following GAA	1
Following irish dance	1
Following Munster	1
Following local FC	1
Going to gym	1
Going to matches	1
Going up the town	1
Greyhounds	1
Gym/pool/sauna	1
Listening to music	1
Mechanicng	1
Mother	2
Music	3
Music&guitar	1
Parenting	2
Parenting/housewife	1
Photography	1
Reading	1
Talking	1
Theatre/cinema	1
Thinking	1
Walking	7
Walking the dog	1
Work	1
Working	1
Total	53



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

**CHAPTER 4**

**Paper 3**

**An investigation of relationships between cause, disability,  
stigma, survivor identity and quality of life following  
Acquired Brain Injury (ABI)**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Abstract**

This study investigates relationships between cause of acquired brain injury (ABI), level of disability, stigma, survivor identity and quality of life amongst a group of adult brain injury survivors. Fifty nine participants engaged in post-acute community neurorehabilitation with a national brain injury service provider in Ireland took part in this study. Mediation analysis indicates a significant indirect pathway between disability severity and psychological quality of life, social relationships quality of life and environmental quality of life via stigma. Analysis also indicates a significant indirect pathway between cause of injury and both overall quality of life and psychological quality of life via survivor identity. Findings support the view that cause of injury and disability severity may be useful predictors of quality of life via stigma and survivor identity. Furthermore, results suggest that stigma and survivor identity are crucial in terms of relationships between cause of injury, disability and quality of life following ABI.

# **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **Introduction**

This study investigated relationships between cause of injury, disability, stigma, survivor identity and quality of life amongst a group of acquired brain injury (ABI) survivors engaged in post-acute community neurorehabilitation. ABI presents survivors, families and rehabilitation clinicians with a unique set of problems (Ponsford, 2013). ABI is devastating, life changing and confusing (Newby, 2013). At present, the mechanisms of recovery from brain injury are not well understood and there is considerable variation in recovery patterns (Ponsford, 2013). ABI can be understood as a complex cluster of symptoms, signs and deficits that are superimposed on survivors and their webs of social connections and contexts including families, friends, work, leisure and childcare commitments.

Andrewes (2001) highlights two distinct phases of recovery from ABI. The acute phase is that period immediately following brain damage during which the brain experiences an acute neurophysiological response to insult, for example oedema or neural shock. In this acute phase, medical measures of severity such as the GCS (Glasgow Coma Scale; Teasdale, & Jennett, 1974) are extremely useful for predicting mortality. For example those with a GCS score of 3 presenting with pupils that are fixed and dilated have no significant potential of survival (Chaudhuri, Malhamab, & Rosenfeld, 2009). However, it is the post-acute phase that is the focus of this study. Using severity measures<sup>2</sup> to predict the day to day difficulties that will be experienced in the post-acute phase of recovery by people with particular classifications of head injuries is extremely problematic (Entwistle & Newby, 2013). The poor predictive efficacy of severity measures points to the

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<sup>2</sup> The Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) is the instrument most often used to determine brain injury severity (Wilson, 2009).

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

need for a holistic approach to ABI and neuropsychological rehabilitation that incorporates the social and interpersonal aspects of brain injury (e.g. Ben-Yishay & Diller, 2011).

The post-acute or adaptation phase can be understood as the ‘healing phase’ during which functional and reorganizational changes can occur. The suggestion investigated by this report is that in the post-acute phase of ABI, disability and cause of injury, because of what they mean to individuals in the contexts of their social worlds, may be useful predictors of outcome.

The social identity approach (SIA) is an emerging paradigm suited to applied research in the field of brain injury that has the capacity to attend to both the biological and social aspects of ABI (Walsh, Fortune, Gallagher, & Muldoon, 2012). The SIA is a psychological metatheory incorporating social identity theory (SIT, Tajfel & Turner, 1979) and self categorisation theory (SCT, Turner, Hogg, Oakes, Reicher, & Wetherell, 1987). Social identity, the socially structured process of self (Simon, 2004) is fundamental both to how individuals understand their worlds and to how they interact with them. Social identities structure individual behaviours, perceptions, relationships and interactions. Social identities determine what people think, do and achieve (Haslam, 2014). The full potential for the practical application of this foundational insight of social identity theory has yet to be fully tapped into and exploration of the opportunities it affords to clinical psychology has barely begun (Haslam, 2014).

A useful start has been made in applying the social identity approach to the study of ABI. In a study of stroke survivors, Haslam et al. (2008) found that social identity continuity predicted well-being after stroke. Social identity continuity refers to a maintained connection to the past that individuals experience through preserved group memberships (Haslam et al., 2008). This finding lends

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

support to the view that how people understand their connectedness to others, and how they think about and understand themselves, their social identities, are important, pivotal and consequent processes for those negotiating the life transition that is presented by ABI (Jones, Jetten, Haslam, & Williams, 2012).

Where Jones et al. (2011) looked to social network measures of improved relationships following ABI, the present study instead investigates the impact of stigma, a factor that has been identified as negatively impacting social interactions across a range of social health domains (Stevenson, McNamara, & Muldoon, 2014). Stigma is a negative social identity. Stigma 'refers to the marked identity of people with traits that are different to what is considered normal or ideal. Felt stigma refers to the knowledge that one's trait may be stigmatized' (Phelan et al., 2011, p.177). Lorenzi-Cioldi (2006) states that stigma constitutes one of the clearest examples of group identification whereby people see themselves as interchangeable examples of a social category rather than as being defined by their individual differences. Felt stigma reflects the experiences associated with a spoilt identity, and it occurs when people believe that others think less of those who are members of their group. Phelan et al. (2011) reported that the experience of stigma can contribute to outcomes that include anxiety and other mental health issues as well as the avoidance of social situations resulting in reduced social support and isolation. Here we hypothesise that people experiencing higher levels of disability would experience themselves as more stigmatised than people with lower levels of disability.

In a recent study conducted with ABI survivors whose injuries result from a variety of causes including road traffic accidents, cerebrovascular accident, falls, assaults and other causes, Jones et al. (2011) found that the relationship between injury severity as determined by length of coma and life satisfaction was mediated

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

by social identities (i.e. 'I think of myself as a survivor' and 'my injury has made me a stronger person'). Survivor identities reside at the positive end of the identity continuum compared to negative identities such as stigma. Identifying as a survivor, considering oneself a stronger person because of adversity, in this study because of brain injury, is an example of a social identity with positive valence that can act as an important psychological resource for health (Muldoon & Lowe, 2012). Survivor identity has the potential to provide a psychologically meaningful way to interpret the experience of brain injury – an event which can be conceptualised as both physically and psychologically traumatic.

In addition to attending to disability severity it is also necessary to attend to outcomes. In terms of outcome measures, life satisfaction is without doubt a useful measure. Life satisfaction refers to the 'cognitively oriented, subjective judgement of one's current life situation in relation to one's own expectations' (Mailhan, Azouvi, & Dazord, 2005). However as rehabilitation shifts from a biomedical approach to a biopsychosocial approach there has been a corresponding increase in focus on quality of life as outcome. Indeed Ackerley, Gordon, Elston, Crawford, and McPherson (2009) report that measurement of quality of life is critical to understanding the effects of rehabilitation delivery and that it is arguably the most desirable outcome of health interventions. The World Health Organisation Quality of Life (WHOQOL) group (1998) define quality of life as 'individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns'.

### ***The present research***

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

The investigations reported herein examined the relationships between causes of injury, disability severity, strength of stigma, and survivor identity and quality of life amongst a cohort of ABI survivors engaged in post-acute community neurorehabilitation. Hayes (2013) advises that mediation analysis is the statistical method best suited to understanding how a hypothesised causal agent transmits its effect on a given outcome. Previous research (Jones et al., 2011), employing mediation analysis, found that identity strength mediated the relationship between length of time in a coma and life satisfaction. Building on these findings, we hypothesised that disability severity and cause of injury would both be related to quality of life. We next hypothesised that disability severity, stigma and survivor identity would be related such that higher levels of disability would relate to stronger stigma identity and weaker survivor identity. Based on the observation by Andrewes (2001) that stroke and traumatic brain injuries can present with differing psychological manifestations, and also following the advice of Belbo, Sinnamon and Baune (2011) regarding the use of aetiologically derived clusters in research, we hypothesised that cause of injury would relate to survivor identities such that those with traumatic injuries would have stronger survivor identities than those with non-traumatic injuries. Our final hypothesis was that the relationship between injury factors (i.e. injury cause and disability severity) and quality of life would be mediated by stigma and survivor identities.

### **Method**

#### **Participants**

Fifty-nine adult survivors of brain injury, engaged in post-acute community neurorehabilitation with a national brain injury service provider in



## A Social Identity Approach to Acquired Brain Injury (ABI)

Ireland were recruited for this study. Average age was 45 years (SD=12.12). The youngest participant was 20 years and the oldest was 65 years. Average time since injury was 7 years (SD=7.39). Inclusion criteria were: people currently accessing services from the national service provider; aged 18 to 65; English as a first language. Exclusion criteria were: people with a level of aphasia or comprehension difficulties that would prevent the successful completion of questionnaires; the presence of a major medical illness unconnected to the ABI (e.g., Dementia). All participants gave informed consent and the study was approved prior to data collection by the local relevant research ethics committee. Only one potential participant who was approached to take part refused to do so. Six participants did not complete the identity component of their questionnaires and three did not fully complete the Mayo Portland Adaptability Inventory (MPAI) component. All bar one participant completed the World Health Organisation Quality of Life survey (WHOQOL-BREF) but three of those who completed the measure omitted one item. Scoring instructions for this instrument state that where an item is missing from a given domain the mean of the other items in the domain should be substituted. This procedure was applied.

Participant demographics are presented in table 1 below.

Table 1. Participant details

		Frequency	%				
<b>Traumatic brain injury</b>	(Traffic accident, fall, assault)	27	46	<b>Gender</b>	Male	44	74.5
					Female	15	25.5
<b>Non-traumatic brain injury</b>	(Stroke, tumour, hypoxia)	32	54	<b>Injury Severity</b> (n=56;incomplete MPAI from 3)	Good outcome	1	1.8
					Mild disability	11	18.6
					Mild to moderate	31	52.5
					Moderate to severe	13	22.0

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Measures**

#### ***Cause of Injury***

In the UK and Ireland, ABI service providers typically engage with clients whose injuries are the result of both traumatic and non-traumatic events (Entwistle & Newby, 2013). Belbo, Sinnamon, and Baune (2011) suggest that attending to the study of the neurobiological factors underpinning psychological well-being is a worthwhile endeavour and they recommend the use of aetiologically defined clusters in research. As such, because distinct neurobiological characteristics tend to be associated with traumatic and non-traumatic injuries (e.g. the nature of head injury after road traffic accidents often give rise to common patterns of cognitive deficit whereas strokes are more often associated with language impairments; Andrewes, 2001) we suggest that it makes sense to separate traumatic from non-traumatic aetiologies.

In this study, traumatic aetiologies were classified on the basis that they were the result of direct mechanical damage to the brain that could be classified in terms of (i) contusion, intracranial haemorrhage and laceration resulting from contact injuries and (ii) acceleration/deceleration cause of injuries resulting in diffuse axonal injuries and/or brain swelling (Werner & Engelhard, 2007). These types of injuries were the result of falls, assaults and road traffic accidents. Non-traumatic aetiologies do not involve direct mechanical forces and include infections, hypoxia, tumours and strokes (Teasell et al., 2007). For the purpose of data analysis non-traumatic injuries were coded as 0 and traumatic injuries were coded as 1.

## A Social Identity Approach to Acquired Brain Injury (ABI)

### *Disability Severity*<sup>3</sup>

The investigations presented herein utilised the Mayo Portland Adaptability Inventory (MPAI-4; Malec & Lezak, 2003) which measures the level of disability that individuals find themselves coping with in their everyday lives. The MPAI-4 measure has been identified by peer-review as a tool appropriate for application in research that assesses disability after brain injury (rehabmeasures.org). The MPAI-4 (Mayo-Portland Adaptability Inventory, Malec & Lezak, 2003) was specifically designed for post-acute assessment of disability following brain injury. The instrument employs a five point Likert format and comprises three subscales measuring ability, adjustment and participation (sample items: Mobility: problems walking or moving; balance problems that interfere with moving about; Inappropriate social interaction: acting childish, silly, rude, behaviour not fitting for time and place; Problems getting started on activities without prompting). The 29 item scale has been found to have internal consistency, reliability and validity across various groups with ABI including TBI, stroke, tumour, and other neurological disorders (“Rehab Measures – Mayo-Portland Adaptability Inventory”) and was designed to be completed by

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<sup>3</sup> The Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974) is the instrument most often used to determine brain injury severity (Wilson, 2009). This measure employs three indices of wakefulness: eye opening, motor response, and verbal response, to construct a 15 point scale indicative of injury severity. Scores of 8 or less are considered severe, 9-12 are considered moderate, and scores of 13-15 are understood to be mild. Notwithstanding its primacy as the measure of severity most often employed by clinicians it has an intrinsic shortcoming – up to half the brain injury victims admitted to hospitals are admitted in the absence of a coma although many of them go on to experience the consequences of ABI (Kolb & Whishaw, 2009). For the present study individuals GCS scores and cause of injury were sourced from medical files which were accessed following the provision of informed consent by participants. GCS scores were only available for 22 of the 59 participants who took part in this study and were therefore not utilised.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

(amongst others) ABI survivors (Malec & Lezak). MPAI scores can be transformed into standard scores however raw scores were used for the present analysis. Cronbach's  $\alpha$  for MPAI-4 in this study = .81

### ***Stigma and survivor identity***

Felt stigma associated with the role of being a person with an ABI was measured using two items sourced from Phelan et al. (2011, p.179)): 'I think there is a stigma that goes with acquired brain injury' and 'I think most people think less of a person with an acquired brain injury'. Individual scores for each of the two items were combined to give an overall total score. Cronbach's  $\alpha$  for this two item measure was .67.

