

**VOLUME I**

**RESEARCH COMPONENT**

**COMMUNITY INTEGRATION AND FRIENDSHIPS FOLLOWING  
BRAIN INJURY**

**NICOLA BAKER**

**A thesis submitted to**

**The University of Birmingham**

**for the degree of**

**DOCTORATE IN CLINICAL PSYCHOLOGY**

Department of Clinical Psychology  
School of Psychology  
The University of Birmingham  
May 2014

UNIVERSITY OF  
BIRMINGHAM

**University of Birmingham Research Archive**

**e-theses repository**

This unpublished thesis/dissertation is copyright of the author and/or third parties. The intellectual property rights of the author or third parties in respect of this work are as defined by The Copyright Designs and Patents Act 1988 or as modified by any successor legislation.

Any use made of information contained in this thesis/dissertation must be in accordance with that legislation and must be properly acknowledged. Further distribution or reproduction in any format is prohibited without the permission of the copyright holder.

## **Overview**

This thesis is submitted in partial fulfilment of the requirements for the degree of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham. The thesis consists of two volumes.

### **Volume One**

This volume consists of three chapters. The first chapter is a systematic literature review of research on social activity and community integration following traumatic brain injury. The second chapter is a qualitative empirical paper looking at the experiences of friendships of those persons with brain injuries, both pre-and post-injury. The final chapter is a public domain document. This is a summary that has been written with the purpose of sharing the findings of the empirical paper with the services involved in the recruitment of participants.

## **Volume Two**

This volume comprises of five Clinical Practice Reports (CPRs). The first report details the case of a 39 year-old-woman with a mild learning disability with a diagnosis of Post-Traumatic Stress Disorder (PTSD), formulated using cognitive-behavioural and psychodynamic approaches. The second report is an evaluation of a new Single Point of Access (SPA) referral pathway for a community learning disability service. The third report presents the case of a 51-year-old man who received a cognitive behavioural therapy (CBT) intervention for a diagnosis of health anxiety and co-morbid panic disorder and depression, in a community mental health team. The fourth report is an abstract of an oral presentation of a single-case experimental design of a Trauma-Focussed CBT intervention for PTSD with a 12-year old boy. The fifth and final report is a neuropsychological assessment of a 39 year old woman with multiple sclerosis and anxiety.

All names and identifying features have been changed to ensure confidentiality.

## **Acknowledgements**

Firstly I would like to thank my research supervisor, Gerry Riley, for all his support, not just on the research elements but with all the obstacles that the doctorate course threw at me. His words of guidance and encouragement were often like a 'verbal hug', leaving me full of hope and determination. I would also like to thank the staff at the services involved for their support of my project and getting it off the ground. A special thank you goes to the participants who so kindly shared their stories with me. Without them none of this would have been possible.

From the course I would like to thank everyone. I feel blessed to have been part of such an amazing cohort. To Kiran, Clare, Sarah M, Sarah B and Michelle H, thank you for listening to my rants and tantrums over the last three years. Hopefully these will turn from tantrums to sharing stories of our amazing careers over the years to come.

To my best friend Sally, none of this could have been achieved without your support and encouragement. Having you by my side has made the whole process so much easier. Thank you for the tea, cakes, chocolate and sympathy. Phern, the 'grounder', thank you for providing an ear and being a source of stability when things got tough.

To my dad, mum and sister, Jessica, thank you for everything you have done for me over the last 10 years of me pursuing my dream and thank you for just being you, my family.

## Contents of Volume 1

### Chapter One: Social Activity and Community Integration Following Traumatic Brain Injury

|  |    |
|--|----|
| Title.....   | 1  |
| Abstract.....  | 2  |
| Introduction .....   | 3  |
| Method.....  | 8  |
| Search strategy.....   | 8  |
| Inclusion criteria.....  | 9  |
| Exclusion criteria.....  | 9  |
| Application of the inclusion/exclusion criteria.....                 | 9  |
| Quality assessment .....   | 10 |
| Data extraction.....   | 12 |
| Findings .....   | 13 |
| Study quality.....   | 13 |
| Study findings.....  | 25 |
| Discussion.....  | 35 |
| Summary of findings .....  | 35 |
| Limitations of the research and directions for future research ..... | 35 |
| Limitations of the Literature Review.....                            | 40 |
| Implications for Clinical Practice .....                             | 41 |
| References .....   | 43 |

### Chapter Two: An Interpretative Phenomenological Analysis of Friendships after Brain Injury.

|   |    |
|---|----|
| Title.....                                      | 54 |
| Abstract.....                                   | 55 |
| Introduction .....                              | 56 |
| Method.....                                     | 60 |
| Participants and recruitment .....              | 60 |
| Semi-structured interviews .....                | 62 |
| Ethical considerations.....                     | 63 |
| Researcher .....                                | 63 |
| Analysis .....                                  | 64 |
| Findings .....                                  | 66 |
| Changes in friendships .....                    | 67 |
| Nature and function of friendships .....        | 75 |
| Emotional and coping responses .....            | 78 |
| Forming and Maintaining Friendships .....       | 79 |
| Discussion.....                                 | 82 |
| Summary of findings.....                        | 82 |
| Methodological considerations .....             | 86 |
| Future research and clinical implications ..... | 88 |
| References .....                                | 90 |

### **Chapter Three: Public Domain Briefing Document**

|                       |     |
|-----------------------|-----|
| Title.....            | 97  |
| Overview .....        | 98  |
| Empirical Paper ..... | 98  |
| Background.....       | 98  |
| Aims .....            | 98  |
| Method.....           | 98  |
| Findings .....        | 99  |
| Conclusions .....     | 100 |

### **Appendices Volume 1**

|                                       |     |
|---------------------------------------|-----|
| A: CASP Tool.....                     | 101 |
| B: Participant information sheet..... | 104 |
| C: Screening form.....                | 109 |
| D: Consent form .....                 | 110 |
| E: Interview Schedule.....            | 111 |

## List of Tables for Volume 1

### Chapter One

|  |    |
|--|----|
| Table 1. Search terms for each database.....   | 8  |
| Table 2. Modified CASP quality framework detail of questions and criteria used to review papers..... | 11 |
| Table 3. Data extraction table.....  | 16 |

### Chapter Two

|   |    |
|---|----|
| Table 4. Descriptive Statistics of the Participants ..... | 62 |
| Table 5. Study Themes .....                               | 66 |

### Chapter Three

|  |    |
|--|----|
| Table 6. Study Themes for the Empirical Paper..... | 99 |
|--|----|

## List of Figures for Volume 1

### Chapter One

|  |    |
|--|----|
| Figure 1. Flow-diagram of the search screening process ..... | 13 |
|--|----|



## Contents of Volume 2

|   |    |
|---|----|
| <b>Clinical Practice Report 1: Psychological Models</b> .....   | 1  |
| <b>Formulating Anxiety Using the Cognitive Model &amp; the Psychodynamic Model</b>                            |    |
| Title.....  | 1  |
| Abstract.....   | 2  |
| Background information.....   | 3  |
| Assessment.....   | 8  |
| Formulations.....   | 11 |
| Cognitive Formulation.....  | 11 |
| Psychodynamic Formulation.....  | 16 |
| Critical Appraisal.....   | 22 |
| Reflections.....  | 24 |
| References.....   | 26 |
| <br>  |    |
| <b>Clinical Practice Report 2: Service Evaluation</b> .....   | 28 |
| <b>Evaluating a New Single Point of Access Referral Pathway for a Community Learning Disability Service</b>   |    |
| Title.....  | 28 |
| Abstract.....   | 29 |
| Background.....   | 30 |
| Method.....   | 38 |
| Results.....  | 41 |
| Discussion.....   | 50 |
| Reflections.....  | 55 |
| References.....   | 57 |
| <br>  |    |
| <b>Clinical Practice Report 3: Case Study</b> .....   | 59 |
| <b>A Cognitive-Behavioural Approach to Complex Health Anxiety in an Adult Community Mental Health Setting</b> |    |
| Title.....  | 59 |
| Abstract.....   | 60 |
| Assessment.....   | 61 |
| Presenting Difficulties.....  | 63 |
| Risk.....   | 65 |
| Focus of Therapeutic Work.....  | 66 |
| Formulation.....  | 68 |
| Intervention.....   | 76 |
| Evaluation.....   | 80 |
| Reflections.....  | 82 |
| References.....   | 85 |
| <br>  |    |
| <b>Clinical Practice Report 4: Oral Presentation of a Single-case Experimental Design</b> .....               | 89 |
| <b>A Cognitive-Behavioural Based Intervention for PTSD in a CAMHS Setting</b>                                 |    |
| Title.....  | 89 |
| Abstract.....   | 90 |

|  |     |
|--|-----|
| <b>Clinical Practice Report 5: Neuropsychological Case report</b> .....                                  | 91  |
| <b>Title: A Neuropsychological Assessment of a 39 Year Old Woman with Multiple Sclerosis and Anxiety</b> |     |
| Title .....  | 91  |
| Abstract .....   | 92  |
| Service .....  | 93  |
| Presenting Difficulties .....  | 93  |
| Initial Assessment .....   | 93  |
| Background Information .....   | 94  |
| Preliminary Formulation .....  | 97  |
| Neuropsychological Assessment .....  | 103 |
| Intervention .....   | 113 |
| Evaluation .....   | 114 |
| Reflections .....  | 116 |
| References .....   | 118 |

## **Appendices Volume 2**

### **CPR 2: Service Evaluation**

|                                |     |
|--------------------------------|-----|
| A: Initial Thematic Map .....  | 123 |
| B: Developed Thematic Map..... | 124 |
| B: Final Thematic Map.....     | 125 |

## List of Tables for Volume 2

### CPR 2: Service Evaluation

|   |    |
|---|----|
| Table 1. Demographics of Referrals made to SPA..... | 41 |
| Table 2. Sources of Referrals .....                 | 42 |
| Table 3. Waiting times for Referrals .....          | 43 |

### CPR 5:

|   |     |
|---|-----|
| Table 1. RBANS Scores .....                         | 105 |
| Table 2. TEA Scores .....                           | 107 |
| Table 3. Test of Executive Functioning Scores ..... | 108 |

## List of Figures for Volume 2

### CPR 1: Psychological Models

|   |    |
|---|----|
| Figure 1. Genogram.....                                   | 4  |
| Figure 2. Timeline .....                                  | 10 |
| Figure 3. Cognitive Formulation .....                     | 14 |
| Figure 4. Cognitive Model of PTSD .....                   | 16 |
| Figure 5. Psychodynamic Triangle of Person/Conflict ..... | 21 |

### CPR 2: Service Evaluation

|  |    |
|--|----|
| Figure 1. Development of the NEW Psychology SPA.....           | 34 |
| Figure 2. The New Psychology Referral Pathway .....            | 36 |
| Figure 3. Development of the Interview Schedule .....          | 40 |
| Figure 4. The 4 Key Principles, 10 Objectives and Themes ..... | 49 |

### CPR 3: Case Study

|   |    |
|---|----|
| Figure 1. CORE Outcome Measure Pre-therapy Scores .....           | 62 |
| Figure 2. The Cognitive Model of Health Anxiety .....             | 69 |
| Figure 3. Cognitive Formulation .....                             | 75 |
| Figure 4. CORE Outcome Measure Pre- and Post-therapy Scores ..... | 80 |

### CPR 5: Neuropsychological Case Report

|  |     |
|--|-----|
| Figure 1. Health Anxiety Formulation ..... | 100 |
|--|-----|

## **Chapter One**

### **Literature Review**

# **Social Activity and Community Integration Following Traumatic Brain Injury**

## ABSTRACT

**Background.** Although a vast amount of research exists exploring community integration following traumatic brain injury, (TBI), to date this has predominantly focussed on work-related activity rather than social aspects of community integration. Therefore this review sought to add to the existing literature to review research on social and leisure based activities following TBI.

**Method.** Research into community integration following TBI published between 2002 and 2013 was collated from the search of four databases. A total of 1593 were initially screened. The studies that met the inclusion criteria were subjected to a quality framework evaluation to establish their quality and credibility.

**Results.** Overall nineteen papers were included in the review and found that TBI did in fact impact on aspects of community integration, such as reduced social/leisure activity and reduced social contact. The literature also revealed consequences of this impact (higher rates of depression), along with the identification of both facilitators of integration (e.g. milder injuries) and barriers to this (e.g. environment).

**Conclusions.** The identification and summarisation of potential barriers and facilitators to integration can aid support to individuals when working with them in a clinical capacity, by developing social/leisure related goals as part of their rehabilitation.

Keywords: *Traumatic brain injury, social activity, social participation, community integration*

## **Social Activity and Community Integration Following Traumatic Brain Injury**

### *Community Integration*

Jacobs (1993) defined community integration as “having ‘something to do’, ‘someone to love’ and ‘somewhere to live’”, (cited in McColl et al., 1998: p.16). Building on this definition McColl et al. (1998) interviewed those with TBI to help gain their definition of community integration. For the participants, integration was built on nine aspects; conformity, orientation, living situation, but more interestingly acceptance, close and diffuse relationships, independence, productivity and leisure. Further support for this came from two reviews; Reistetter and Abreu (2005) found that being connected to natural contacts along with close friends and others is a fundamental element in community integration. Sander, Clark and Pappadis (2010) also reported the importance of engaging in productive activity but felt that equal weighting was not always given to social relationships and leisure outcomes in the clinical setting.

### *Community Integration and Mental Health*

Community integration or being part of a community socially is something that has been highlighted as important to all people, not just those with TBIs. Reduced community integration, specifically social integration has been found to lead to poorer mental health outcomes (Seemen, 1996). Several papers have looked at the links between integration, lack of social relationships and health, finding that a reduction of these can cause increases in stress and anxiety (Berkman, 2001; House, 2001; Seemen, 1996). In a recent report commissioned by the Mental Health Foundation (2010) it was found that 42% of people surveyed felt depressed because of isolation and loneliness. This link between depression and

## Social Activity, Community Integration and TBI

poor community integration and social isolation is something suggested by the behavioural theory of depression. It suggests that reduced access to positive reinforcement (which could result from aspects of poor community integration, such as being lonely) is the basis of depression (Carvalho & Hopko, 2011; Veale, 2008).

### *Community Integration and TBI*

In a review conducted almost 20 years ago, Morton and Wehman (1995) reported that following TBI individuals reported an increase in loneliness and social isolation as well as a marked decrease in social activities, including returning to work, engagement in leisure activities and social contacts in their community. Subsequent research looking at the long-term outcomes of TBI has also concluded that this population were likely to experience poor community integration outcomes, including depression (Buliński, 2010; Dikmen, Machamer, Powell & Temkin, 2003; Hoofien, Gilboa, Vakil, & Donovan, 2001; Kersel, Marsh, Havill, & Sleigh, 2001; Jorge, Robinson, Moser, Tateno, Crespo-Facorro, & Arndt, 2006; Koskinen, 1998; McColl et al., 1998; Tate, Simpson, Lane-Brown, Soo, de Wolf, & Whiting, 2012; Yates, 2003).

Some aspects of community integration following TBI have been more extensively researched than others. One of these aspects is the impact of TBI on close personal relationships. A wealth of research suggests that following TBI individuals are more likely to experience a breakdown in their romantic relationships alongside relationship difficulties with their wider family, (Arango-Lasprilla et al., 2008; Oddy, Coughlan, Tyerman, & Jenkins, 1985; Weddell, Oddy, & Jenkins, 1980; Wood, Liossi, & Wood, 2005; Wood & Yurdakul, 1997). Livingston, Brooks and Bond (1985<sup>a</sup>, 1985<sup>b</sup>) found a significant deterioration of marital relationships at just 12 months post injury. Although a more recent paper did find that

the majority of their sample did remain 'maritally stable' (85%), this was at a 2 year follow-up (Arango-Lasprilla et al., 2008) and there appear to be increasingly poorer outcomes with an increase in time since injury. At 5-8 year follow-up, Wood and Yardakul (1997) found that 49% of their sample had divorced or separated from their partners.

Another aspect of community integration that has received relatively more research attention is employment. In a review, Shame, Treger, Ring, and Giaquinto (2007) found that rates of returning to work following TBI varied from 12-70%. In an earlier paper less than 40% of a sample that were employed pre-injury were employed post-injury at a 4-year follow-up (Sander, Krentzer, Rosenthal, Delmonico, & Young, 1996). Much research has been focused on returning to work, which appears to be the aim of many rehabilitation programmes, despite not every TBI patient being able to return to some form of employment (Truelle, Fayol, Montreuil, & Chevignard, 2010; Yates, 2003).

#### *Other aspects of community integration*

Although the impact on family life and employment has been more extensively researched, there are other aspects of community integration that have been relatively neglected. These include friendships and social contacts outside the family, and community-based occupational and leisure activities other than employment (Reistetter & Abreu, 2005). Using questionnaires with both the participants and a significant other (i.e. a family member) Thomsen (1984) found that people with TBI reported little opportunity for meeting and making new friends, the dissolution of pre-injury friendships and a decline in socially-based community activities. This loss of meaningful social activity was also found by Oddy, Humphrey and Uttley (1978). Temkin, Corrigan, Dikmen and Machamer (2009) reviewed research that confirmed this reduction in 'social relationships', this included aspects such as



social interaction; reflecting the impact of TBIs on a person's engagement in this particular area of living.

Two qualitative studies have also illustrated the importance of community integration following brain injury. Firstly Haggstrom and Larsson-Lund (2008) reported that brain injury impacted on participants' ability to engage in many of their pre-injury activities and consequently reduced their 'social contexts'. For participants there was a need for a sense of engagement in meaningful activities if they were to experience a true sense of participation. One participant described the importance of participation in activities to promote a sense of belonging and to feel bonded through the shared activity; "...but participation, you feel in another way...that you are accepted...in a group for example" (Haggstrom & Larsson-Lund, 2008: p.93). In a subsequent study (Schipper, Visser-Meily, Hendrikx, & Abma, 2011) the importance of social and occupational activities other than work and family life were also highlighted, showing again the importance of engaging in social activities with others for participants.

### *Aim of current review*

The aim of the current paper is to review recent research on these relatively neglected aspects of community integration (i.e. social contact outside the family, and community-based occupational and leisure activities other than employment). These are aspects that TBI can have a major impact on, and people with a TBI have highlighted them as important parts of their life. They may be particularly important to those people with brain injuries who do not recover fully enough to return to full-time employment and who therefore need to fulfil the 'having something to do' in other ways, such as leisure activities (Buliński, 2010; Hoofien et

## Social Activity, Community Integration and TBI

al., 2001; Kersel et al., 2001; Koskinen, 1998; McColl et al., 1998; Morton & Wehman, 1995; Tate et al., 2012; Yates, 2003).

The questions asked of the literature were:

1. What impact do TBIs have on social contact outside the family, and community-based occupational and leisure activities other than employment (i.e. what impact do they have on community integration excluding the impact on the family contact and employment)?
2. What are the consequences of this impact for the person with the TBI?
3. What factors are associated with a decrease in community integration and what factors are associated with an increase?

## METHOD

Four main databases were utilised to search for literature relating to community participation in a traumatic brain injury adult population.

### Search Strategy

In order to keep the number of papers reviewed within manageable limits, the database searches were confined to papers published since 2000. The search was undertaken in November 2013. The search criteria on each database were identical. The databases utilised were; Embase, PsycInfo, Web of Science (WoS) and Applied Social Sciences Index and Abstracts (ASSIA). The search strategy undertaken is presented in Table 1. Search terms were chosen to encompass the review objectives and reflect the, at times, interchangeable nature of brain injury terminology.

Table 1

*Search terms for each database (Search 1 & 2 utilised the OR function)*

| <b><u>Search 1</u></b><br>Brain Injury Related<br>Terms | <b><u>Search 2</u></b><br>Participation Related<br>Terms | <b><u>Search 3</u></b><br>Age Population<br>(Independent<br>search) | <b><u>Search 4</u></b><br>Combined Search |
|---|--|---|---|
| Brain injur*  | Social function*   | Adult*  | Search 1                                  |
| Head Injur*   | Social* activ*   |   | <b>AND</b>                                |
| TBI   | Social* integrat*  |   | Search 2                                  |
| Traumatic Brain Injur*                                  | Community integrat*                                      |   | <b>AND</b>                                |
| ABI   | Social participat*                                       |   | Search 3                                  |
| Acquired brain Injur*                                   | Community participat*                                    |   |   |
|   | Social* Isolat*  |   |   |
|   | Social contact*  |   |   |
|   | Social* inclu*   |   |   |
|   | Social interact*   |   |   |
|   | Leisure activit*   |   |   |
|   | Leisure  |   |   |

### **Inclusion Criteria**

The following inclusion criteria were used:

- The paper was original research reporting data about social contact outside the family, and community-based occupational and leisure activities other than employment.
- The paper collected data from participants that had suffered a traumatic brain injury classified as moderate or severe. Studies that included participants with mild brain injury were included as long as the overall sample in the paper included some that had moderate or severe TBI. Papers with samples that were exclusively mild TBI were excluded. Papers that included participants with acquired brain injuries other than TBI were also included provided that at least 70% of the sample had TBI.