In order to determine survivor identification participants rated two statements sourced from Jones et al. (2011, p. 358) that were designed specifically to tap into the survivor identity experienced by ABI survivors. These item assessed survivor identity via the statements 'Having a brain injury has made me a stronger person' and 'I think of myself as a survivor'. As with stigma identification, individual scores for each of the two items were combined to give an overall total score. Cronbach's  $\alpha$  for the two item survivor identity measure was .61.

All identity items were measured on a 7 point Likert scale where 1= Agree and 7= Disagree. Scores were then reversed for analysis in order that higher scores equated to stronger agreement.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### ***Quality of Life.***

The WHOQOL-BREF has been found to offer robust psychometric performance in a diverse range of patient samples that include people with neuro-disability and stroke survivors receiving neuro-rehabilitation services (Skevington & McCrate, 2012). The WHOQOL-BREF incorporates one general item designed to assess an individual's overall perception of quality of life ('How would you rate your quality of life?') and one general item designed to assess an individuals' overall perceptions of their health ('How satisfied are you with your health?'). Both of these items are scored on a 5 point Likert scale. The WHOQOL-BREF also includes 4 domains designed to elicit 'individuals' perceptions of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards and concerns' (The WHOQOLGroup, 1998). Domain 1, Physical Health, incorporates 7 items pertaining to medication, activities of daily living, energy and fatigue, mobility, pain, sleep, and capacity for work. (Sample item = How much do you need medical treatment to function in your everyday life?) Domain 2, Psychological incorporates 6 items relating to bodily image, negative and positive feelings, self esteem, personal beliefs, thinking, learning, memory and concentration. (Sample item = Are you able to accept your bodily appearance?) Domain 3 Social Relationships includes 3 items relating to personal relationships, support from friends, and sexual activity. (Sample item = How satisfied are you with your personal relationships?) Domain 4 Environment incorporates 8 items relating to financial resources, physical safety and security, health care, participation, physical environment and transport. (Sample item = Have you enough money to meet your needs?). All items were measured on a 5 point Likert

## A Social Identity Approach to Acquired Brain Injury (ABI)

Scale. The WHOQOLBREF allows that raw scores of each domain be converted to a 0-100 scale however raw scores rather than transformed scores were used in this study. Cronbachs  $\alpha$  for these measures were: Domain 1  $\alpha = .76$ ; Domain 2  $\alpha = .73$ ; Domain 3  $\alpha = .77$ ; Domain 4  $\alpha = .83$ . The WHOQOL-BREF allows that scored for each domain be transformed onto a 1-100 scale. However, this study used the raw scores for each subscale.

### Results

Preliminary analyses examined relationships between cause of injury, disability severity as per the MPAI-4, stigma, survivor identification and quality of life outcomes as per the WHOQOL-BREF using bivariate correlations (Pearson's  $r$ ). Analysis indicated that disability severity was negatively correlated with individual's overall perceptions of quality of life and overall perceptions of health. Disability severity was positively related to stigma but not to survivor identity. Cause of injury was associated with survivor identity but not stigma. Figures are presented in table 2 below.

Table 2. Relationships between disability severity and WHOQOL-BREF outcomes

	Disability severity	Stigma	Survivor identification	Overall Quality of life	Overall Health Satisfaction	Physical Health Quality of life	Psychological Quality of life	Social Relationships Quality of life	Environmental Quality of life
Cause	-.22	.13	-.29*	-.10	-.00	-.02	-.12	-.10	-.06
Disability severity		.29*	-.09	-.29*	-.39**	-.05	-.25†	-.16	-.03
Stigma			.08	-.05	-.30*	-.10	-.27†	-.35*	-.32*
Survivor identification				.28*	.21	.20	.26†	.15	-.03

† =  $p < 0.06$  (2 tailed); \* =  $p < 0.05$  (2 tailed); \*\*  $p < 0.01$  (2-tailed)

## A Social Identity Approach to Acquired Brain Injury (ABI)

Analysis next proceeded to employ t-tests to further examine the relationship between cause of injuries (i.e. those with TBI injuries v others) in terms of strength of stigma and survivor identification. Results indicate that TBI survivors ( $n=24$ ) had significantly stronger survivor identities than survivors of other cause of injuries ( $n=29$ )<sup>4</sup>. Mean survivor identity TBI survivors = 12.04; Mean survivor identity other cause of injuries = 10.21 ( $p = .035$ ). There was no significant difference in the strength of stigma between the same groups (mean stigma TBI survivors = 7.79; mean stigma other cause of injuries = 8.83;  $p = .36$ ). T-tests also indicated no significant difference between quality of life (QoL) outcomes based on cause of injury. Mean overall QoL TBI = 3.96, Mean overall QoL others = 3.81; mean overall health satisfaction TBI = 3.78, mean overall health satisfaction others = 3.77; mean physical health QoL TBI = 3.19, mean physical health QoL others = 3.20; mean psychological QoL TBI = 20.78; mean psychological QoL others = 20.00; mean social QoL TBI = 11.48, mean social QoL others = 11.00; mean environmental QoL TBI = 31.89, mean environmental QoL others = 31.29.

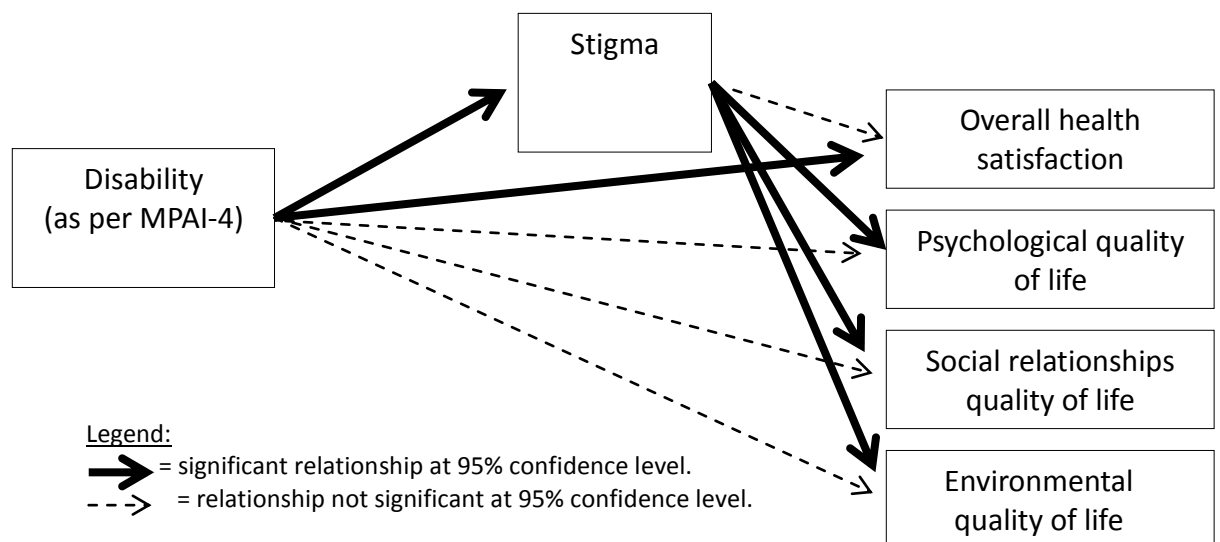
Finally, path analyses tested for mediated pathways between disability, cause of injury, and WHOQOL outcomes. Hayes (2013, p.88) states that contemporary mediation analysis 'no longer imposes evidence of simple association between  $X$  and  $Y$  as a precondition'. Following the guidance offered by Hayes (2009), where path analysis was employed bootstrapping to 5000 was conducted and the data tested for indirect effects in both the presence and the absence of total effects. PROCESS (model 4) was used to examine relationships between variables. Significant pathways are indicated by an unbroken line in figures 1 and 2 below and those pathways that were not significant are indicated

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<sup>4</sup> 6 participants returned incomplete identity questionnaires and their scores are not included in this analysis

## A Social Identity Approach to Acquired Brain Injury (ABI)

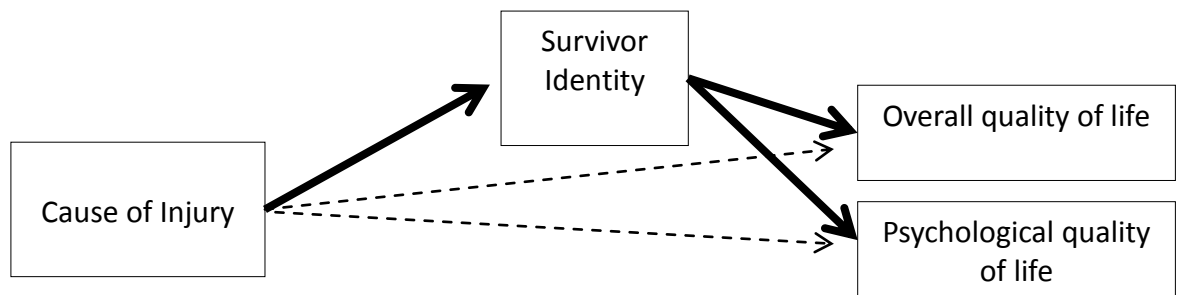
by a broken line. Hayes (2013) states that standardised effect sizes deriving from a dichotomous predictor variable should not be reported. As such, standardized effect sizes are not reported for cause of injury.  $K^2$  (Preacher & Kelley, 2011) indicates the ratio of the obtained indirect effect to the maximum possible indirect effect. Preacher and Kelley suggest that small, medium and large effect sizes might be defined as .01, .09 and .25 respectively. This figure is suitable for application with both dichotomous and continuous predictor variables and as such was employed in the reporting of these results.



**Figure 1.** Relationships between disability, stigma, overall health satisfaction, psychological quality of life, social relationships quality of life and environmental quality of life.



## A Social Identity Approach to Acquired Brain Injury (ABI)



### Legend:

→ = significant relationship at 95% confidence level.

--> = relationship not significant at 95% confidence level.

**Figure 2** Relationships between cause of injury, survivor identity, overall perceived quality of life and psychological quality of life

### *Disability as predictor; stigma as mediator; QoL as outcome*

Disability was correlated with stigma. In turn, stigma was found to be correlated with the following WHOQOL-BREF domains: overall health satisfaction, psychological quality of life, social relationships quality of life, and environmental quality of life. Mediation analysis was therefore conducted to test these indirect pathways. Because stigma was not significantly correlated with the WHOQOL outcomes overall quality of life and physical health quality of life mediation analysis was not necessary with respect to these pathways as they were not significant.

The indirect relationship between disability and overall health satisfaction via stigma was not significant,  $B = -.00$ ;  $SE = .00$ ; 95% CI  $[-.01; .00]$ . The direct relationship between disability and overall health satisfaction was significant,  $B = -.02$ ;  $SE = .01$ ; 95% CI  $[-.04; -.00]$ .

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

The indirect relationship between disability and psychological quality of life via stigma was significant  $B = -.02$ ,  $SE = .0$ ,  $95\%CI[-.05;-.00]$ ;  $\beta = -.07$ ,  $SE = .05$ ,  $95\% CI [-.22,-.00]$ ;  $K^2 = .07$ ,  $SE = .05$ ,  $95\%CI [.00;.20]$ . The direct relationship between disability and psychological quality of life was not significant,  $B = -.04$ ,  $SE = .04$ ,  $95\% CI [-.11, .04]$ . Disability was not directly related directly to psychological quality of life. Rather the relationship is indirect such that disability is working via stigma and exerting a significant indirect effect on psychological quality of life.