### **Exclusion Criteria**

The following exclusion criteria were used:

- Paper did not appear in a peer-reviewed journal.
- Paper reported on intervention studies designed to increase community participation, and did not report any data satisfying the inclusion criteria.

### **Application of the inclusion/exclusion criteria**

The title and abstract of papers identified by the search were reviewed. Those that were duplicates or that were clearly not relevant to the review were discarded. If there was doubt about their relevance, the full text of the paper was reviewed to determine if they satisfied the inclusion criteria or were to be excluded.

### **Quality Assessment**

There has been much debate on the reviewing of empirical studies and a variety of assessment frameworks developed to evaluate the quality of these (Chambless & Hollon, 1998; Caldwell, Henshaw, & Taylor, 2005; Sale & Brazil, 2009; Heyvaert, Hannes, Maes & Onghena, 2013). The majority of these frameworks appear to assess a particular method of research; however the nature of performing a literature review often requires studies of different methodologies to be evaluated. Sale and Brazil (2004) developed a list of mixed-method critical appraisal criteria for mixed-method studies, although in essence it is still two separate frameworks. The present systematic review poses such a problem with a variety of methodologies being assessed.

For this review a modified version of the Critical Appraisal Skills Programme (CASP, Public Health Resource Unit in England, 2006) tool has been utilised (see Appendix C for CASP Tool). The original tool was developed for the evaluation of a variety of qualitative methods, however on review the ten questions could be seen as transferrable to the evaluation of quantitative methods. The questions appear to map onto those proposed by Caldwell et al. (2005, 2011); but it is shorter and more concise in its presentation. The first two questions act as a screen to help decide whether the study is adequate for further evaluation. The questions covered by the CASP tool help to address the rigour, credibility and relevance of a research study. Due to the utilisation of this framework for quantitative methodologies, question 6 (*Has the relationship between researcher and participants been adequately considered?*) was removed as it was felt this was only reflective of qualitative methodologies. Below Table 2 gives a description of the nine questions from the CASP. This framework was used to evaluate the papers reviewed.

Table 2

*Modified CASP Quality Framework Detail of Questions and Criteria used to Review Papers*

- 1: Was there a clear statement of the aims of the research? *This covers information relating to the goal or aim of the research proposed, and the rationale behind it.*
2. Is the methodology appropriate? *For qualitative research this refers to whether the participant's subjective experiences have been captured. For both methodologies the justification of the type of study design needs to be clearly described and justified (e.g. quantitative vs. qualitative vs. mixed-methods).*
3. Have ethical issues been taken into consideration? *Here both methodologies need to describe what efforts have been made to align with ethical standards such as informed consent and confidentiality.*
4. Was the research design appropriate to address the aims of the research? *When looking at the qualitative research elements in the review the philosophical background and rationale for this choice and the context of the study needs to be discussed. For quantitative it would be whether the design and rationale are referred to, as well as a clear experimental hypothesis and clear key variables.*
5. Was the recruitment strategy appropriate to the aims of the research? *For both methodologies the researcher needs to describe the population and how the sample was identified. It also must include why some did not take part in the research.*
6. Were the data collected in a way that addressed the research issue? *The criteria here address both methodologies. To meet the quality mark the paper needs to ascertain justification for the collection and that it was done so in a valid and reliable way. For example discussing issues around the method and whether any modifications were made to tools used.*
7. Was the data analysis sufficiently rigorous? *Here a description of the analysis is needed to meet the criteria, along with confirmation that this is a valid and reliable method. For qualitative methodology there also need to be information relating to the analysis process, saturation of data, the development of categories/themes as well as reporting of potential bias.*
8. Is there a clear statement of findings? *Results need to be displayed in a clear, appropriate way and in relation to the research questions.*
9. How valuable is the research? *For qualitative research the paper needs to consider whether the results contribute to the existing knowledge/theory, how they can be potentially transferred/generalised to other populations, and suggestions for future research.*

### **Data Extraction**

The data extraction was structured around the main aims of the review highlighted previously, giving the review shape and consistency (see Table 3). Data extracted included the main aims of the research, the participants sampled (including size, power analysis, recruitment procedure, location of sample and description of injury), data collection (how this was done, measures used and their reliability validity values), analysis (method and types of statistical analysis where applicable), and finally the findings in relation to the literature review aims (whether there has been a decline in those aspects of community integration that were the focus of the review, the consequences of any decline, and factors/barriers associated with reduced/increased community integration).

## FINDINGS

On applying both the inclusion and exclusion criteria a total of 19 papers were identified for review. Figure 1 displays the search strategy process.

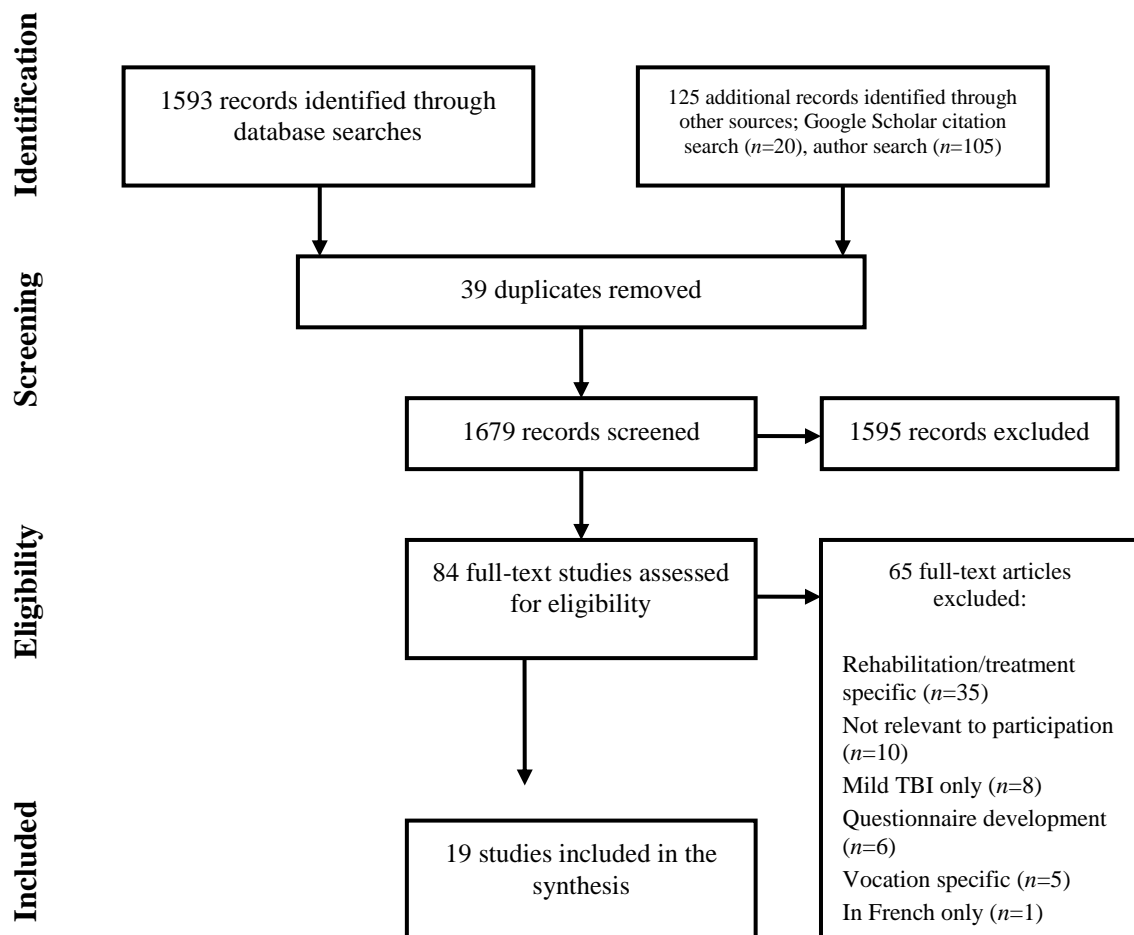


Figure 1. Flow-diagram of the search screening process. Diagram adapted from Moher et al. (2009).

### Study Quality

Reviewed using CASP all 19 met the two screening markers, therefore subject to the full quality assessment. Below is a description of how the papers met the specific quality markers overall:



*Ethical Issues:* Ten of the nineteen papers described in detail their ethical considerations or stated their research had been approved by an ethics committee. Six partially met this criterion by discussing specific considerations such as informed consent, but did not go into detail. This meant that three did not discuss any ethical considerations at all (Brown, Gordon & Spielman, 2003; Riley, Brennan & Powell, 2004; Sander, Pappadis, Clark & Struchen, 2011).

*Appropriate Research Design:* On review of the research designs only one of the qualitative papers did not detail the theoretical/philosophical background to their study (Conneeley, 2002). This criterion was met for the other methodologies including those utilising a mixed-method. Of the quantitative papers, eight provided full descriptions of their design rationale and hypotheses. The remaining ten neglected this level of reporting, only giving their aims for the research, or questions posed.

*Recruitment Strategy:* The majority of papers gave full descriptions of their participant sample including inclusion and exclusion criteria. However one paper gave minimal details, and did not refer to why some participants declined to take part in the research, hence they were deemed to only partially meet this quality criterion (Pappadis, Sander, Leung & Struchen, 2012). For one paper this criterion was classed as not applicable due to the nature of the study (Roscigno & Van Liew, 2008). This particular paper only had one participant who approached the author independently.