The indirect relationship between disability and social quality of life via stigma was significant  $B = -.02$ ,  $SE = .01$ ,  $95\% CI [-.05; .00]$ ;  $\beta = -.10$ ,  $SE = .05$ ,  $95\% CI [-.24; -.02]$ ;  $K^2 = .09$ ,  $SE = .05$ ,  $95\%CI [.02;.22]$ . The direct relationship between disability and social quality of life was not significant,  $B = -.02$ ,  $SE = .03$ ,  $95\%CI [-.08; .04]$ .

The indirect relationship between disability and environmental quality of life via stigma was significant  $B = -.04$ ,  $SE = .02$ ,  $95\% CI [-.10; -.01]$ ;  $\beta = -.10$ ,  $SE = .06$ ,  $95\%CI [-.27; -.01]$ ;  $K^2 = .10$ ,  $SE = .06$ ,  $95\% CI [.01;.26]$ . The direct effect of disability on environmental quality of life was not significant,  $B = .02$ ,  $SE = .06$ ,  $95\%CI [-.10; .13]$ .

### ***Cause of injury as predictor; survivor identity as mediator; QoL as outcome***

Cause of injury was correlated with survivor identity. In turn, survivor identity was found to be correlated with the following WHOQOL-BREF domains: overall quality of life, and psychological quality of life. Mediation analysis was therefore conducted to test these indirect pathways. Because survivor identity was

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

not significantly correlated with the WHOQOL outcomes overall health satisfaction, physical health quality of life, social relationships quality of life, and environmental quality of life there were no significant indirect pathways between cause of injury via survivor identity and these outcomes.

The indirect relationship between cause of injury and overall perceived quality of life via survivor identity was significant,  $B = .13$ ,  $SE = .08$ , 95% CI [.02, .40];  $K^2 = .08$ ,  $SE = .04$ , 95% CI [.02, .20]. Rather than having a direct impact on overall quality of life, cause of injury is exerting a significant indirect effect on overall quality of life via participants understanding themselves as being survivors. The direct effect of cause of injury on overall perceived quality of life was not significant,  $B = .04$ ,  $SE = .24$ , 95% CI [-.43, .52].

Similarly, the indirect relationship between cause of injury and psychological quality of life via survivor identity was significant,  $B = .45$ ,  $SE = .36$ , 95% CI [.02, 1.42];  $K^2 = .07$ ,  $SE = .05$ , 95% CI [.00, .21]. The direct effect of cause on psychological quality of life was not significant,  $B = .37$ ,  $SE = .94$ , 95% CI [-1.51, 2.25].

### **Discussion**

Cause of injury, i.e. traumatic or other type of ABI was found to predict quality of life amongst this cohort of post-acute ABI survivors. Brain injury survivors often feel that everything that they once took for granted has been called into question and that they have lost control over their own lives (Patterson & Staton, 2009). Being able to blame oneself for trauma is a strategy that often allows people maintain cherished beliefs about the world and their place in it (Joseph, 2011). McGrath (2004) argues that in the context of ABI rehabilitation

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

being able to blame oneself for misfortune confers a significant psychological advantage because it gives rise to a sense of control and options for change which are unavailable if one perceives misfortune as random. Traumatic brain injuries resulting from road traffic accidents, falls and assaults are misfortunes that people often feel were avoidable – if I hadn't got into that car, if I had been wearing a helmet, if I hadn't gone to that pub and so on. In contrast, non-traumatic injuries such as strokes and tumours are more often perceived by individuals as random, unavoidable misfortunes that have befallen them. Shaver and Drown (1986) suggest that what is often referred to as self-blame is really a self attribution of causality. In line with this idea that being able to attribute causality to oneself might have utility in contributing to well-being, we found that traumatic aetiologies were more positively associated with positive quality of life outcomes via identifying as being a survivor. It is also of course true that blame, where inappropriately placed, may be harmful. Consideration of that harmful aspect was however beyond the scope of the present study.

The second thing to emerge from this study is that the picture of relationships between ABI, identity and outcomes is nuanced. Different aspects of brain injury appear to relate to different types of identities which in turn relate to distinct quality of life outcomes. The aim of this research was to expand the understanding of relationships between brain injury, social identities and quality of life outcomes. Our results, by extending the approach to include measures of disability, stigma, and survivor identity has increased understanding of predictors of brain injury outcome, at least in terms of quality of life. Findings suggested that a positive social identity, survivor identity, and a negative social identity, stigma, were correlated to different quality of life outcomes (see Table 2).

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Survivor identity was found to be related to overall perceptions of quality of life. In contrast, stigma was negatively correlated with overall health satisfaction, social relationships quality of life, and environmental quality of life. In a future study it would be interesting to further investigate the contrast between social identities of a positive and negative valence.

Disability severity also emerges from these results as a useful predictor of outcome in the post-acute phase of ABI. This finding is of potential utility because measures of injury severity have been established as problematic (e.g. Ponsford, 2013; Newby, Coetzer, Daisley, & Weatherhead, 2013). This makes sense because disability severity impacts functional abilities in an immediate way. In contrast to historic GCS scores, disability reflects the daily life of survivors in the post-acute phase. Disability is often omnipresent; for example the survivor of a postpartum stroke who is now a mother but cannot pick up her child because of hemiparesis. We also suggested that the relationship between disability severity and quality of life would be mediated by stigma and survivor identity. This was supported with regard to stigma but not with regard to survivor identity. Disability severity was positively related to stigma. Stigma was in turn found to mediate the pathway between disability severity and WHOQOL psychological, social relationships and environmental quality of life. The results of this study show that stigma following ABI is central to mediating the relationship between disability, health satisfaction, psychological, social relationships and environmental quality of life.

Disability severity was not correlated with survivor identity. We found that cause of injury was related to survivor identity such that survivors of traumatic brain injuries had stronger survivor identities compared with survivors

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

of other types of brain injury. Path analysis revealed that survivor identity mediated the relationship between cause of injury and individual perceptions of quality of life as well as psychological quality of life<sup>5</sup>. In a previous paper we suggested that people who understand their injuries as arising from causes outside themselves are likely to appraise their injury in a different way from people who perceive their injuries as arising from causes within themselves (Walsh, Fortune, Gallagher, & Muldoon, 2012), the findings of the present study seem to bear this out. In particular, this finding seems to lend support to the view proposed by McGrath (2004) that being able to blame oneself for misfortune might confer a psychological advantage because it gives one a sense of control.

It seems that as Large and Marcussen (2000) suggest, subjective meaning may be crucial in terms of relationships between injury related factors and quality of life outcomes following brain injury. Large and Marcussen argue that identities play a crucial role in predicting different forms of distress. According to the Large and Marcussen argument, identities are different than other sociological concepts (e.g. roles) because concepts of identity emphasise the subjective meaning of a position in the social structure of the self concept. From this point of view, the form of distress experienced by an individual is a function of meaning. In the present study it may be that the relationship between cause of injury and psychological quality of life is mediated by survivor identity because of what their brain injury means to the survivor, and indeed what it means to be a survivor. This may also be the case with disability. Such a view would certainly seem to ‘fit’ with the idea that social identity determines symptom appraisal and response (Haslam, Jetten, Postmes, & Haslam, 2009). It seems reasonable to

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<sup>5</sup> This analysis was not conducted for stigma as stigma was not significantly correlated with cause of injury

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

suggest that one reason why stigma mediates the pathway between disability severity and psychological quality of life, social relationships quality of life, and environmental quality of life may be because of the subjective meaning of brain injury to survivors. This understanding is important because it potentially offers the basis for practical intervention.

### **Conclusion**

In sum, our investigations explored relationships between ABI cause and severity of disability, stigma, survivor identity and quality of life outcomes. Findings support the view that social identities are crucial in terms of complex relationships between cause, disability and quality of life following brain injury. It is incumbent upon social and clinical psychologies to attempt to come to grips with this complexity. It is our hope that these investigations constitute a step towards that goal.

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## **A Social Identity Approach to Acquired Brain Injury (ABI)**

**CHAPTER 5**

**Paper 4**

**A longitudinal study of relationships between self-categorisation,  
consistency of identification and anxiety following acquired brain  
injury (ABI)**

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Abstract**

Mental health, specifically anxiety has particular importance following acquired brain injury (ABI) because anxiety has been identified as a significant predictor of functional outcomes. Continuity of self has also been linked to post ABI adjustment and research has linked self discrepancy to anxiety. This longitudinal study investigates how the understandings that people have of themselves as expressed in their affiliative and self as doer self categorisations, along with the consistency of these self categorisations, impacts anxiety. Data was collected at two time points. Fifty three ABI survivors taking part in post-acute community neuro-rehabilitation participated at time one and thirty two of these participated at time two. Moderated mediation analysis indicated a significant mediated relationship between affiliative identification and anxiety via self as doer identification. This relationship was significant for those with consistency in affiliative self categorisation and variation in self as doer self categorisation. These findings evidence the importance of identity continuity and multiplicity following ABI and contribute to the understanding of these through the use of a social identity approach.

**Key Words:** Brain Injury; Social Identity; Self Categorisation; Identity Continuity; Anxiety.



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Introduction**

In the context of acquired brain injury (ABI) mental health is of marked importance because mental health, particularly with regard to anxiety, has been identified as a significant predictor of functional outcome following brain injury (Ponsford, Draper, & Schonberger, 2008). We believe that ‘Continuity of self’, a concept originating in the nursing literature (Sechrest & Zeller, 2003) that has recently been used in the context of integration of meaning and doing in a relational approach to rehabilitation (Bowen, Yeates & Palmer, 2003), may be fundamental to mental health, specifically anxiety, following ABI. Previous research has shown that higher levels of pre to post injury self-discrepancy (i.e., ‘who I am now’ v. ‘who I was before my injury’) are associated with higher levels of anxiety in survivors of traumatic brain injuries (Cantor et al., 2005). In contrast to self discrepancy, continuity of self, defined as ‘the experience of oneself as continuous with ‘who I was before’ (Sechrest & Zeller, 2003, p.244) has been linked to adjustment following traumatic brain injury (Bowen, Yeates, & Palmer, 2010).

The present study then investigates how the understandings that people have of themselves, as evidenced by their self categorizations, might impact anxiety following ABI. Self categorization refers to the individual self-assignments that people make to social groups. Self-categorizations matter because they provide the psychological basis for identification and its knock on consequences. In the majority of contexts, identities structure what people do, what they think and what they can achieve (Haslam, 2014). Hence it is not a person’s nominal group memberships that need to be considered by researchers but their subjective self-categorizations (Haslam, 2014). Researchers need to attend to how people understand themselves. So in this study we explore the

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

impact of self-categorization, and of (in)consistency across time of these self categorization, in those affected by ABI. We also examine whether strength of identification with two distinct types of self-categorizations, those related to inclusion in social groups and those contingent on engagement with activity (Walsh, Fortune, Gallagher, & Muldoon, 2014), impacts on levels of anxiety.

Membership of social groups is a fundamental base on which individuals construct their sense of self. Social, or collective, identities have been defined as those identities that individuals derive from membership of social groups that hold emotional and value significance for them (Tajfel, 1982). Secrest and Zeller (2003) report that identity discontinuity in stroke survivors was experienced as a threat to integrity whereas continuity of self was associated with an experience of integrity of being. Tying this continuity of self back to mental health, Sani et al. (Sani, Bowe, & Herrera, 2008) suggest that when individuals have a coherent, collective, self understanding there are positive consequences for psychological well-being.

Identity or ‘self’ can be understood as a dynamic process (Simon, 2004). For each of us, knowing who we are, where we have come from, and feeling an inner sense of personal and collective continuity across time is fundamental to our individual and collective well-being (Sani, Bowe, & Herrera, 2008). Previous research into identity and ABI has looked at the discrepancy between pre and post injury selves. This line of inquiry indicates that brain injury is often accompanied by a feeling of discrepancy between ‘who I am now’ and ‘who I was before the injury’ (Cantor et al., 2005) that is in turn related to affective disorder. But what of consistency and change regarding self categorization in the post injury self? Gracey et al. (2008) concluded that, in part at least, ABI survivors make sense of themselves in terms of the meanings attached to social activities that they engage

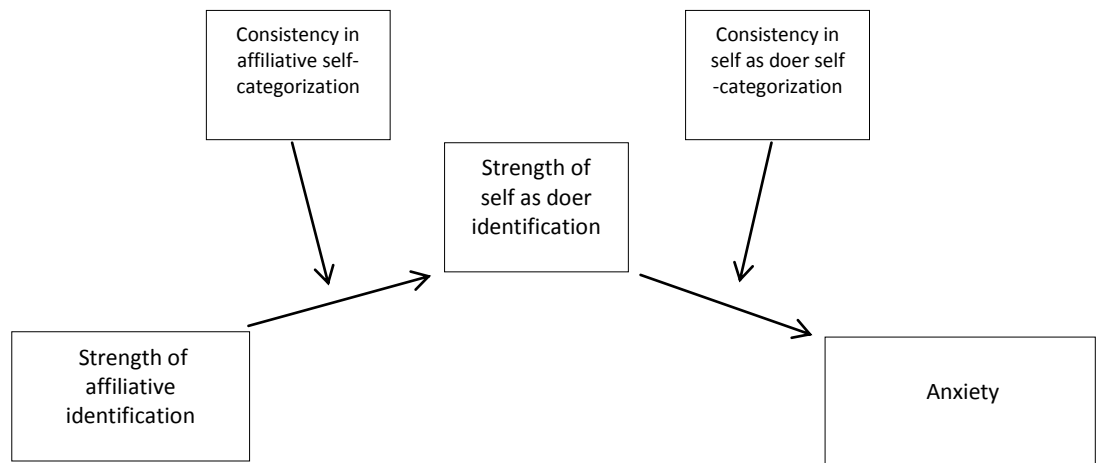
## **A Social Identity Approach to Acquired Brain Injury (ABI)**

in and that are significant to them after their injury. In a similar vein, Douglas (2012) reported that when ABI survivors engaged in meaningful social activity, this engagement supported social identity construction with knock on effects for affective well-being. Further, in previous cross-sectional research, a differential impact of the type of identifications arising from affiliative (or belonging) identities (such as family) and social identities that build around participation in meaningful vocational and leisure activities was observed in those recovering from ABI (Walsh, Muldoon, Gallagher & Fortune, 2014).

In the context of ABI, to the best of our knowledge relationships between strength of self categorized identifications, the consistency of these self categorizations, and anxiety have not been investigated. We hypothesise that a key variable is whether or not people are consistent in their self-categorisations over time. To illustrate this with a concrete example we suggest that those who consistently identified strongly with their families would have an identity base which would allow them to engage with meaningful activity. Further, in line with previous research we suggest that affiliative identification has a significant effect on anxiety via strength of self as doer identification and so in our example, strong family identification would effectively facilitate, for instance, attending and watching sport with family members which would in turn allow survivors to see themselves as active sports fans. In order to be significant, this relationship would also require consistency in affiliative self categorization. Finally we expected that these identifications/self categorizations with meaningful activities would have a beneficial impact upon individual's anxiety levels.

The hypothetical model is represented in figure 1 below.

## A Social Identity Approach to Acquired Brain Injury (ABI)



**Figure 1.** *Hypothetical model of relationships between identification, consistency and anxiety*

### Method

#### *Participants*

Fifty-three adult survivors (39 men and 14 women) of brain injury, taking part in post-acute community neurorehabilitation with a national brain injury service provider in south west and mid west Ireland took part in phase one of this study. Participants average age was 44 years (SD=12.32). The youngest participant was 20 years and the oldest was 65 years. Average time since injury was 7 years (SD=7.54). 22 participants had an ABI as a result of stroke. The other 31 participants had an ABI as a result of road traffic accidents (n=15), falls (n=7), tumour (n=4), assault (n=2), hypoxia (n=2) and other (n=1). One participant did not complete the affiliative identification component of the questionnaire and another participant did not complete the self as doer identification component of the questionnaire.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Thirty two of those who took part in the first phase of this study took part in the second phase. Reasons that participants were not available for follow up included discharge from service, hospitalization and being on holiday. Participants were spread over a large geographical area and this meant that if participants were not available while we were in their area it was not always possible to meet with them. Twenty five of those who participated at time 2 were men and 7 were women. 14 had a brain injury as a result of stroke and 18 as a result of other causes\* (Other causes: road traffic accident = 10; falls = 3; hypoxia = 2; assault = 1; unknown = 1). The mean age of participants was 44 years. The youngest participant was 20 and the oldest was 65. Mean time since injury was 6 years with the most recent injury being 1 year and the most distant being 27 years (SD time since injury = 5.73 years). Independent samples t-tests were conducted to examine whether the demographics, in terms of age and time since injury, of those who participated at both times 1(n=21) and 2 (n=32) differed significantly from the demographics of those who participated at time 1 only. There were no significant differences. The mean age of those who participated at time 1 only was 47.04 years (SD=10.97). The mean age of those who participated at both times was 43.69 years (SD=12.89).  $t(51) = .98, p=.33$ . The mean time since injury of those who participated at time 1 only was 8.80years (SD=9.57), the mean time since injury of those who participated at both time points 1 and 2 was 5.94 years (SD=5.73).  $t(50)=1.35, p=.18$ . A chi-squared test was performed to investigate whether gender was a significant difference between those who participated at time 1 only and those who participated at both time points. Fifteen men and 6 women participated at time 1 only. Twenty five men and 7 women

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\* 'Other causes' is essentially TBI participants + 2 participants with hypoxia and 1 whose cause of injury is unknown.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

participated at both time points. Gender was not significantly different between those who participated at time 1 only and those who participated at both time points,  $\chi^2 (1, N=53) = .31, p=.58$ . A second chi-squared test was performed to examine whether cause of injury (i.e. stroke v other) was significantly different between those who participated at time 1 only and those who participated at both time points. Of the 21 participants who took part only at time point 1, 9 had a brain injury as a result of stroke, 12 had a brain injury as a result of other causes. Fourteen participants who took part at both time points had an injury as the result of stroke and 18 had a brain injury as a result of other causes. Cause of injury was not significantly different between these groups  $\chi^2 (1, N=53) = .00, p=.95$ .

### ***Measures***

#### ***Self Categorization***

Participants completed a 28-item identity questionnaire based on Leach et al.'s valid and reliable (2008) multicomponent model of ingroup identification which measured the strength of affiliative and self as doer identities. Self categorized affiliative identity was established with the question 'Which group of people you belong to is most important to who you are?' Self-categorized self as doer identity was accessed via the question 'Which of the things you do is most important to who you are?' et al. ingroup

#### ***Strength of affiliative and self as doer identification***

The strength of identification measure comprises a 13 item questionnaire which measures group level self investment (solidarity; satisfaction and centrality) and group level self definition (individual self stereotyping; ingroup homogeneity). In a slight change, question 7 of the original, 'Being [in-group] gives me a good feeling', was left out because it appears to be very similar to another item 'It is

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

pleasant to be [in-group]’ and it was felt that this had the potential to cause confusion with ABI participants. A 7 point Likert scale was employed to ascertain individual item scores (1= Agree; 7 = Disagree) as per Leach, Rodriguez Mosquera, Vliek, and Hirt (2010). All five subscales of the multicomponent model of in-group identification were summed to provide an overall measure of identity strength for both active and affiliative identity. The identity questionnaire first measured self as doer identity and then affiliative identity. Sample items include ‘I feel committed to...’; ‘The fact that I am....is an important part of my identity’; ‘I feel glad to be...’ Cronbach’s  $\alpha$  for affiliative identity in-group identification = .81. Cronbach’s  $\alpha$  for the self as doer in-group identification questionnaire = .82.

### ***Consistency and variability in self categorization***

Self categorized affiliative and self as doer identities were established at time 1 and time 2 Where participants chose the same identity at time 1 and time 2 participants were coded as having self categorization consistency (code=0). Where participants chose a different identity at time 1 and time 2 participants were coded as having self categorization variability (code =1). This procedure was followed for both affiliative and self as doer self categorizations.

### ***Anxiety***

Anxiety was measured with the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). The anxiety subscale contains 7 four-point items, from 0 (not present) to 3 (considerable) designed to assess anxiety (e.g., ‘Worrying thoughts go through my mind’) with scores of 8 or more being indicative of caseness (Snaith, 2003; 8 of the 32

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

participants in this study scored 8 or over on HADSA). The HADS scale was designed in the setting of an outpatient clinic in a general medical hospital. Many studies have since confirmed the validity of the HADS scale and it has been shown to be an instrument suited to broad application (Snaith, 2003). In the present study a Cronbach's  $\alpha$ 's of .84 was obtained for the anxiety subscale.

### ***Procedure***

Following receipt of ethical approval, data was collected across two time points with an average interval of 13 months between time 1 and time 2 data collection. The shortest individual interval between data collection time points was 8 months and the longest was 16 months ( $SD = 2.64$ ). It was explained to all participants, at both time points, that participation was optional and that they were free to withdraw at any time.

Participants were interviewed in locations most convenient for them. Data was collected by two researchers, both of whom had police clearance to engage with vulnerable participants.

### ***Statistical analyses***

Hayes (2013) argues that establishing relationships between variables is an important part of scientific research. Hayes (2013) also cautions that even when a relationship between variables can be established, the identification of an association does not necessarily equate to understanding. One way to improve understanding is to consider questions regarding how and when one variable might impact another. 'How' is a question of underlying process and 'when' a question pertaining to the boundary conditions of a putative association, for



## A Social Identity Approach to Acquired Brain Injury (ABI)

example for whom does x exert an effect on y. Mediation analysis is suited to the former and moderation the latter (Hayes, 2013).

The mean, standard deviation and reliability for all measures was calculated. Associations between strength of affiliative identification, strength of self as doer identification, anxiety, cause of injury, age, gender and time since injury were investigated with correlation analysis (Pearson's *r*). Lastly, PROCESS model 21 (2013), was employed to investigate whether there was a mediated relationship between strength of affiliative identification and anxiety via strength of self as doer identification that was moderated by stability of self categorizations. Following the guidance offered by Hayes (2009) bootstrapping to 5000 was conducted.

## Results

### *Preliminary analyses*

Analyses began by calculating the mean, standard deviation and range of all variables. These along with t-tests indicated that there was no significant difference between measures across time points are presented in Table 1.

**Table 1** Means and standard deviations of all variables

		T1 Strength of affiliative identification	T1 Strength of self as doer identification	T1 HADSA	T2 Strength of affiliative identification	t-test T1 affil – T2 affil	T2 Strength of self as doer identification	t-test T1 doer – t2 doer	T2 HADSA	t-test T1 HADSA – T2 HADSA
N	Valid	52	52	53	32		32		32	
Mean		82.56	75.65	6.08	82.41		78.69		5.53	
Std. Deviation		9.11	12.37	4.50	8.54	t=.000	10.86	t=.123	4.17	t=.308
Minimum		57	44	0	62.00	p=1.00	56.00	p=.90	.00	p=.76
Maximum		91	91	17	91.00		91.00		19.00	

## A Social Identity Approach to Acquired Brain Injury (ABI)

### *Associations between identities, demographics and anxiety*

Analysis next proceeded to examine relationships between variables using correlation analysis (Pearson's  $r$ ). Results indicated that strength of affiliative identification was significantly associated with strength of self as doer identification, and self as doer identification was significantly associated with anxiety. The demographic factors cause of injury (stroke/other) and gender (male/female) were significantly correlated with strength of affiliative identification and strength of self as doer identification respectively. Figures are presented in Table 2

**Table 2** Correlations between identification, anxiety and demographic variables (Time 1 correlations are above the diagonal and Time 2 correlations below)

	Affiliative	Self as doer	Anxiety	Cause of injury	Age	Gender	Time since injury
Strength of affiliative identification	1	.54*	-.04	-.29*	.16	.08	-.03
Strength of self as doer identification	.50**	1	-.32*	-.19	.19	-.32*	-.06
Anxiety	.11	-.36*	1	-.03	-.07	.23	.04
Cause of injury	-.34†	-.23	.14	1	-.58**	-.19	.29*
Age	.15	.13	-.05	-.73**	1	-.11	.14
Gender	.12	-.25	.06	-.14	.13	1	-.10
Time since injury	.01	-.09	.14	.27	.03	-.06	1

\*\*Correlation is significant at the 0.01 level (2-tailed); \*Correlation is significant at the 0.05 level (2-tailed); †correlation < .06

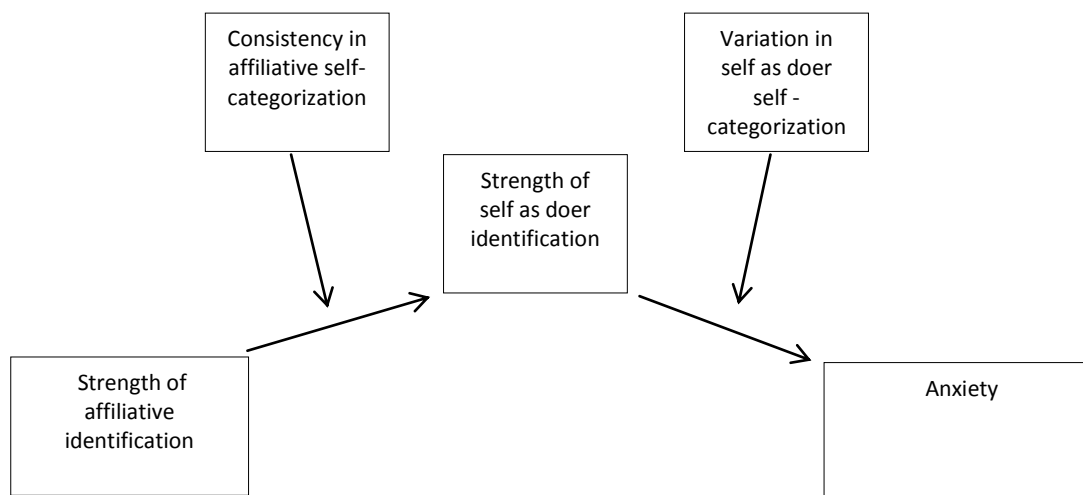
### *Stability and variability in self categorization*

Twenty three participants (72%) self categorized with the same affiliative identities at time points 1 and 2. Nine participants (28%) changed affiliative self categorization from T1 to T2. Fourteen participants (44%) self categorized with the same self as doer identities at time points 1 and 2. Eighteen participants (56%) offered different self as doer self categorizations at each time point. The specific self categorizations elicited from participants are presented in Appendix 1.