*Data collection:* Fourteen of the nineteen papers gave full details of the way in which the data were collected and justified their actions for how it was implemented. The remaining papers only partially met this criterion for various reasons. For one, the way in which the interviews were conducted appeared to be inconsistent (Johnston, Goverover & Dijkers, 2005). Here the interviews with participants were conducted either by the primary investigator or a research

assistant, whereas the other papers appeared to use the same interviewer throughout. Another paper modified a measure to individualise it to each participant (Fleming, Braithwaite, Gustafsson, Griffin, Collier & Fletcher, 2011), whereas two papers used family member responses when the participant was unable to give the information themselves (Willemse-van Son, Ribbers, Hop & Stam, 2009; Wise et al., 2010). With reference to the last paper that partially met this criterion, it stated that the measures they used were translated to Spanish for the participants that did not speak English (Pappadis et al., 2012). They failed to report whether the measures had been validated cross-culturally, which could potentially impact on the validity of the measure.

*Data analysis:* All but one of the reviewed papers fulfilled this quality criterion. The qualitative paper in question failed to fully describe the method used to analyse and how the results were generated (Conneeley, 2002).

*Findings:* Conneeley (2002) also did not fully meet this quality criterion. It was unclear how many participants contributed to each section, and how each section was developed. For the remaining papers each results section was clear and concise, mapping on to the raised research questions.

*Value of research:* On review of the papers they all appeared to meet the criteria for fulfilment of this quality criterion, with the exception of two papers. Conneeley (2002) failed to describe how the findings could contribute to the existing literature. For the remaining paper (Pappadis et al., 2012), although it gave a clear description of how it relates to the literature and can be applied to the population, the translation of the measures raises issues about the generalisability of the findings.

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>        | <u>Aim of research</u>  | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)  | <u>Data Collection</u><br>(How collected, measures<br>used)   | <u>Analysis</u>  | <u>Findings</u><br>(Valid & reliable?)   |
|---------------------------------|---|--|---|--|--|
| Bier, Dutil & Couture (2009)    | Looked at pre and post trauma leisure participation following TBI. The authors also investigated the participant's attitudes towards their participation in leisure and barriers to engagement. | <i>N</i> = 27, (73.1% moderate to severe TBI, 26.9% mild TBI)<br>Aged 42.3 years (mean)<br>Male 69.2%, ethnicity not reported.   | Used The Leisure Profile (Dutil & Forget, 1991), questionnaire to assess pre and post levels of recreational activity, attitudes towards leisure, personal factors that may influence leisure and difficulties that may explain a reduction in leisure participation.                 | <i>t</i> -tests used to compare pre and post data.<br>Correlations were conducted on the independent variables that may affect leisure participation.<br>Multiple regression was used to following the correlations.                                     | <b>D:</b> More than 92% of the participants reported a reduction in leisure participation. Severe TBI appeared to show less variety in type of activity.<br><b>C:</b> Social isolation appeared to be a problem.<br><b>B/F:</b> Facilitators; less severe injuries, greater time since injury, higher GCS, more time to adapt.<br><b>V/R:</b> Although repeatable, the results are difficult to generalise due to the small sample size along and an opportunity sample. |
| Brown, Gordon & Spielman (2003) | Looked at social and recreational activity and the level of engagement in these in the community for those with TBI.  | <i>N</i> = 279 with TBI disability (17% mild TBI), 10.4 years since injury (mean)<br><i>N</i> =224 without disability (ND).<br>Male TBI- 59.1%, ND- 55.4%; Aged 37.9 yrs (TBI, mean), 38.3yrs (ND, mean); TBI- W 79.9%, 10.0% AA, other 10.1%; ND- W 71.9%, AA 15.2%, other 13%. | Administered the CIQ, CHART, TIRR Symptom Checklist, BDI, BQLQ, The SF-36 and CQR.<br>From the original data 5 items were developed to use as a measure of the extent of social-recreational engagement.<br>Cronbach's Alpha (CA) values reported (.63-.92, with one outlier of .25). | Unclear of the analysis used to develop the 5 specific items, although CA's reported.<br>Chi-square, <i>t</i> -tests utilised to investigate differences of frequency in the 5 items between the 2 groups. ANCOVA used to look at demographic variables. | <b>D:</b> TBI group significantly less active than ND on all aspects ( $p \leq .01$ ).<br><b>C:</b> TBI group had significant depression in comparison to ND group.<br><b>B/F:</b> Facilitators; being single, higher income, less depression, more vocational work.<br><b>V/R:</b> The new measure (5 items) reports good reliability in all but one construct. Appears to be generalisable its population.   |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>   | <u>Aim of research</u>  | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)  | <u>Data Collection</u><br>(How collected, measures<br>used)   | <u>Analysis</u>   | <u>Findings</u><br>(Valid & reliable?)   |
|--|---|--|---|---|--|
| Conneeley (2002)   | Explored the issues involved in social integration following TBI.   | <i>N</i> = 18 (severe TBI), <i>n</i> = SO.<br>Aged 35 years (mean); 5 F, 13 M.<br>Assessed 6 months and 12 months post injury<br>Recruited via a neurological rehab hospital, UK.  | Interviews covered four main areas; perceptions of functional ability, perceptions of rehab, life patterns and other issues that the respondent wished to raise. Professional staff also interviewed but views not reported in results. | Only states that “themes and categories formed to describe data” (p. 357).  | <b>D:</b> Social isolation not significant<br><b>C:</b> Isolation and loneliness reported ( <i>n</i> = 2).<br><b>B/F:</b> Barriers; personality change, memory impairment, societal attitudes, public preconceptions, fatigue<br><b>V/R:</b> Replicable, but hard to generalize.   |
| Dumont, Gervais, Fougeyrollas & Bertrand (2004)                      | Looking to develop an explanatory model of personal characteristics in those with TBI that could constitute resiliency factors in social participation. | <i>N</i> = 53 (TBI mild- 10, mod- 18, severe- 24); age 37 years (mean); 70% M.<br>Assessed 4 years (mean) post-injury.<br>Recruited via a rehabilitation service.                  | Interviews into the personal perceptions of the participants experiences of social participation.<br>Assessment using LIFE-H, The Self-efficacy Scale, Test de Personnalité PER.  | Thematic analysis using NVivo software, reaching saturation. The LIFE-H scores entered into a multiple regression as the DV, and the LIFE-H scores, PER . | <b>D:</b> Not stated.<br><b>C:</b> Non reported<br><b>B/F:</b> Facilitators; dynamism (absence of fatigability), perceived self-efficacy, will.<br><b>V/R:</b> Caution needed in generalization of the results due to its inclusion and exclusion of participants in the study.  |
| Fleming, Braithwaite, Gustafsson, Griffin, Collier & Fletcher (2011) | Investigated pre and post leisure activities of people with ABI, undergoing rehabilitation.   | <i>N</i> = 20 inpatients; 18 outpatients (78.9% of sample TBI); aged 36.9 years (mean); 81.6% M<br>Assessed 6 months (mean) post-injury.<br>Recruited via a rehab unit, Australia. | Shortened Version of the NLQ and Changes in Leisure Questionnaire (developed for this study).<br><br>No reliability/validity statistics reported.   | Manually ‘tabulated’ responses and calculated percentages for each activity.<br>T-tests (paired) used to look at pre-post responses.                      | <b>D:</b> Social activities less frequent post-injury. Many not re-engaging in pre-injury activities.<br><b>C:</b> Reduction in satisfaction between pre & post activities.<br><b>B/F:</b> Barriers; medical restrictions, disability, financial.<br><b>V/R:</b> Reliability/validity questionable due to individualized changes in NLQ. |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>  | <u>Aim of research</u>  | <u>Participants</u><br><i>(Size of sample, recruitment procedure)</i>   | <u>Data Collection</u><br><i>(How collected, measures used)</i>   | <u>Analysis</u>   | <u>Findings</u><br><i>(Valid &amp; reliable?)</i>   |
|---|---|---|---|---|---|
| Hart, Whyte, Polansky, Kersey-Matusiak & Fidler-Sheppard (2005) | Investigating the impact of race and pre-injury status on community outcomes following TBI.   | <i>N</i> = 94 (moderate to severe TBI); 55 W, 39 AA, aged 41.6 years (mean W sample); 37.3 years (AA sample); 73% Male (W sample), 95% (AA sample).<br>Assessed at 6 months and again at 1 year post injury<br>Recruited from a TBI rehabilitation hospital (inpatient and outpatient), Philadelphia. | Collected demographic details and information on employment status and income.<br>Used the CIQ, SWLS and NFI-R, administered via an interview conducted face-to-face or via telephone.<br>Information was gathered as soon after injury as possible (min 6 months) then at 1 year post-injury.          | Descriptive stats calculated for each variable in the study. ANCOVAs used to analyse the outcome measures used and t-tests used for independent variables between –groups for 1 year follow-up. | <b>D:</b> W and AA’s showed significant decline in productivity. AA’s did show lower levels of social integration (contact with friends, participation in recreational activities).<br><b>C:</b> Both have significantly more symptoms of depression and lower levels of life satisfaction 1 year post-injury.<br><b>B/F:</b> Barrier here appeared to be race.<br><b>V/R:</b> Small sample; sampled from specific programme therefore cannot be generalised to rest of population. |
| Huebner, Johnson, Miller-Bennett & Schneck (2003)               | Examined the prediction of long-term outcomes from the acute rehabilitation outcomes, and those with TBI’s level of activity, participation and QoL post rehabilitation . | <i>N</i> = 25 (12% mild, 12% mod, 76% severe); aged 41 years (mean); 68% M; assessed on average, 21 months post-injury.<br>Recruited from an inpatient rehabilitation centre, Utah, America.  | Measures completed on admission and at 16 and 29 months post-injury.<br>Measures administered at follow-up by telephone.<br>Administered the FIM, ALS, CIQ, QOLR and Satisfaction with Occupational Therapy Questionnaire.<br>Cronbach’s Alphas and test-retest reliability reported for all measures . | Descriptive stats provided for all measures.<br>FIM scores analysed using ANCOVA.<br>Regression analysis used for the follow-up outcome measures.   | <b>D:</b> All reported at least one limitation in activity.<br><b>C:</b> Reports of depression and withdrawal.<br><b>B/F:</b> Facilitators; social support and compassion. Also found that fewer activity limitations are associated with higher levels of social integration, higher self-esteem and recreational aspects.<br><b>V/R:</b> Participants similar to other studies increasing generalisability and credibility.   |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>                      | <u>Aim of research</u>  | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)  | <u>Data Collection</u><br>(How collected, measures<br>used)   | <u>Analysis</u>   | <u>Findings</u><br>(Valid & reliable?)   |
|---|---|--|---|---|--|
| Johnston,<br>Goverover &<br>Dijkers (2005)    | Looked at people with TBI's satisfaction with and value of community activities, and their quality of life one year after their brain injury.   | <i>N</i> = 162 (including mild TBI- 34% of the sample); aged 44.8 years (mean); 73 M, 27 F; 67 W, 21 AA, 4 Asian, 8 H, 1 other. Assessed at 1 month and again at 12mths post-injury.<br>Recruited via a local TBI system database of a rehabilitation hospital, New Jersey, America. | Data on community activities and Quality of Life (QoL) were collected 1 month after discharge and at 12 months post injury, by telephone.<br><br>Used the CIQ-2 (revised version using its original 47 item format with supplemented questions for each item), allowing for the collation of how satisfied people were with each activity on the CIQ-2., SWLS and other demographic data. | Used both parametric and nonparametric tests.<br>Kendall correlation. Rasch analyses to check for empirical validity of the two sub-groups created by the authors; instrumental or functional activities (obligatory) and, social and recreational activities (optional). | <b>D:</b> No real pre-post comparisons. Found the frequency of social/recreational activities improved very little over time.<br><b>C:</b> Found few significant correlations between community activities and participants satisfaction/QoL.<br><b>B/:</b> Not reported. Argue that it is a challenge to quantify such information using outcome measures and state how the individual should be the focus.<br><b>V/R:</b> Although repeatable, generalizing to the TBI population should be done with caution. |
| Kim, Colantonio,<br>Dawson &<br>Bayley (2013) | Investigating differences in rehabilitation outcomes of those with intentional (assault) vs. unintentional TBI, and whether intentional TBI was a predictor of community integration. | <i>N</i> = 243; 24 (9.9%) with intentional TBI; age range 30-39 years; 78.2% M. Assessed at 3 months and 6 months<br>Recruited from National Rehabilitation Reporting System, Canada.  | Collected the FIM, Reintegration to Normal Living Index (RNLI), demographics and basic injury related information collated.   | Correlations (Spearman rho) used to examine relationships between RNLI scores and community integration variables. Multivariate linear regression analysis used.  | <b>D:</b> Less than half of the sample achieved complete integration into recreation and social activities.<br><b>C:</b> None reported.<br><b>B/F:</b> Found that intentional TBI was a predictor of poorer community integration 3 to 6 months post rehab.<br><b>V/R:</b> State to generalize with caution due to inclusion/exclusion criteria.   |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>                                     | <u>Aim of research</u>   | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)  | <u>Data Collection</u><br>(How collected, measures<br>used)   | <u>Analysis</u>   | <u>Findings</u><br>(Valid & reliable?)  |
|--|--|--|---|---|---|
| Lamontagne,<br>Poncet, Careau,<br>Sirois & Boucher<br>(2013) | Investigated the impact of different living environments on those with TBI's social participation and life habits performance. | <i>N</i> = 136 moderate to severe TBI; 92 in a natural, 20 in intermediate settings, 24 lived in structured settings; Age range 38-44 years; 71.3% M<br>Assessed 12 years (mean) post-injury.<br>Recruited from 13 community associations of the Quebec Coalition of TBI Associations, Canada. | LH questionnaire (LIFE-H 3.1, reported high internal consistency CA's 0.79 and 0.83, also reports mod to high test re-test reliability 0.60-0.99).  | Pearson chi-square used to highlight associations between LH performance and type of living environment.<br>Kruskal-Wallis test used to look at social participation due to non-normal distribution.<br>Thematic analysis used. | <b>D:</b> Found significant disturbance of social participation following TBI. Social roles differ significantly in structured settings compared to natural.<br><b>C:</b> None reported.<br><b>B/F:</b> Intermediate settings appeared to better support social participation and they also appeared to complete more LH's without difficulty.<br><b>V/R:</b> Convenience sample does not allow the results to be generalized to the entire TBI population.         |
| Lefebvre,<br>Cloutier & Levert<br>(2008)                     | To explore the long-term impact of TBI on social integration. Also explored the impact on family and friends.                  | <i>N</i> = 22 moderate to severe TBI; age 42.4 years (mean); 68.2% M; 86.4% Canadian, 9.1% Haitian, 4.5% Portuguese.<br>Assessed 12.8 years post-injury.<br>Convenience sample recruited from a Trauma Project conducted 10 years previously, Canada.  | Semi-directed question guide was developed for the interview from recommended guidelines and based on review of literature on conceptual frameworks, social integration and focus group findings (validation of the concept of social participation). | Methodological rigor supported by applying quality criteria to address:<br>-credibility<br>-transferability<br>-consistency   | <b>D:</b> 54.5% was ambivalent or dissatisfied with their social integration. Satisfaction with social integration was closely linked with having a social life.<br><b>C:</b> Feelings of being 'cut-off' or 'left out'. Also a third of the sample reported depressive symptoms.<br><b>B/F:</b> Barriers; physical and cognitive impairments, stigma, fatigue, emotional sequelae.<br><b>V/R:</b><br>Small sample size cannot be representative of TBI population. |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>                  | <u>Aim of research</u>  | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)  | <u>Data Collection</u><br>(How collected, measures<br>used)  | <u>Analysis</u>   | <u>Findings</u><br>(Valid & reliable?)  |
|---|---|--|--|---|---|
| Pappadis, Sander, Leung & Struchen (2012) | Looked at the environmental barriers to community integration in an ethnically diverse sample of TBI persons. | <i>N</i> = 167; aged 36.3 years (mean); 73.7% M; 52- W, 58- B, 57- H.<br>Assessed a minimum of 6 months post injury<br>Recruited via a local trauma centre, Texas, America.                                    | Used the CHIEF-SF to assess environmental factors, CIM, and the CHART-SF used to assess community participation after neurological impairment and disability.  | Correlations between the CIM and CHART-SF followed by a MANCOVA. CHIEF-SF barriers used as covariates to identify significant associations with the dependant variables (DVs).<br>Multiple regressions of the CIM and CHART-SF subscales (used as DVs). | <b>D:</b> No direct impact reported.<br><b>C:</b> Report a lesser sense of belonging and a decreased sense of independence.<br><b>B/F:</b> Barriers; mobility (restricted), physical/structural restrictions, more severe injuries, race, restrictions in the availability of services.<br><b>V/R:</b> This appears to be a replicable study. However the translation of the measures for some of the participants could impact the validity of the measures. |
| Riley, Brennan & Powell (2004)            | Looked at the effect of threat appraisal on the avoidance of activities following TBI.                        | <i>N</i> = 51 moderate to severe TBI; aged 31.5 years (mean); 41 M, 9 F; 100% W.<br>Assessed between 10 months up to 32 years post injury.<br>Recruited via UK charity that support people with TBI (Headway). | Qualitative data obtained information relating to specific threat appraisals. The data from 3 interviews (individual), 5 focus groups and published autobiographical accounts from TBI persons developed 2 measures: Specific Activities and Avoidance Questionnaire (SAAQ), Appraisal of Threat and Avoidance Questionnaire (ATAQ). | Qualitative: Thematic analysis used to evaluate the data. Piloted with a small sample of individuals (n=4). Quantitative: Cronbach alpha's calculated for the ATAQ and SAAQ; both showed a good level of internal consistency.                          | <b>D:</b> Found reduced participation in at least 1 activity and 10% reported a reduction in at least 10 activities.<br><b>C:</b> Participants were found to be higher in anxiety and have low confidence.<br><b>B/F:</b> Barriers appear to be appraising social situations as threatening along with avoiding tasks.<br><b>V/R:</b> Makes suggestions for future research. Not generaliseable due to small sample size.                                     |



## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>      | <u>Aim of research</u>  | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)   | <u>Data Collection</u><br>(How collected, measures<br>used)  | <u>Analysis</u>   | <u>Findings</u><br>(Valid & reliable?)   |
|-------------------------------|---|---|--|---|--|
| Riley, Dennis & Powell (2010) | Investigated perceived resources that people have that enable them to cope with potential difficulties arising from their TBI and level of self-esteem on a person's participation in activities. | N=41 moderate/severe TBI; aged 43 years (mean); 33 M, 9 F; 40 Caucasian, 2 South Asian. Assessed between 12 months up to 13 years post injury. UK charity that support people with TBI (Headway). | Collected the ATAQ, RSES and the CRQ (pilot study reports good internal consistency- C'sA .908).   | No separate data analysis section, so unclear at first how the data was analysed. Descriptive statistics reported. Correlation analysis used on the measures. | <b>D:</b> No direct impact reported, however the avoidance is indicative of a decline/impact.<br><b>C:</b> None reported.<br><b>B/F:</b> Found that those with low self-esteem and a poorer evaluation of their coping resources were more likely to avoid activities when making threat appraisals.<br><b>V/R:</b> Newer measures questionable in their reliability and validity. Sample not generalisable as not representative. Repeatable.                       |
| Roscigno & Van Liew (2008)    | To highlight an individual's subjective experience of life after TBI particularly his social interactions.  | N= 1; M; aged 35 years; severe TBI aged 18 years, 2 <sup>nd</sup> TBI at 19 yrs American participant approached author who was conducting TBI research in another area.                           | Journal narratives covering a 5yr period plus face-to-face and phone discussions to get his reflections. Journals written between the ages of 30-35 yrs. | Used 'symbolic interactionism' (grounded theory) as the framework.  | <b>D:</b> Described people treating him differently, loss of social status and social isolation due to his impairments.<br><b>C:</b> None reported.<br><b>B/F:</b> Reported that physical impairments and the attitudes of others as barriers to his ability to socially interact.<br><b>V/R:</b> The participant's experiences appear to map on to other research conducted into this area. However, they do state that it is difficult to generalize the findings. |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>                              | <u>Aim of research</u>   | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)   | <u>Data Collection</u><br>(How collected, measures<br>used)   | <u>Analysis</u>  | <u>Findings</u><br>(Valid & reliable?)   |
|---|--|---|---|--|--|
| Sander, Pappadis,<br>Clark & Struchen<br>(2011)       | Looked at the meaning<br>of community integration<br>and barriers to this from<br>an ethnically diverse<br>sample.                                   | <i>N</i> = 167, 58.6 % mild TBI;<br>mean ages- 34.4 years (B),<br>33.21 years (H), 41.62<br>years (W); 58 B, 57 H, 52<br>W.<br>Assessed at least 6 months<br>post injury<br>Recruited from a Level 1<br>trauma centre, Texas,<br>America. | Structured interview using<br>2 open-ended questions.<br>Questions administered by<br>a trained, bilingual<br>research assistant.<br>Questions translated into<br>Spanish (29 interviews).<br>Used the PCINQ used that<br>was created by the authors<br>(no validity or reliability<br>information reported). | Qualitative analysis:<br>Grounded theory<br>used.<br>Quantitative analysis:<br>Activity rated by<br>participant,<br>percentage then<br>calculated. Chi-<br>square analysis used<br>to compare the<br>perceived importance<br>by each ethnic group. | <b>D:</b> Not reported.<br><b>C:</b> Reports of depressive<br>symptoms and isolation.<br><b>B/F:</b> Found integration is more<br>than just 'productive activity',<br>'belonging' is closely related to<br>relationships with others. The<br>environment, including perceived<br>safety of this was a potential<br>barrier.<br><b>V/R:</b> Limitations with the<br>generalisability.           |
| Willemse-Van<br>Son, Ribbers,<br>Hop & Stam<br>(2009) | Investigating<br>participation following<br>mod-severe TBI until<br>36mths post injury &<br>identifying determinants<br>of community<br>integration. | <i>N</i> = 119 mod-severe TBI;<br>aged 34 years (mean); 86<br>M, 33F.<br>Assessed at 3, 6, 12, 18, 24<br>and 36 months post injury.<br>Recruited from 3 Dutch<br>local hospitals.   | Used the BI and FIM/FAM<br>at baseline, 3, 6, 9, 12, 18,<br>24, and 36 months, CIQ.<br>Predictor variables<br>(potential determinants<br>such as age, gender and<br>discharge destination),<br>were collated from<br>reviewing patient notes.   | ANOVA PROC<br>mixed, as does not<br>need complete<br>follow-up data to<br>complete the<br>analysis.<br>Correlations<br>(Spearman's) and t-<br>tests used to identify<br>the potential<br>determinants of CIQ.                                      | <b>D:</b> Significant decline in SI at 3<br>months. Increased by 24 months,<br>but still lower compared to pre-<br>injury.<br><b>C:</b> None reported.<br><b>B/F:</b> Age, BI scores, discharge<br>destination and pre-injury CIQ<br>scores (rated by SO) were found<br>to be determinants of level of<br>community integration.<br><b>V/R:</b> Findings are generaliseable<br>and repeatable. |