## A Social Identity Approach to Acquired Brain Injury (ABI)

Correlation analysis indicated that for those participants whose self categorized affiliative identities were stable across time there was a significant correlation between strength of affiliative and self as doer identities:  $r = .647$ ,  $p = .00$ ,  $N = 23$ ; for those whose affiliative identities varied there was no significant correlation between affiliative and active identities:  $r = -.045$ ,  $p = .909$ ,  $N = 9$ .

Analysis indicated a significant correlation between strength of self as doer identification and anxiety,  $r = -.66$ ,  $p = .00$ ,  $N = 18$ , for those whose self categorized self as doer identification varied across time. In contrast, there was no significant correlation between strength of self as doer identification and anxiety for those whose self categorized active identifications were stable:  $r = .01$ ,  $p = .73$ ,  $N = 14$ .



**Figure 2** Moderated mediation in the relationship between strength of affiliative identification and anxiety via strength of self as doer identification, moderated by stability of affiliative and self as doer self categorizations

Moderated mediation analysis was conducted (using PROCESS model 21(Hayes), 2013 and SPSS v.21). Confidence intervals were set at 99%. The model

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

controlled for gender and cause of injury (because as illustrated in the associations between identities, demographics and anxiety section above, gender and cause of injury were significantly related to strength of identification in the preliminary analysis). There was a significant conditional indirect effect of strength of affiliative identification on anxiety when there was consistency in affiliative self categorization and variation in self as doer self categorization  $B = -.29$ ,  $SE = .10$ , 99% CI  $[-.58, -.02]$ . In contrast, where there was stability in both affiliative self categorization and self as doer self categorization the indirect effect of strength of affiliative identification on anxiety was not significant:  $B = -.03$ ,  $SE = .14$ , 99%CI  $[-.43, .32]$ . In people where there was variation in affiliative self categorization and stability in self as doer self categorization the indirect effect of strength of affiliative identification on anxiety was not significant:  $B = .01$ ,  $SE = .13$ , 99%CI  $[-.50, .46]$ . Similarly, with variation in both affiliative and self as doer self categorizations the indirect effect of strength of affiliative identification on anxiety was not significant:  $B = .04$ ,  $SE = .27$ , 99% CI  $[-.716, 1.16]$ . These results indicate that along with strength of identification a key variable is who stable in their self categorizations and who is not. Stability in affiliative self categorization and variability in self as doer identification is the significant combination. The direct effect of strength of affiliative identification on anxiety was not significant  $B = .21$ ,  $SE = .09$ , 99% CI  $[-.05, .47]$ . PROCESS does not generate standardised coefficient figures where covariates are included in the model. The overall model fit was  $R^2 = .47$ ,  $p = .02$ .

## **Discussion**

Results of the present study indicate that identification with the groups that ABI survivors belong to, groups such as family, constitute a base from which

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

individuals can construct self as doer identities. This finding is consistent with the social identity approach advocated by Haslam, Jetten, Postmes, and Haslam (2009) that builds on the self-categorization theorising of Turner (1982) who suggested that social identities are a resource that makes group behaviour possible. The applied social identity approach recently propounded by Haslam (2014) suggests that when people are severely incapacitated, in situations such as that pertaining after ABI, the groups that they belong to constitute a resource that can contribute to sustaining them. Family is perhaps the most obvious example but clubs, communities and social circles also offer resources with the capacity to contribute perceptions of consistency and maintain individuals in times of acute stressors such as ABI. The results of the present study are supportive of the idea that belonging to groups offers a basis from which individuals can engage with meaningful functional activities that then become internalised as identities (Douglas, 2012). Strongly identifying with the groups they belong to and being consistent in that self categorization were related to lower levels of anxiety amongst those who participated in this study. This much was predicted.

However, the next finding was not predicted. The indirect pathway from affiliative identification to anxiety was significant for those who reported different self as doer identities across time 1 and 2. It was *not* significant for those who were consistent across time points in their self as doer self categorizations. We had predicted that this mediated aspect of the relationship between strength of self as doer identification and anxiety would be moderated such that the relationship would be significant for those with stable self as doer self categorizations. This is not what was found. The data indicated that the relationship between strength of self as doer identification was significant for those whose self categorizations

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

varied across time. This may be because the use of alternative self as doer identifications evidences adjustment and flexibility in self categorization. Strength of self as doer self categorization mattered, in this instance, only for those participants who reported different self as doer identities at each time point. For this group of people there was a significant negative relationship between self as doer identification and anxiety: the stronger their self as doer identity the less anxious they were likely to be. We suspect that the explanation for this may be as follows: In parallel with understanding the importance of collective identification across time, Haslam et al. (2008) emphasised the significance of multiple identifications for psychological well-being after stroke. Haslam et al. (2008) have shown that belonging to multiple social groups following stroke is a better predictor of psychological well-being than reported cognitive difficulties or than pre-injury group memberships. Iyer, Jetten, Tsivrikos, Postmes, and Haslam (2009) presented findings that show compatibility between old and new identities and that having multiple group memberships increases the likelihood that individuals will identify with new groups at a time of major upheaval or change in their lives. Importantly, Iyer et al. (2009) also demonstrated that identification with a new group can buffer individuals from the negative effects of change on psychological well-being. Stability and multiplicity regarding identity are thus both relatively well established as important to well-being after ABI. It seems that the findings of this study may reflect the importance of both and that the results go some way towards accounting for stability and multiplicity through distinct identity sub-types. Stability was required in order for affiliative identities to exert a significant effect and variability in self as doer identities was required for them to exert a significant effect.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Haslam (2014) argues that groups and social identities matter. In the context of post-acute ABI survivors, the results of this study support Haslam's position. Gracey and Ownsworth (2012) focused on processes involved in survivor's capacity to internalise an adaptive and coherent post-injury identity and found that engagement in meaningful activities with which individuals identify contributes to emotional adjustment. Again, the present study supports the position advocated by Gracey and Ownsworth. What the present study adds to these studies is the understanding that identifications with different identity subtypes, and the stability of these identifications, are a significant factor requiring consideration. It is our hope that the findings presented herein might serve to inform clinical practice and stimulate further research. In this regard, some additional suggestions advanced by Haslam (2014) are especially salient. First, the power of social identity can be unlocked by working with rather than against it. We suggest that the concepts of affiliative and self as doer identities might offer the basis for interventions designed around, and working with, the understandings that people have of themselves following ABI. We have provided evidence that continuity of belonging and multiplicity of doing identities are associated with lower levels of anxiety and we hope that this finding will constitute a basis for future research both by ourselves and others. Haslam (2014) also argues that social identities must be made to matter. This suggestion raises intriguing possibilities in the context of ABI rehabilitation. Haslam (2014) suggests that it is possible to work with individuals in such a fashion as to transform abstract notions of 'us' into lived experience. Participation in meaningful activities, as suggested by Gracey and Ownsworth (2012), and others (Gracey et al., 2008; Douglas, 2012) may be one avenue via which this end can be achieved. Provision of structured, meaningful activities in DIY and craft groups

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

by a rehabilitation service provider is one practical example of the type of facilitated identification with activity advocated by researchers including Douglas (2012) and Gracey and Ownsworth (2012) and supported by the results of the present study. Again, we hope that the distinction between identity sub-types that has been evidenced in this study might offer a point of embarkation for the development of practical interventions that might further develop and apply this insight.

### **Conclusion**

In sum, our results suggest that in the context of post-acute neurorehabilitation social identity theorising, a social neuropsychological approach (Haslam et al. 2008; Gracey & Ownsworth, 2012) is ‘good’. It offers predictive and practical utility. Haslam (2014), one of the principal drivers of contemporary social identity theorising, quotes Lewin’s (1952) dictum that ‘there is nothing as practical as a good theory’. If Lewin, and Haslam, are correct (and we suggest that they are), it is incumbent upon clinicians and researchers alike to explore innovative ways of making the type of theoretically informed social neuropsychological approach advocated by Haslam (2008), Gracey and Ownsworth (2012), and others practical through application. It is our hope the research presented herein might contribute to this end.



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## A Social Identity Approach to Acquired Brain Injury (ABI)

### Appendix 1.

#### Self categorized 'self as doer' identities at T1 and T2

Time 1 self as doer identity	Time 2 self as doer identity	Continuity Code
following Munster rugby	following rugby	0
child care	home life	0
going to matches	sport	0
thinking	thinking	0
farming	farming	0
Mechanical work	Mechanical work / fix tractors	0
art	art	0
coffee with friends	socialising	0
listening to music	music	0
theatre/cinema	cinema	0
baking	baking	0
parenting	family	0
fitness	running	0
fixing / being handy	handyman	0
parenting	praying /AA	1
photography	service provider activities	1
music & guitar	caring for grandmother	1
music	following sport	1
gym/pool/sauna	Poker	1
walking	getting out	1
farming	being out and about	1
mother	collecting	1
walking	being a dad	1
walking	socialising	1
following GAA	DIY group	1
music	college	1
greyhounds	walking	1
computers	getting hair done	1
going up the town	exercises	1
cooking and baking	shopping	1
dressing/clothes	spiritualism	1
bird breeding	parenting	1

## A Social Identity Approach to Acquired Brain Injury (ABI)

### Self categorized affiliative identities at T1 and T2

Time 1 affiliative identity	Time 2 affiliative identity	Continuity Code
family	family	.00
married	family	.00
friends	friends	.00
friends	friends	.00
family	family	.00
family	family	.00
family	family	.00
my kids	family	.00
family	family	.00
friends	family	.00
family	family	.00
family	family	.00
my family	family	.00
family	Rehab group	1.00
family	family	.00
family	husband	.00
family	family	.00
family	family	.00
friends	friends	.00
family	family	.00
family	family	.00
family	family	.00
family	family	.00
family	family	.00
Rehab group	family	1.00
friends	people	1.00
people in bookies	family	1.00
friends	Rehab group	1.00
my partner	friends	1.00
family	GAA	1.00
humankind	Rehab group	1.00
family	Rehab group	1.00

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

## **CHAPTER 6**

### **General Conclusion**

The research presented in this thesis applied a social identity analysis to the study of relationships between acquired brain injury (ABI), social identity and outcomes following ABI. The thesis builds on a body of work that began with the theorising of Luria and Vygotsky (Cole, Levitin, & Luria, 2006) in neuropsychology and Tajfel and Turner (1979) in social psychology. Both sets of authors advocated an approach to psychology which is cognisant of the need for ecologically valid research and which recognizes the social origins of mind.

From the type of individualistic perspective which understands the human mind as bounded and computational (e.g. Kolb & Whishaw, 2009), rehabilitation following ABI is of necessity about coming to terms with permanent irreversible change. It is a 'clinical 'dead end' (Yeates, Gracey, & Collicutt McGrath, 2008, p.568). In contrast to the type of bounded computational view opposed by Yeates et al. (2008), there is a social turn in contemporary neuropsychological rehabilitation practice towards a more holistic approach. Gracey et al. (2008) for example have concluded that following ABI people make sense of themselves in terms of the meanings associated with social and practical activities. Given this apparent tension in the literature between 'individualistic' and 'social' approaches to ABI the purpose of this body of research was to investigate whether the application of social identity theorising to the study of ABI might yield results of practical utility. The importance of self in rehabilitation has been recognized for many years and the interface between social psychology and cognitive neuroscience allows for a more nuanced understanding of how it is that selves arise (Ownsworth, 2014). The first article in this thesis 'Acquired brain injury: combining social psychological and neuropsychological perspectives' presented a



## **A Social Identity Approach to Acquired Brain Injury (ABI)**

theoretical rationale for integrating social psychology and neuropsychology in the study of ABI. This paper argues because of its unique perspective that analysis should begin with the ‘group in the individual’ rather than the ‘individual in the group’ (Reicher, Spears, and Haslam, 2010), the social identity approach is a theoretically coherent vehicle particularly well suited to such integration. A significant influence on the approach to psychology manifest in this thesis is that of practical paradigms which recognize the importance of pragmatism and utility. One prominent example of this type of approach is the sort of empirical psychology advocated by the social constructionism of Gergen (2001). This influence requires some reflexivity at this point of the conclusion. Rooted in theoretical arguments, the need for a social approach to neuropsychology is strongly advocated in the second chapter which was written prior to any empirical investigations. This strongly held position undoubtedly influenced the research which followed. Particularly in terms of the research questions that were pursued. It may also be the case that the type of social perspective adopted (and advocated) has overshadowed both a critical evaluation of the existing literature and of the studies presented. However, spoken or unspoken, research is always conducted within a paradigm and the social paradigm that informs this body of research is attuned towards ‘a search for useful theories and findings with significant meaning’ (Gergen, 2001). Potential pragmatic utility is the focus. None of the questions addressed by this thesis have been answered with finality and all of the ‘facts’ it has produced can only be considered provisional. This body of work is a start point, rather than an end point, and much research and theorising remains to be done.

Proceeding with a social identity approach, Jetten, Haslam, Haslam, and Dingle (2014) argue that theoretical advancement is important because insights

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

can be translated into interventions. As stated above, the aim in undertaking the program of research was to produce studies with the potential for practical utility. To this end, the research presented herein contributes to existing theory in three ways. First, it adds to a growing applied social identity literature which speaks to the importance of internalized group memberships for people's health and well-being (Haslam, 2014). Second, with particular regard to ABI, our results emphasise the importance of both belonging to groups, and of meaningful activity, to quality of life outcomes and affective status following ABI. Third, our results highlight the heterogeneous nature of social identities and the importance of attending to distinct identity sub-types. In terms of existing practice, the results of this research lend a quantum of support to the type of broad social turn in rehabilitation advocated by contemporary neuropsychological clinicians including Gracey and Ownsworth (2012), Douglas (2012) and others.

. A model was proposed in the first article, 'Acquired brain injury: combining social psychological and neuropsychological perspectives' which was intended to provide a framework for the studies that followed. Unfortunately this intention was not realised. In particular, it was intended that injury related factors such as anatomical location and severity would have been included in the analysis. When individual medical files were accessed details pertaining to radiology, medical notes, and severity scores, were often unavailable to the extent that useful analysis of these factors was impossible. Thus questions relating to relationships between neurobiology and social identity processes were not addressed, beyond cause of injury, in the manner we had desired and suggested in the model presented in chapter 2. As such they remain open. It is my hope, and my intention, to address these questions in future research.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

In reflecting on the weaknesses of the present research it is also important to mention another omission from the research conducted. A significant factor not controlled for in the body of research presented was the possible impact of cognitive impairment on the reliability and validity of the measures administered. Gracey and Ownsworth (2012) highlight how acquired cognitive impairments can impede the ‘updating’ of a post injury self. This impact of cognitive impairment may have limited the reliability and validity of the questionnaire based methods employed in this research. While it is not possible to control retrospectively for cognitive impairment cognitive impairment is a feature of ABI that requires consideration in future research.

It has been established elsewhere that social identity and social support are important factors with regard to psychological well-being (e.g. Haslam, O’Brien, Jetten, Vormedal, & Penna, 2005) but it seems that in the social identity literature the precise nature of relationships between social identity, social support and psychological well-being was unclear. The second article ‘Affiliative and ‘self as doer’ identities: relationships between social identity, social support, and emotional status amongst survivors of acquired brain injury’ applied the concepts of affiliative and self as doer identities to an analysis of relationships between social identity, social support and emotional status amongst a group of participants who had survived ABI. This study evidences the type of ‘upward spiral’ suggested by Haslam, O’Brien, Jetten, Vormedal, and Penna (2005, p.367) whereby social identity makes social support possible and social support increases identification. This study adds to the literature in that it brings a measure of clarity to the nature of these reciprocal relationships between social identity and social support. Utilising the concepts of affiliative and self as doer identification illuminated the role played by identity sub-types in this reciprocal relationship.

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

Affiliative identities were found to make social support possible and social support was found to drive self as doer identification. Importantly, this relationship was found to have positive knock on consequences for the emotional status of individuals in terms of anxiety and depression. Results of this study highlight the heterogeneous nature of social identities and point to the conclusion that social identities matter. This study had a correlational design and as such it must be acknowledged that the study design precludes any assertion of a definitive causal relationship between variables. It is also necessary to note that the sample size for this study was relatively small.

The third article ‘An investigation of relationships between cause, disability, survivor identity and quality of life following acquired brain injury (ABI)’ continued the identities matter theme. Stigma, a social identity with negative valence, is one of the clearest examples of a group level identity (Lorenzi-Cioldi, 2006) that occurs when people believe that others think less of those who are members of their group (Phelan et al. 2011). Survivor identity, in contrast, is a social identity with positive valence that can act as an important psychological resource for health (Muldoon & Lowe, 2012). The suggestion investigated by this study was that in the post-acute phase of ABI, cause of injury, and level of disability, because of what they mean to individuals, would predict quality of life outcomes via stigma and survivor identification. Results again indicated the utility of attending to different types of identity. Cause of injury was related to survivor identity but survivor identity was not related to level of disability. Level of disability was related to stigma but stigma was not related to cause of injury. This study indicates that different types of identity, namely survivor identity and stigma, were related to distinct quality of life outcomes. These findings lend support to the view that cause of injury and level of disability

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

are useful predictors of outcomes and that social identities are crucial in terms of complex relationships between cause, disability and quality of life following ABI. Furthermore these findings suggest that through attending to identity sub-types the social identity approach can contribute to reducing this complexity and facilitate understanding of relationships between ABI and outcomes. In addition to the fact that correlational studies cannot provide causal evidence there are other limitations to this second correlational study. Perhaps the most important of these is the absence of an objective measure of injury severity. On this point it should be noted that the use of the GCS as a measure of severity is focused on TBI and the severity of stroke is not typically measured with the GCS. GCS scores were only available for a handful of participants, a proportion too small to be useful. Furthermore, radiology was generally absent from participants files. This is a significant limitation as it precluded an examination of relationships between social factors and medical factors (other than cause of injury). In future research this is a theme that requires revisiting.

The ‘social identities matter’ thread continued into the fourth and final paper in this program of research, ‘A longitudinal study of relationships between self-categorization, consistency and anxiety following acquired brain injury (ABI)’. This study found that, amongst a group of ABI survivors, identification with meaningful activity mediated the relationship between belonging and anxiety. Significantly, this relationship was such that, over time, those who were stable in their affiliative identities, for example identification with their family, had stronger self as doer identifications. Interestingly, the same study showed that the relationship between affiliative identities and anxiety was mediated by self as doer identification such that those with stronger self as doer identifications who self categorized with different self as doer identities at times one and two were

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

less anxious. This is important because it shows that stability and multiplicity of identity is important following ABI. Moreover these results speak to the findings of Gracey et al. (2008) who employed a personal construct approach in a study of self after ABI and found that ABI survivors make sense of themselves in terms of the meanings attaching to social and practical activities. This finding speaks to the potential for harnessing meaningful practical activities as potential resources for identity construction. As with the first two studies the third, longitudinal, study had its limitations. The size of the sample was again small and it is difficult to generalise from such a limited and heterogeneous sample. The influence of cognitive impairment was not taken into account and it is possible that a lack of insight impacted the results in ways we have not considered.

A consideration of some general limitations that run throughout the research presented in this thesis is also worth undertaking. The participants were drawn from a relatively small geographical area and were predominantly white, male, and Irish. This raises the question of culture – are cultural factors playing a ‘hidden hand’ in the dynamics that correlational analysis identified? Would these same processes exist in a culture more collectivist than mainstream Irish culture? This is an angle not pursued by the present research but an important angle to investigate in future research. Another general limitation is that we did not collect qualitative data. In retrospect, allowing that any single piece of research cannot achieve everything, this was a big omission. As participants filled up their questionnaires and talked around who it is that they understand themselves to be it became increasingly obvious that there was a wealth of valuable data being made available that I was neglecting to collect. The third study in particular highlighted this – the data in study 3 is very interesting but in terms of an explanation for the findings one cannot go beyond the data available. Qualitative data, if it had been

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

collected, may have shed some valuable light on the dynamics around multiplicity of identities that was found to be significant regarding self as doer identification. Finally, it is important to recognize that there are other potentially important factors, internal to the individual, that have not been considered by this research but that may exert a significant influence on post ABI outcomes. These factors include (but are not limited to) cognitive reserve, individuals' mental health histories, and neuroplasticity. These types of factors must also be attended to in future research.

Taken in the round, notwithstanding the caution required in their interpretation, these results indicate that, with regard to emotional status and quality of life outcomes, social identities matter in the lives of ABI survivors. Furthermore, these findings add to, and extend, the existing literature because they contribute to understanding some of the complexities attaching to social identity and they illustrate the importance of attending to identity sub-types as well as the importance of identity processes with regard to emotional status and quality of life outcomes following ABI. In terms of clinical recommendations, consistent with Ylvisaker and Feeney (2000), Gracey and Ownsworth (2012) and Ownsworth (2014) this research highlights the importance that attaches to the integration of doing, meaning, and social identity following ABI. It is important that this recognition is not confused with the assignment of people living with ABI to generic structured activities. Such an approach (i.e. the assignment of people to generic, structured activities such as DIY groups) is emphatically neither advocated nor supported by the findings of the research contained in this thesis. Rather, this research lends support to a person centred, context sensitive approach to neurorehabilitation which attends to the meaning of activity. From this point of view identity is an important resource in the reconstruction of a sense of self that

## **A Social Identity Approach to Acquired Brain Injury (ABI)**

is individually satisfying and it is fundamental to this approach that interventions be meaningful to individual clients. Activity was noted by Ylvisaker and Feeney, Gracey and Ownsworth, and Ownsworth to be central to this.

As a final thought, Yeates, Gracey, and Collicutt McGrath (2008) argue against the type of reductionist, biomedical view which positions brain injury rehabilitation as being about coming to terms with permanent irreversible change. Instead, in a consideration of ‘personality change’ following ABI, Yeates, Gracey, and Collicutt McGrath place the emphasis on psychological and psychosocial processes rather than altered biology. The body of research presented in this thesis turned on processes of social identity and found them to be pivotal with regard to quality of life and emotional status following ABI. Haslam (2014) argues that in the majority of social contexts social identities determine what people think, do and achieve. Improving understanding of social identity processes can be considered a step towards harnessing them. I believe that this research makes a contribution towards that understanding. Future research must deepen that understanding and apply it.



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## **A Social Identity Approach to Acquired Brain Injury (ABI)**

### **Appendices**

Appendix 1. ABI and Identity Questionnaire

Appendix 2. HADS

Appendix 3. MPAI

Appendix 4. MOS Social Support Survey

Appendix 5. WHOQOL BREF

## Appendix 1 ABI Questionnaire



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### ABI & Identity Questionnaire

#### Section 1 Please circle the number that best represents how you feel

1. Which of the things that you do is most important to who you are? \_\_\_\_\_
2. I feel a bond with \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
3. I feel solidarity with \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
4. I feel committed to \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
5. I feel am glad to be \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
6. I think [group from 1] \_\_\_\_\_ have a lot to be proud of. Agree 1 2 3 4 5 6 7 Disagree
7. It is pleasant to be \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
8. I often think about the fact that I am \_\_\_\_\_ [group from 1] Agree 1 2 3 4 5 6 7 Disagree
9. The fact that I am [group from 1] \_\_\_\_\_ is an important part of my identity. Agree 1 2 3 4 5 6 7 Disagree
10. Being \_\_\_\_\_ [group from 1] is an important part of how I see myself. Agree 1 2 3 4 5 6 7 Disagree
11. I have a lot in common with the average \_\_\_\_\_ [group from 1] person. Agree 1 2 3 4 5 6 7 Disagree
12. I am similar to the average \_\_\_\_\_ [group from 1] person. Agree 1 2 3 4 5 6 7 Disagree

## A Social Identity Approach to Acquired Brain Injury (ABI)



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### ABI & Identity Questionnaire

13. [Group from 1] \_\_\_\_\_ Agree 1 2 3 4 5 6 7 Disagree  
people have a lot in common with each other.

14. [Group from 1] \_\_\_\_\_ Agree 1 2 3 4 5 6 7 Disagree  
people are very similar to each other.