## Social Activity, Community Integration and TBI

Table 3 Data Extraction Table

| <u>Author &amp; Date</u>  | <u>Aim of research</u>   | <u>Participants</u><br>(Size of sample,<br>recruitment procedure)   | <u>Data Collection</u><br>(How collected, measures<br>used)  | <u>Analysis</u>  | <u>Findings</u><br>(Valid & reliable?)  |
|---|--|---|--|--|---|
| Winkler,<br>Unsworth &<br>Sloan (2006)  | Investigating levels of community integration (CI) 3 to 15 years post TBI and identification of factors that may predict successful integration.   | N=40 severe TBI; aged 28 years (mean).<br>Assessed 3 to 15 years post-injury.<br>Recruited from 2 brain injury rehab services, Australia.               | Used the CIQ, CIM, SPRS, LDSQ, CBS, the Medical Outcomes Study-Social Support Survey and the National Adult Reading Test.<br>SO completed the CBS and retrospective CIQ.   | A summary of descriptive statistics developed that identified factors and demographics in CI literature. Cluster analysis used to identify subgroups.  | <b>D:</b> Variation in level of participation.<br><b>C:</b> None reported.<br><b>B/F:</b> Facilitators; less severe injury, less physical limitations, less challenging behaviour<br><b>V/R:</b> Small sample limits generalisability.  |
| Wise, Matthew-<br>Dalton, Dikmen,<br>Temkin,<br>Machamer, Bell<br>& Powell (2010) | Assessing the impact of TBI on participation in leisure activities. Looked specifically at activities participated in before injury only, after injury only and activities continued from before to after. | N=160 mod-severe TBI; 77% M; 77% W.<br>Mean age of time of injury was 35.3yrs (+/- 14.4yrs).<br>Recruited via an inpatient rehab unit, Washington, USA. | Used the FSE via interview, specifically the leisure and recreation section (includes social activity). Activities were coded by 2 independent raters, inter-rater agreement was calculated but scores not reported. | Descriptive analysis of FSE codes was used to look at leisure participation.<br>Spearman Rank correlation and Mann Whitney U used to look at relationship between age, gender and bothersome rating. | <b>D:</b> Shows a decline in mean activities but does not state if it is sig. Changes in social activities reported.<br>Sig diff. (<.001) found between leisure code and bothersome rating.<br><b>C:</b> Depression (also seen as a barrier)<br><b>B/F:</b> Barriers; physical limitations, fatigue, cautiousness and fear, finances, doctors orders, seizures and depression.<br><b>V/R:</b> Results can't be generalized to mild or ex. severe TBI. FSE is a self-report measure and the reliability is not reported. |

\*\*AA- African Americans; W- White; H- Hispanic; B- Black; SO- Significant Other; F- Female; M- Male; D- Decline; C- Consequences; B/F- Barriers and facilitators; V/R- Validity and reliability; GCS- Glasgow Coma Scale; BDI- Beck Depression Inventory; BQLQ- Bigelow Quality of Life Questionnaire; CRQ<sup>1</sup>- Community Re-entry Questionnaire; LIFE-H- Life Habits; RNLI- Reintegration to Normal Living Index; NLQ- Nottingham Leisure Questionnaire; SWLS- Satisfaction with Life Scale; NFI-R- Neurobehavioral Functioning Inventory-Revised; FIM- Functional Independence Measure; ALS- Activity Limitations Survey; QOLR- Quality of Life Rating; CIQ- Community Integration Questionnaire; CHIEF-SF- Craig Hospital Inventory Environmental Factors-Short Form; CIM- Community Integration Measure; CHART-SF- Craig Handicap Assessment Reporting Technique-Short Form; CHART- Craig Handicap Assessment Reporting Technique; SAAQ- Specific Activities and Avoidance Questionnaire; ATAQ- Appraisal of Threat and Avoidance Questionnaire; RSES- The Rosenberg Self-Esteem Scale, CRQ<sup>2</sup>- The Coping Resources Questionnaire; PCINQ- Perceived Community Integration Needs Questionnaire; BI- Barthell Index; SPRS- Sydney Psychosocial Reintegration Scale; LDSQ- The Lambeth Disability Screening Questionnaire; CBS- The Current Behaviour Scale; FSE- Functional Status Examination\*\*

## **Study Findings**

The findings of the studies were collated and analysed in line with the three main questions asked of the literature. With the variety of methodologies covered in this literature review and the broad classification of the terms used in research, such as community integration, not all of the papers contained information relating to each specific question asked.

### **1. What impact do TBIs have on friendships and social contact outside the family and community-based occupational and leisure activities other than employment?**

When reviewing the content of the articles with regard to the notion of an impact on participation in the community, the information was varied and limited in some. The quantitative papers however do agree that following TBI participant's level of socially based activity was reduced, (Dumont, Gervais, Fougeyrollas, & Bertrand, 2004; Pappadis et al., 2012; Riley et al., 2004; Riley, Dennis, & Powell, 2010; Sander et al., 2011; Winkler, Unsworth, & Sloan, 2006), however, differences were evident across the papers in regard to the extent. In Bier, Dutil, and Couture's (2009) study, their sample of moderate/severe TBI reported a 92% decrease in the leisure activities when comparing pre- and post- injury activity levels on The Leisure Profile (Dutil and Forget, 1991). As measured by a specific leisure and recreation tool (a section of the Functional Status Examination, FSE), Wise et al. (2010) found that of 160 moderate to severe TBI persons, 36.9% had dropped some leisure activities, and up to 22.5% had disengaged in almost all of their previously reported leisure activities. Other papers report significant reduction in socially orientated activities such as meeting friends and recreational activities when comparing pre- and post- injury scores (Brown et al., 2003; Fleming et al., 2011; Hart, Whyte, Polansky, Kersey-Matusiak, & Fidler-Sheppard,

2005; Lamontagne, Poncet, Careau, Sirois, & Boucher, 2013; Willemse-von Son et al., 2009; Wise et al., 2010). Brown et al. (2003) compared people with a TBI to a control group and found those with TBI were significantly less active.

Two of the quantitative papers reported changes, but did not have pre-injury data as a comparison. For Johnston et al. (2005) and Kim, Colantonio, Dawson, and Bayley (2013), a post injury baseline score was recorded and compared with follow-up data ranging from 1 month to 12 months. Johnston et al. (2005) found that over time there was little change in the frequency of recreational activities. In Kim et al.'s (2013) paper they found that, for those that had suffered a TBI intentionally (intentional injury caused by violence, e.g. war, interpersonal violence), fewer had achieved complete integration in recreation and social activities as measured by the Reintegration to Normal Living (RNLI), compared to the unintentional TBI group (road traffic accident, falls; 36% vs. 51% respectively).

Overall, from the literature reviewed, there does appear to be a decline or impact on community participation for those who have sustained a brain injury. Activities such as going out to a bar and going to the cinema, appear to reduce post-injury for those with TBI and there is an increase in solitary activities like watching TV (Bier et al., 2009; Fleming et al., 2011; Johnston et al., 2005; Riley et al., 2004; Wise et al., 2010). However, due to methodological issues about the research (covered in the Discussion), these findings should be interpreted with caution.

## **2. What are the consequences of this impact?**

Of the nineteen papers reviewed, twelve suggested consequences as a result of the decline in community participation; these were documented as depression, isolation and lower life satisfaction. Of the six papers with qualitative elements four reported a sense of loneliness

and isolation rising from this reduction in social contact (Conneeley, 2002; Lefebvre, Cloutier, & Levert, 2008; Roscigno & Van Liew, 2008; Sander et al., 2011). Lefebvre et al.'s (2008) participants spoke about feeling 'left out' and 'isolated' as well as feeling cut off from friends; whereas Van Liew (Roscigno & Van Liew, 2008), made a statement that really highlighted this feeling of isolation:

“Only a couple of times when the diner was really full and there was no place else for other students to sit, would other students come and join me at the table where I was sitting. Otherwise, I would sit and have dinner by myself.” (p. 215, Roscigno & Van Liew, 2008)

Pappadis et al. (2012) reported a reduced sense of 'belonging' in their community due to this reduction in participation.