15. What was your favourite thing that you liked to do before your injury? \_\_\_\_\_

### Section 2

16. Having a brain injury has made me a stronger person. Agree 1 2 3 4 5 6 7 Disagree

17. I think of myself as a survivor. Agree 1 2 3 4 5 6 7 Disagree

18. All things considered I am satisfied with my life. Agree 1 2 3 4 5 6 7 Disagree

19. I feel that there is a stigma that goes with ABI. Agree 1 2 3 4 5 6 7 Disagree

20. I think most people think less of a person with ABI. Agree 1 2 3 4 5 6 7 Disagree

21. I have been treated with less courtesy than other people because of my ABI. Agree 1 2 3 4 5 6 7 Disagree

22. I have been treated with less respect than other people because of my ABI. Agree 1 2 3 4 5 6 7 Disagree

23. The services I receive are poorer than other people because of my ABI. Agree 1 2 3 4 5 6 7 Disagree

24. People have acted as if they were afraid of me because of my ABI. Agree 1 2 3 4 5 6 7 Disagree

## A Social Identity Approach to Acquired Brain Injury (ABI)



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OILScoil LUIMNIGH

### ABI & Identity Questionnaire

25. People have acted as if they were better than me because of my ABI. Agree 1 2 3 4 5 6 7 Disagree

26. I am typical of a person with a brain injury. Agree 1 2 3 4 5 6 7 Disagree

### Section 3

27. Which group of people you belong to is most important to who you are? \_\_\_\_\_

28. I feel a bond with \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

29. I feel solidarity with \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

30. I feel committed to \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

31. I feel am glad to be \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

32. I think [group from 27] \_\_\_\_\_ have a lot to be proud of. Agree 1 2 3 4 5 6 7 Disagree



33. It is pleasant to be \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

34. I often think about the fact that I am \_\_\_\_\_ [group from 27] Agree 1 2 3 4 5 6 7 Disagree

35. The fact that I am [group from 27] \_\_\_\_\_ is an important part of my identity. Agree 1 2 3 4 5 6 7 Disagree

36. Being \_\_\_\_\_ [group from 27] is an important part of how I see myself. Agree 1 2 3 4 5 6 7 Disagree

## A Social Identity Approach to Acquired Brain Injury (ABI)

	 UNIVERSITY OF LIMERICK SCHOOL OF PSYCHOLOGY
<b>ABI &amp; Identity Questionnaire</b>	
37. I have a lot in common with the average _____, [group from 27] person.	Agree 1 2 3 4 5 6 7 Disagree
38. I am similar to the average _____, [group from 27] person.	Agree 1 2 3 4 5 6 7 Disagree
39. _____, [group from 27] people have a lot in common with each other.	Agree 1 2 3 4 5 6 7 Disagree
40. _____, [group from 27] people are very similar to each other.	Agree 1 2 3 4 5 6 7 Disagree

## A Social Identity Approach to Acquired Brain Injury (ABI)

### Appendix 2 Hospital Anxiety and Depression Scale (HADS)


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L69 3GB, LIVERPOOL, ENGLAND

Chart 1 — Hospital Anxiety and Depression Scale

This questionnaire will help your physician know how you are feeling. Read every sentence. Place an "X" on the answer that best describes how you have been feeling during the LAST WEEK. You do not have to think too much to answer. In this questionnaire, spontaneous answers are more important. Mark only one answer for each question.

<p>A (1) I feel tense or wound up:</p> <p>3 ( ) Most of the time</p> <p>2 ( ) A lot of times</p> <p>1 ( ) From time to time</p> <p>0 ( ) Not at all</p> <p>D (2) I still enjoy the things I used to:</p> <p>0 ( ) Definitely as much</p> <p>1 ( ) Not quite so much</p> <p>2 ( ) Only a little</p> <p>3 ( ) Hardly at all</p> <p>A (3) I get a sort of frightened feeling as if something awful is about to happen:</p> <p>3 ( ) Very definitely and quite badly</p> <p>2 ( ) Yes, but not too badly</p> <p>1 ( ) A little, but it doesn't worry me</p> <p>0 ( ) Not at all</p> <p>D (4) I can laugh and see the funny side of things:</p> <p>0 ( ) As much as I always could</p> <p>1 ( ) Not quite as much now</p> <p>2 ( ) Definitely not so much now</p> <p>3 ( ) Not at all</p> <p>A (5) Worrying thoughts go through my mind:</p> <p>3 ( ) Most of the time</p> <p>2 ( ) A lot of times</p> <p>1 ( ) From time to time</p> <p>0 ( ) Only occasionally</p> <p>D (6) I feel cheerful:</p> <p>0 ( ) Most of the time</p> <p>1 ( ) Usually</p> <p>2 ( ) Not often</p> <p>3 ( ) Not at all</p> <p>A (7) I can relax at ease and feel relaxed:</p> <p>0 ( ) Definitely</p> <p>1 ( ) Usually</p> <p>2 ( ) Not often</p> <p>3 ( ) Not at all</p>	<p>D (8) I feel as if I am slowed down:</p> <p>3 ( ) Nearly all the time</p> <p>2 ( ) Very often</p> <p>1 ( ) From time to time</p> <p>0 ( ) Not at all</p> <p>A (9) I get a sort of frightened feeling like butterflies in the stomach:</p> <p>0 ( ) Not at all</p> <p>1 ( ) From time to time</p> <p>2 ( ) Quite often</p> <p>3 ( ) Very often</p> <p>D (10) I have lost interest in my appearance:</p> <p>3 ( ) Definitely</p> <p>2 ( ) I don't take so much care as I should</p> <p>1 ( ) I may not take quite as much care</p> <p>0 ( ) I take just as much care as ever</p> <p>A (11) I feel restless, as if I had to be on the move:</p> <p>3 ( ) Very much indeed</p> <p>2 ( ) Quite a lot</p> <p>1 ( ) Not very much</p> <p>0 ( ) Not at all</p> <p>D (12) I look forward with enjoyment to things:</p> <p>0 ( ) As much as I ever did</p> <p>1 ( ) A little less than I used to</p> <p>2 ( ) Definitely less than I used to</p> <p>3 ( ) Hardly at all</p> <p>A (13) I get a sudden feeling of panic:</p> <p>3 ( ) Very often indeed</p> <p>2 ( ) Quite often</p> <p>1 ( ) From time to time</p> <p>0 ( ) Not at all</p> <p>D (14) I can enjoy a good TV or radio program or book:</p> <p>0 ( ) Often</p> <p>1 ( ) Sometimes</p> <p>2 ( ) Not often</p> <p>3 ( ) Hardly at all</p>
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## A Social Identity Approach to Acquired Brain Injury (ABI)

### Appendix 3 Mayo Portland Adaptability Inventory (MPAI)

<b>Mayo-Portland Adaptability Inventory-4</b> Muriel D. Lezak, PhD, ABPP & James F. Malec, PhD, ABPP																																
Name: _____ Clinic # _____ Date _____																																
Person reporting (circle one):    Single Professional    Professional Consensus    Person with brain injury    Significant other: _____																																
Below each item, circle the number that best describes the level at which the person being evaluated experiences problems. Mark the greatest level of problem that is appropriate. Problems that interfere rarely with daily or valued activities, that is, less than 5% of the time, should be considered not to interfere. Write comments about specific items at the end of the rating scale.																																
<i>For Items 1-20, please use the rating scale below.</i>																																
0    None	1    Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2    Mild problem; interferes with activities 5-24% of the time	3    Moderate problem; interferes with activities 25-75% of the time	4    Severe problem; interferes with activities more than 75% of the time																												
<table border="1" style="width: 100%; border-collapse: collapse;"> <thead> <tr> <th style="width: 50%; padding: 5px;">Part A. Abilities</th> <th style="width: 50%; padding: 5px;">Part B. Adjustment</th> </tr> </thead> <tbody> <tr> <td style="padding: 5px;">                             1. <b>Mobility:</b> Problems walking or moving; balance problems that interfere with moving about                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             13. <b>Anxiety:</b> Tense, nervous, fearful, phobias, nightmares, flashbacks of stressful events                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             2. <b>Use of hands:</b> Impaired strength or coordination in one or both hands                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             14. <b>Depression:</b> Sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             3. <b>Vision:</b> Problems seeing; double vision; eye, brain, or nerve injuries that interfere with seeing                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             15. <b>Irritability, anger, aggression:</b> Verbal or physical expressions of anger                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             4. <b>*Audition:</b> Problems hearing; ringing in the ears                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             16. <b>*Pain and headache:</b> Verbal and nonverbal expressions of pain, activities limited by pain                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             5. <b>Dizziness:</b> Feeling unsteady, dizzy, light-headed                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             17. <b>Fatigue:</b> Feeling tired; lack of energy; tiring easily                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             6. <b>Motor speech:</b> Abnormal clearness or rate of speech; stuttering                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             18. <b>Sensitivity to mild symptoms:</b> Focusing on thinking, physical or emotional problems attributed to brain injury; rate only how concern or worry about these symptoms affects current functioning over and above the effects of the symptoms themselves                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             7A. <b>Verbal communication:</b> Problems expressing or understanding language                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             19. <b>Inappropriate social interaction:</b> Acting childish, silly, rude, behavior not fitting for time and place                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             7B. <b>Nonverbal communication:</b> Restricted or unusual gestures or facial expressions; talking too much or not enough; missing nonverbal cues from others                              0    1    2    3    4                         </td> <td style="padding: 5px;">                             20. <b>Impaired self-awareness:</b> Lack of recognition of personal limitations and disabilities and how they interfere with everyday activities and work or school                              0    1    2    3    4                         </td> </tr> <tr> <td style="padding: 5px;">                             8. <b>Attention/Concentration:</b> Problems ignoring distractions, shifting attention, keeping more than one thing in mind at a time                              0    1    2    3    4                         </td> <td style="padding: 5px;"> <div style="border: 1px solid black; padding: 5px;">                                 21. <b>Family/significant relationships:</b> Interactions with close others; describe stress within the family or those closest to the person with brain injury; "family functioning" means cooperating to accomplish those tasks that need to be done to keep the household running                             </div> </td> </tr> <tr> <td style="padding: 5px;">                             9. <b>Memory:</b> Problems learning and recalling new information                              0    1    2    3    4                         </td> <td></td> </tr> <tr> <td style="padding: 5px;">                             10. <b>Fund of Information:</b> Problems remembering information learned in school or on the job; difficulty remembering information about self and family from years ago                              0    1    2    3    4                         </td> <td></td> </tr> <tr> <td style="padding: 5px;">                             11. <b>Novel problem-solving:</b> Problems thinking up solutions or picking the best solution to new problems                              0    1    2    3    4                         </td> <td></td> </tr> <tr> <td style="padding: 5px;">                             12. <b>Visuospatial abilities:</b> Problems drawing, assembling things, route-finding, being visually aware on both the left and right sides                              0    1    2    3    4                         </td> <td></td> </tr> </tbody> </table>					Part A. Abilities	Part B. Adjustment	1. <b>Mobility:</b> Problems walking or moving; balance problems that interfere with moving about 0    1    2    3    4	13. <b>Anxiety:</b> Tense, nervous, fearful, phobias, nightmares, flashbacks of stressful events 0    1    2    3    4	2. <b>Use of hands:</b> Impaired strength or coordination in one or both hands 0    1    2    3    4	14. <b>Depression:</b> Sad, blue, hopeless, poor appetite, poor sleep, worry, self-criticism 0    1    2    3    4	3. <b>Vision:</b> Problems seeing; double vision; eye, brain, or nerve injuries that interfere with seeing 0    1    2    3    4	15. <b>Irritability, anger, aggression:</b> Verbal or physical expressions of anger 0    1    2    3    4	4. <b>*Audition:</b> Problems hearing; ringing in the ears 0    1    2    3    4	16. <b>*Pain and headache:</b> Verbal and nonverbal expressions of pain, activities limited by pain 0    1    2    3    4	5. <b>Dizziness:</b> Feeling unsteady, dizzy, light-headed 0    1    2    3    4	17. <b>Fatigue:</b> Feeling tired; lack of energy; tiring easily 0    1    2    3    4	6. <b>Motor speech:</b> Abnormal clearness or rate of speech; stuttering 0    1    2    3    4	18. <b>Sensitivity to mild symptoms:</b> Focusing on thinking, physical or emotional problems attributed to brain injury; rate only how concern or worry about these symptoms affects current functioning over and above the effects of the symptoms themselves 0    1    2    3    4	7A. <b>Verbal communication:</b> Problems expressing or understanding language 0    1    2    3    4	19. <b>Inappropriate social interaction:</b> Acting childish, silly, rude, behavior not fitting for time and place 0    1    2    3    4	7B. <b>Nonverbal communication:</b> Restricted or unusual gestures or facial expressions; talking too much or not enough; missing nonverbal cues from others 0    1    2    3    4	20. <b>Impaired self-awareness:</b> Lack of recognition of personal limitations and disabilities and how they interfere with everyday activities and work or school 0    1    2    3    4	8. <b>Attention/Concentration:</b> Problems ignoring distractions, shifting attention, keeping more than one thing in mind at a time 0    1    2    3    4	<div style="border: 1px solid black; padding: 5px;">                                 21. <b>Family/significant relationships:</b> Interactions with close others; describe stress within the family or those closest to the person with brain injury; "family functioning" means cooperating to accomplish those tasks that need to be done to keep the household running                             </div>	9. <b>Memory:</b> Problems learning and recalling new information 0    1    2    3    4		10. <b>Fund of Information:</b> Problems remembering information learned in school or on the job; difficulty remembering information about self and family from years ago 0    1    2    3    4		11. <b>Novel problem-solving:</b> Problems thinking up solutions or picking the best solution to new problems 0    1    2    3    4		12. <b>Visuospatial abilities:</b> Problems drawing, assembling things, route-finding, being visually aware on both the left and right sides 0    1    2    3    4	
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Use scale at the bottom of the page to rate item #21																																
0    Normal stress within family or other close network of relationships	1    Mild stress that does <u>not</u> interfere with family functioning	2    Mild stress that interferes with family functioning 5-24% of the time	3    Moderate stress that interferes with family functioning 25-75% of the time	4    Severe stress that interferes with family functioning more than 75% of the time																												