Higher symptoms of depression were reported by six papers, however only half of these provided statistical outcomes to highlight this impact (Brown et al., 2003; Hart et al., 2005; Huebner, Johnson, Bennett, & Schneck, 2003). Hart et al.'s (2005) longitudinal study compared retrospective pre-injury and post-injury levels of depression in both African Americans and White participants, and found that both reported a significant increase post-injury. However, their results are limited as the paper did not directly analyse the relationship between depression and social integration. Brown et al. (2003) and Huebner et al. (2003) did provide such an analysis. Although they reported a link between a reduction of activities and higher depressive symptomatology their findings are limited because the studies were not longitudinal and so the causal nature of the relationship between the two is unclear. The association has also been supported qualitatively, where the participants spoke of emotional difficulties following TBI. It appeared that this was more of a 'vicious circle' (Lefebvre et al.,

2010) with depressed mood limiting community integration which then lead to further depressed mood (Sander et al., 2011; Wise et al., 2010). Lower levels of life satisfaction were reported by only two quantitative papers (Hart et al., 2005; Johnston et al., 2005). In the paper by Johnston et al. (2005) they stated that the associations between reduced social activities and satisfaction with life “were weak at best”. However, when looking at participant’s individual responses it appeared that self-reported life satisfaction was linked to a combination of activities that were uniquely valued by that person

Although it is less plausible to view a heightened sense of isolation and decreased life satisfaction as causes of reduced community integration, depression may play a role as both a consequence of reduced community integration, and a barrier to maintaining or increasing it. Riley et al. (2004, 2010) suggest that what is seen as a barrier to engagement in activities, in their case anxiety/fear or threat, could also be a direct consequence of reduced participation, thus becoming a vicious cycle. In the case of depression, if one is expressing symptoms of depression they may feel less likely or less able to participate in social activities, however, in line with the behavioural model of depression (Carvalho & Hopko, 2011; Veale, 2008) not participating in said activities could lead to more symptoms of depression.

### **3. What factors are associated with a decrease in community integration, and what factors are associated with an increase?**

When reviewing the literature to look for factors that may decrease or increase levels of community integration, several barriers and facilitators were identified.

#### Barriers

*Physical/Injury Related Barriers:* One of the most common factors referred to under this term is fatigue. Fatigue, is a very well evidenced consequence of TBI (Hoofien et al., 2001, Kersel

et al., 2001; Koskinen., 1998; Oddy et al., 1978; Yates, 2003), often leaving people unable to sustain activity levels and therefore interfering with their ability to socialise with others (Brown et al., 2003; Conneeley, 2002; Dumont et al., 2004; Lefebvre et al., 2008; Sander et al., 2011; Wise et al., 2010).

Physical disability as a consequence of TBI is also widely reported as impairing those with TBIs ability to participate in certain activities that they may have enjoyed pre-injury. This was reported by many of the papers reviewed (Conneeley, 2002; Fleming et al., 2011; Lefebvre et al., 2008; Pappadis et al., 2012; Roscigno & Van Liew, 2008; Sander et al., 2011; Wise et al., 2010). For example, Bier et al. (2009) found motor impairments and a dependency for physical support (as they are unable to get around independently) was a barrier within their sample.

*Environmental Barriers:* For seven of the studies the physical environment also played a part in the reduction of active participation (Conneeley, 2002; Fleming et al., 2011; Lamontagne et al., 2010; Pappadis et al., 2012; Sander et al., 2011). Some papers referred to physical restrictions in the environment such as poor accessibility, structural barriers and lack of access to equipment (Conneeley, 2002; Fleming et al., 2011; Pappadis et al., 2012). From participants responses to community integration measures Willemse van-Son et al. (2009) and Winkler et al. (2006) found the discharge destination of those with TBI had a significant impact on their participation/integration, reporting activity restrictions when discharged to another hospital or group home compared to those discharged to their pre-injury home. Further support for discharge destination comes from Lamontagne et al. (2010) where they specifically looked at the impact of an element of community integration, namely social participation, as measured by the LIFE-H. They found that living in intermediate care settings (such as group homes) was associated with higher social participation, in comparison



to living independently or in a long-term care facility. It was suggested that this could be due to the level of support provided by those they are residing with.

*Finance:* Being unable to work and not having a normal/reduction in income has also been found to be a barrier (Lefebvre et al., 2008; Sander et al., 2011; Wise et al., 2010). Brown et al. (2003) found lower income to be, what they describe as, a ‘resource that promotes social activity’ (p.271), suggesting that engaging in social activities cost money. This is echoed by Fleming et al.’s (2011) study, where their participants stated financial limitations as a reason for discontinuation of activities.

*Demographics (race/ethnicity, age and gender):* Two papers specifically looked at race and the impact on community integration. Firstly Hart et al. (2005) found that overall both ethnicities in their sample population (African American, White) had a significant decline in ‘productivity’. However, African Americans had a greater reduction in contact with friends and in participation in recreational activities in comparison to the White sample. Sander et al. (2011) highlighted differences between Hispanic, Black and White populations in terms of their perceptions of community integration and barriers to this. They found that Hispanics gave more importance to others making them feel loved and accepted as well as reporting more social barriers (such as mistrust of others, social isolation and unfriendly people), which appeared to be impacting on their participation. A third paper (Pappadis et al., 2012) also supported the finding that African Americans reported a decrease in social integration.

Only two of the nineteen papers explore whether age influenced participation. Willemse van-Son et al. (2009), found that older people were more likely to report lower levels of community integration; however they explained this in terms of a natural reduction in participation due to the ageing process rather than a consequence of TBI. Winkler et al.

## Social Activity, Community Integration and TBI

(2008) looked specifically at the age at the time of injury and found that those who were younger when the incident occurred achieved a higher level of community integration.

Finally, it was found by one paper (Riley et al., 2004) that gender impacted on levels of social activities, where males tended to be more avoidant of activities than females, a finding which was independent of the type of TBI (i.e. intentional versus unintentional TBI).

*Cause of TBI:* A recent paper by Kim et al. (2013) focussed on the type of incident that caused the TBI. In their study they compared those with unintentional TBI to intentional TBIs. They found those that fell into the latter category had poorer community integration at 6 months post-injury and were most dissatisfied with family roles and recreational activities. However, the uneven sample sizes between groups, (unintentional TBI group  $N=219$ ; intentional TBI group  $N=24$ ) reduced the reliability and validity of these results. However, the finding of an association between assault and reduced activity levels was also found by Riley et al. (2004, 2010) and Hart et al. (2005).

*Attitudes of Others:* Several papers discussed how the attitudes and behaviour of others towards the person with the brain injury can act as a barrier to their integration. Two of Conneeley's (2002) themes expressed this idea – 'societal attitudes' and 'public preconceptions'. In relation to the first, one of the participants commented,

“Because I've been classed as this head-injured patient, other people approach me and talk to me and I can tell they're making assumptions about what I can take and what I can't take, or coming to conclusions”

(p.360)

The theme of 'public preconceptions' concerned the lack of understanding, oversensitivity and fear of others in relation to 'personality changes'. However, as this theme was not

identified by participants, rather by one of the participant's significant other's (wife) it should be interpreted with caution. Another qualitative paper also talked about the attitudes of others impacting on their ability to engage socially due to the stigma around their condition (Lefebvre et al., 2008). For Van Liew (Rosignano & Van Liew, 2008), 'social embarrassment' was experienced because of other people misinterpreting his behaviours; for him the behaviours were normal, but to others his behaviour appeared to be socially deviant, leaving him feeling "...pushed to the margins of society" (p. 218).

*Personal Factors:* Surprisingly few papers have looked at the impact of psychological traits and constructs on people's community participation. The papers by Riley et al. (2004, 2010), explored the idea that those with TBI who have lower-self esteem, confidence and a negative evaluation of their coping resources, are more likely than those scoring more positively in these respects to perceive activities as threatening and thereby more likely to avoid activities. This finding was supported by Sander et al. (2011) who found that some of their participants felt embarrassed about their impairments thus avoiding activities. This was alongside Wise et al.'s (2010) findings of reports of fear and cautiousness leading to a decrease in leisure participation.

### Facilitators

*Milder Injuries:* For three of the papers (Bier et al., 2009; Pappadis et al., 2012; Winkler et al., 2006), those with milder injuries appeared to have higher levels of participation and activity. Bier et al. (2009) discussed little variety in the type of leisure activity and fewer contacts with those outside the family for the severe TBI samples, whereas this was much greater for milder TBIs. The lack of the other literature finding this outcome could be due to the exclusion of milder injuries in their sample, research has found that those with more moderate to severe

## Social Activity, Community Integration and TBI

brain injuries tend to have poorer social outcomes (Dikmen et al., 2003; Hoffien et al., 2001; Morton & Wehman, 1995; Schretlen & Shapiro, 2003).

*More Time to Adapt:* Two of the studies found that activity levels appeared to increase the longer the person was since injury suggesting that having more time to adapt in their community following injury can help to increase integration (Bier et al., 2009; Brown et al., 2003). However, it must be noted that the levels of activity reported at post injury (up to 10 years post-injury) were still lower than levels pre-injury, and, in the case of Brown et al. (2003), also still lower than a sample of the general population. These two particular papers also include a number of mild TBI participants (26.9% and 17% respectively), which has already been highlighted not to have such an adverse impact on a person as a moderate/severe TBI.

*Less Activity Limitations/Environment:* It was suggested by four of the papers that having fewer limitations of activity and a more suitable environment promoted higher levels of participation and integration. For the participants in Sander et al. (2011) having a sense of safety and security in their environment was important in the facilitation of activity. It is possible that this may link to the reporting of a link between assault and higher levels of avoidance of activity (Kim et al., 2013; Riley et al., 2004; 2010).

*Response of Others:* The participants in Sander et al. (2011) commented that positive relationships with others (including respectfulness, emotional support and having common goals) and other people making them feel involved and accepted helped with their sense of 'belonging to a community', and that this, in turn, encouraged their participation. This was something echoed by Huebner et al. (2003), who found that social support and compassion from others is a moderator of participation in the community.