MPAI-4 3/31/03



## A Social Identity Approach to Acquired Brain Injury (ABI)

Part C. Participation				
<b>22. Initiation:</b> Problems getting started on activities without prompting				
0 None	1 Mild problem but does <u>not</u> interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time
<b>23. Social contact with friends, work associates, and other people who are not family, significant others, or professionals</b>				
0 Normal involvement with others	1 Mild difficulty in social situations but maintains normal involvement with others	2 Mildly limited involvement with others (75-95% of normal interaction for age)	3 Moderately limited involvement with others (25-74% of normal interaction for age)	4 No or rare involvement with others (less than 25% of normal interaction for age)
<b>24. Leisure and recreational activities</b>				
0 Normal participation in leisure activities for age	1 Mild difficulty in these activities but maintains normal participation	2 Mildly limited participation (75-95% of normal participation for age)	3 Moderately limited participation (25-74% of normal participation for age)	4 No or rare participation (less than 25% of normal participation for age)
<b>25. Self-care: Eating, dressing, bathing, hygiene</b>				
0 Independent completion of self-care activities	1 Mild difficulty, occasional omissions or mildly slowed completion of self-care; may use assistive device or require occasional prompting	2 Requires a little assistance or supervision from others (5-24% of the time) including frequent prompting	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)
<b>26. Residence:</b> Responsibilities of independent living and homemaking (such as, meal preparation, home repairs and maintenance, personal health maintenance beyond basic hygiene including medication management) but <u>not</u> including managing money (see #29)				
0 Independent; living without supervision or concern from others	1 Living without supervision but others have concerns about safety or managing responsibilities	2 Requires a little assistance or supervision from others (5-24% of the time)	3 Requires moderate assistance or supervision from others (25-75% of the time)	4 Requires extensive assistance or supervision from others (more than 75% of the time)
<b>27. *Transportation</b>				
0 Independent in all modes of transportation including independent ability to operate a personal motor vehicle	1 Independent in all modes of transportation, but others have concerns about safety	2 Requires a little assistance or supervision from others (5-24% of the time); cannot drive	3 Requires moderate assistance or supervision from others (25-75% of the time); cannot drive	4 Requires extensive assistance or supervision from others (more than 75% of the time); cannot drive
<b>28A. *Paid Employment:</b> Rate either item 28A or 28B to reflect the primary desired social role. Do not rate both. Rate 28A if the primary social role is paid employment. If another social role is primary, rate only 28B. For both 28A and 28B, "support" means special help from another person with responsibilities (such as, a job coach or shadow, tutor, helper) or reduced responsibilities. Modifications to the physical environment that facilitate employment are not considered as support.				
0 Full-time (more than 30 hrs/wk) without support	1 Part-time (3 to 30 hrs/wk) without support	2 Full-time or part-time with support	3 Sheltered work	4 Unemployed; employed less than 3 hours per week
<b>28B. *Other employment:</b> Involved in constructive, role-appropriate activity other than paid employment. Check only one to indicate <u>primary</u> desired social role: Childrearing/care-giving Homemaker, no childrearing or care-giving Student Volunteer Retired (Check retired only if over age 60; if unemployed, retired as disabled and under age 60, indicate "Unemployed" for item 28A.)				
0 Full-time (more than 30 hrs/wk) without support; full-time course load for students	1 Part-time (3 to 30 hrs/wk) without support	2 Full-time or part-time with support	3 Activities in a supervised environment other than a sheltered workshop	4 Inactive; involved in role-appropriate activities less than 3 hours per week
<b>29. Managing money and finances:</b> Shopping, keeping a check book or other bank account, managing personal income and investments; if independent with small purchases but not able to manage larger personal finances or investments, rate 3 or 4.				
0 Independent; manages small purchases and personal finances without supervision or concern from others	1 Manages money independently but others have concerns about larger financial decisions	2 Requires a little help or supervision (5-24% of the time) with large finances; independent with small purchases	3 Requires moderate help or supervision (25-75% of the time) with large finances; some help with small purchases	4 Requires extensive help or supervision (more than 75% of the time) with large finances; frequent help with small purchases

MPA1-4 3/31/03



## A Social Identity Approach to Acquired Brain Injury (ABI)

**Part D: Pre-existing and associated conditions.** The items below do not contribute to the total score but are used to identify special needs and circumstances. For each rate, pre-injury and post-injury status.

**30. Alcohol use:** Use of alcoholic beverages.

Pre-injury	Post-injury				
0 No or socially acceptable use	1 Occasionally exceeds socially acceptable use but does not interfere with everyday functioning, current problem under treatment or in remission	2 Frequent excessive use that occasionally interferes with everyday functioning, possible dependence	3 Use or dependence interferes with everyday functioning, additional treatment recommended	4 Inpatient or residential treatment required	

**31. Drug use:** Use of illegal drugs or abuse of prescription drugs.

Pre-injury	Post-injury				
0 No or occasional use	1 Occasional use does not interfere with everyday functioning, current problem under treatment or in remission	2 Frequent use that occasionally interferes with everyday functioning, possible dependence	3 Use or dependence interferes with everyday functioning, additional treatment recommended	4 Inpatient or residential treatment required	

**32. Psychotic Symptoms:** Hallucinations, delusions, other persistent severely distorted perceptions of reality.

Pre-injury	Post-injury				
0 None	1 Current problem under treatment or in remission; symptoms do not interfere with everyday functioning	2 Symptoms occasionally interfere with everyday functioning but no additional evaluation or treatment recommended	3 Symptoms interfere with everyday functioning; additional treatment recommended	4 Inpatient or residential treatment required	

**33. Law violations:** History before and after injury.

Pre-injury	Post-injury				
0 None or minor traffic violations only	1 Conviction on one or two misdemeanors other than minor traffic violations	2 History of more than two misdemeanors other than minor traffic violations	3 Single felony conviction	4 Repeat felony convictions	

**34. Other condition causing physical impairment:** Physical disability due to medical conditions other than brain injury, such as, spinal cord injury, amputation. Use scale below #35.

Pre-injury	Post-injury				
0 None	1 Mild problem but does not interfere with activities; may use assistive device or medication	2 Mild problem; interferes with activities 5-24% of the time	3 Moderate problem; interferes with activities 25-75% of the time	4 Severe problem; interferes with activities more than 75% of the time	

**Comments:**

Item #

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MPAL-4 3/31/03

## A Social Identity Approach to Acquired Brain Injury (ABI)

### Appendix 4 MOS Social Support Survey

#### MOS Social Support Survey

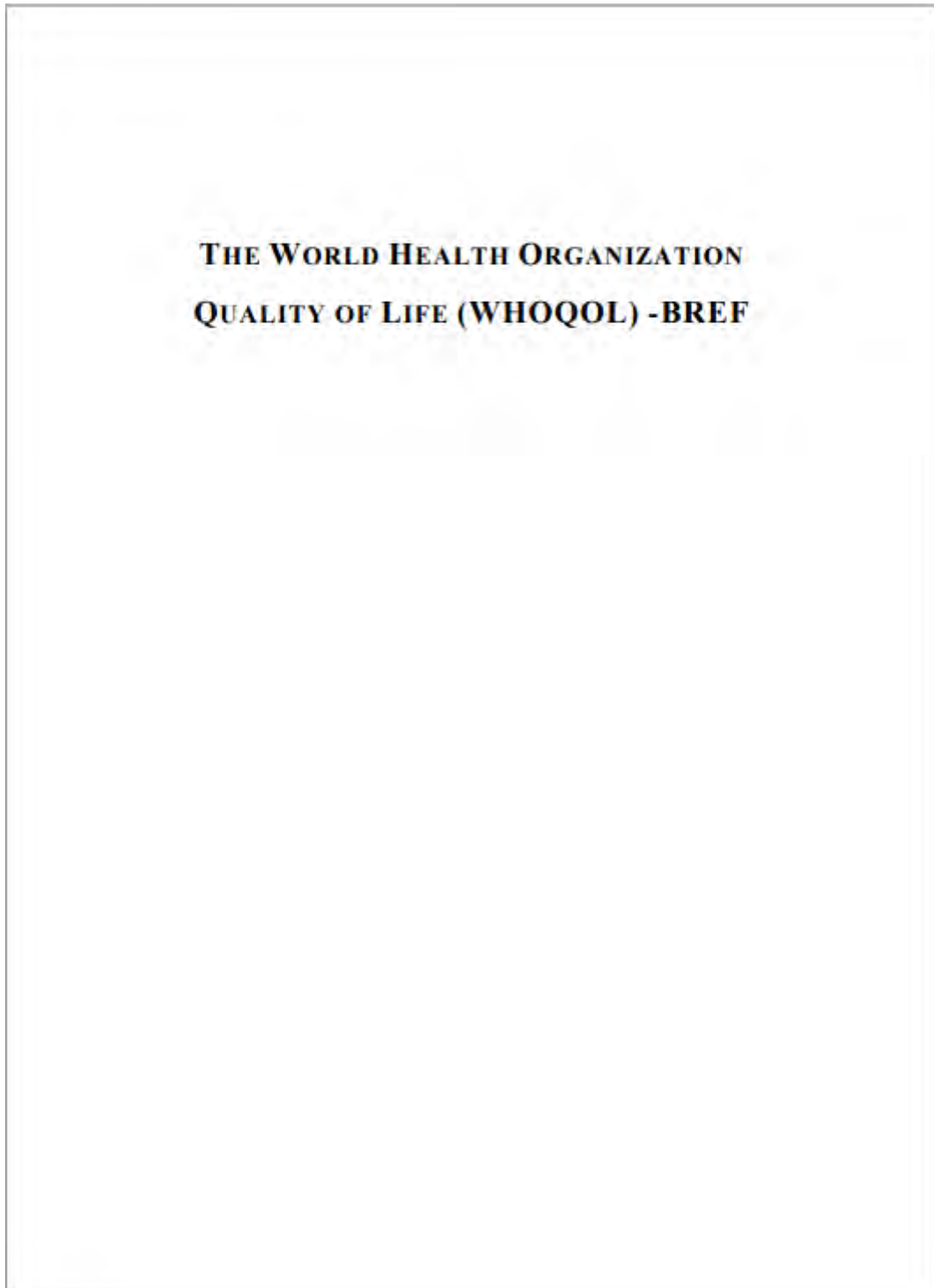
People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
<b>Emotional/Informational support</b>					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Someone whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
<b>Tangible support</b>					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
<b>Affectionate support</b>					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5

## A Social Identity Approach to Acquired Brain Injury (ABI)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5

**Appendix 5 WHOQOL-BREF**



## A Social Identity Approach to Acquired Brain Injury (ABI)

### WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options. **Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks**.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

## A Social Identity Approach to Acquired Brain Injury (ABI)

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5



## A Social Identity Approach to Acquired Brain Injury (ABI)

20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

**Do you have any comments about the assessment?**

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*[The following table should be completed after the interview is finished]*

		Equations for computing domain scores	Raw score	Transformed scores*	
				4-20	0-100
27.	<b>Domain 1</b>	$(6-Q3) + (6-Q4) + Q10 + Q15 + Q16 + Q17 + Q18$ $\square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:
28.	<b>Domain 2</b>	$Q5 + Q6 + Q7 + Q11 + Q19 + (6-Q26)$ $\square + \square + \square + \square + \square + \square$	a. =	b:	c:
29.	<b>Domain 3</b>	$Q20 + Q21 + Q22$ $\square + \square + \square$	a. =	b:	c:
30.	<b>Domain 4</b>	$Q8 + Q9 + Q12 + Q13 + Q14 + Q23 + Q24 + Q25$ $\square + \square + \square + \square + \square + \square + \square + \square$	a. =	b:	c:

\* See Procedures Manual, pages 13-15