*Personal Factors:* The only paper to specifically look at people's strengths and resilience in relation to social participation was that by Dumont et al. (2004). Just as they found fatigue to be a barrier, they found that 'dynamism', in essence less fatigue, to be a facilitator of participation along with 'will' or determination and perceived self-efficacy. The latter could be seen to be supported by the findings of Riley et al. (2004; 2010), as they found that those who perceived themselves to be less self-efficacious were more likely to avoid activities.

## DISCUSSION

The findings of this literature review into community integration following TBI has provided a good insight into the levels of activity and what may prevent or promote participation in these. Like the literature conducted prior to 2000 and reviews conducted into social outcomes following TBI (Buliński, 2010; Dikmen et al., 2003; Hoofien et al., 2001; Kersel et al., 2001; Koskinen, 1998; McColl et al., 1998; Tate et al., 2012; Yates, 2003), the research reviewed here suggests that TBI has a significant impact on individual's community integration and that reduced community integration may lead to increased loneliness and depression. Potential barriers to community integration include fatigue, physical disability, cognitive impairment, environmental constraints, living situation, finance, ethnicity, gender, age, being the victim of assault, the negative aspects and responses of others, and certain psychological traits and dispositions. Potential facilitators include less severity and more time since injury, positive reactions from others, 'dynamism' and higher self-efficacy. However, there are methodological issues which raise some doubt about these conclusions. Gaps and other areas of weakness in the research are also evident.

### **Limitations of the research and directions for future research**

#### *Measurement issues*

The quantitative papers used a variety of measures to assess community integration, with the most popular being the Community Integration Questionnaire (CIQ and the CIQ-2; Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993) which was used in six of the sixteen studies. Other measures used in these studies also focused on general areas of integration/participation. These measures included the Craig Handicap Assessment and Reporting Technique (CHART; Whiteneck, Charlifue, Gerhart, Overholser, & Richardson,

1999), the Community Integration Measure (CIM; McColl, Davies, Carlson, Johnston, & Minnes, 2001), The Sydney Psychosocial Reintegration Scale (SPRS; Tate, Hodgkinson, Veerabangsa, & Maggiotto, 1999), the Assessment of Life Habits (LIFE-H; Noreau, Fougereyrollas, & Vincent, 2002), the Functional Status Examination (FSE; Dikmen, Machamer, Miller, Doctor, & Temkin, 2001), and the Reintegration to Normal Life Index (RNLI; Wood-Daughinee, Opzoomer, Williams, Marchand, & Spitzer, 1988). Salter, Foley, Jutal, Bayley, and Teasell (2008) reviewed the most common measures used to assess community integration. They looked at the CIQ, CHART, CIM, SPRS and the RNLI and found variations in their reliability and validity, particularly for those devised for use with brain injury. They also considered these measures in terms of whether community participation was assessed in relation to objective outcomes or in terms of capturing the subjective perspective of the individual. They concluded that the CIQ was the most thoroughly evaluated, valid and reliable objective measure of community integration; whereas the RNLI was the best of the subjective measures.

There are other criticisms of the way in which community integration has typically been measured in the quantitative studies. Although deemed valid and reliable generic measures such as the CIQ do not give us a clear picture on specific types of community activity that people with a TBI are less likely to resume or maintain. Only a handful of papers used specific measures that allowed separate consideration of different aspects of community integration (Bier et al., 2009; Brown et al., 2003; Fleming et al., 2011; Wise et al., 2010). Sander et al., (2010) have highlighted a number of other problems. Currently, the main measures used appear not to correlate particularly well with each other, which is concerning if they are attempting to measure the same outcome. They also highlighted an issue with one of the most popular measures; the Community Integration Questionnaire (Willer et al., 1993).

Many of the items are more related to activities of daily living (e.g. Approximately how many times a month do you usually participate in shopping *outside* your home) rather than to the idea of community integration as having defined by Jacobs (1993). In essence, activities of daily living could be seen as those of responsibility or necessity, whereas leisure/recreational or more socially based activities are those chosen by people to freely engage in to experience enjoyment (Parr & Lashua, 2004).

To advance research in this area, we need to develop a clearer definition of community integration. Subsequently this would enable an appropriate standardised measure to be developed to measure community integration across studies. Alternatively, it may be that community integration is too broad a concept, and that research would be better served by breaking it down into its different components (such as social outings, leisure pursuits that bring the person into contact with others in the wider community etc.) and measures utilised which reflect these more specific terms.

Other issues related to measurement in the quantitative studies include reliance on self-report and, in some cases, on retrospective self-report. Both raise issues of accuracy given that participants may have significant cognitive impairments (Hoofien et al., 2001; Koskinen, 1998; Morton & Wehman, 1995). Fleming et al. (2011) argued that assessing those with TBI over 2.5 years post-injury would lead to inaccurate reports of pre-injury activities. There is also a possibility that mood could influence their responses, possibly seeing everything as good or positive before the injury in comparison to their lives after injury. The use of more objective measures of community participation would be a useful development (e.g. a diary record kept by a family member of the number of social outings made over a monthly period).



*Gaps in the research*

In line with the previous literature looking at social outcomes following TBI (Buliński, 2010; Dikmen et al., 2003; Hoofien et al., 2001; Kersel et al., 2001; Koskinen, 1998; McColl et al., 1998; Tate et al., 2012; Yates, 2003) the research reviewed here has supported the negative impact of TBI on community integration. Compared to earlier literature, the more recent literature has focused less on the consequences of this change in activity levels and more on the identification of factors that may decrease or increase community integration. This shift in focus, particularly on facilitators of participation may result in a better understanding of how rehabilitation programmes can improve levels of community participation.

Another problem with some of the research is insufficient integration with theoretical approaches. Only a handful of papers make links to theoretical accounts that might explain the consequences of reduced participation or the barriers/facilitators to participation (Dumont et al., 2004; Hart et al., 2005; Huebner et al., 2003; Kim et al., 2013; Riley et al., 2004, 2010; Sander et al., 2011). For example, when addressing the issues of race/ethnicity, Hart et al. (2005) and Sander et al. (2011) discussed the differences between levels of contact with friends and family in terms of the theories around kinship networks; that is; African Americans and Hispanics are more likely to put more importance on contact with these relationships than friendships, unlike their White counterparts. Other theories that have been used include Bandura's social cognitive theory (Dumont et al., 2004), seeing perceived self-efficacy as part of an explanatory model why someone with a TBI may participate socially. Closely linked to this is the work by Riley et al. (2004; 2010), who in their latter paper draw conclusions from the 'stress appraisal coping model' as helping to explain why someone who sees themselves as less able to cope, would potentially see activity as threatening/stressful and

therefore meet it with avoidance. Kim et al. (2013) also made links to the theory of Post-Traumatic Stress Disorder (PTSD), pointing out that the main coping strategy suggested within this theory is avoidance of activities that the person sees as threatening. Greater use of theory could advance our understanding of the consequences, barriers and facilitators of community integration.

### *Sampling issues*

The majority of the papers assessed people several years following injury (two years up to 15 years, with one paper including someone 32 years post injury, Riley et al., 2004), although for some participation took place shortly after injury, as little as 3 months post-injury in some cases (Bier et al., 2009; Conneeley., 2002; Fleming et al., 2011; Hart et al., 2005; Johnston et al., 2005; Kim et al., 2013; Pappadis et al., 2012; Sander et al., 2011; Wise et al., 2010). It has been argued that leaving a longer gap between the injury and participation could decrease the validity of the measures because of doubts about the ability of participants to accurately recall pre-injury activities (Fleming et al., 2011). Although this is an argument that is relevant only to those studies that sought to compare pre- and post-injury levels of participation. On the other hand, it could be argued that if the time since injury is less than a year, this may be too soon for the person to establish themselves in the community adequately, particularly those with more severe injury.

### *Broader methodological considerations*

Application of the quality framework suggested that few of the studies had well established methodologies in general. Although the majority of the papers met most of the criteria at least partially there were weaknesses around the reporting of ethical considerations (three not reporting on this at all and six partially) and the appropriateness of the research

design (one not fulfilling this and ten partially). In terms of the quantitative papers, not one of them reported a power analysis and, although noted in their limitations, one study had as little as 25 participants in their sample (Huebner et al., 2003). Another limitation around participants is the selection. None of the papers chose their samples at random. The use of self-selected samples increases the chance of sampling bias and raises questions about the generalisability of the findings to the overall population.

With respect to the qualitative papers there are also methodological issues that need to be addressed. The majority of the papers reviewed discussed the process of achieving data saturation, decreasing the risk of subjective interpretation and researcher bias increasing their validity and the credibility of the interpretations made from the data. However, one paper (Conneeley, 2002) failed to do this as well as neglecting to discuss the analysis used, seriously undermining the quality of the results. Other methodological considerations to note when looking at this type of data relates to the difficulty in replicating the studies, and the generalisability of the results. It is difficult to make assumptions beyond the responses of the sample group, i.e. applying the results to the remaining target population.

### **Limitations of the Literature Review**

Despite detailed information being gleaned from the literature, this review is not without its limitations. Firstly, including a range of methodologies made it difficult to provide a coherent evaluation of quality. Another challenge arose from the complexity of the idea of community integration and the confusion that this gives rise to. Different papers used different measures and focused on different aspects of community integration, or they used generic measures which do not allow a clear distinction between different aspects, making it difficult to draw precise conclusions. For example some papers specifically looked at social

and leisure activities (Bier et al., 2009; Brown et al., 2003; Fleming et al., 2011; Wise et al., 2010) making it easier to glean the required information. However, when more generic measures of community integration were used, it was difficult to know whether the findings reflect community participation relating to social and leisure activities, or reflect more questionable aspects such as activities of daily living. This point hints at the complexity of this phenomenon and reverts back to the point made earlier of the need for a clearer conceptual framework to address community integration.

### **Implications for Clinical Practice**

The evidence reviewed does highlight that TBIs impact on community integration is associated with elements of poor mental health (e.g. depression) and general well-being, in line with what has been suggested by other literature looking at sample of the general population (Berkman, 2001; House, 2001; Mental Health Foundation, 2010; Seemen, 1996). Community integration should therefore be a focus for clinical practice. As noted in the Introduction, much of the clinical focus is on employment and family relationships, but the aspects of community integration that were the focus of this review (leisure and social activities involving the wider community outside the family) also merit attention (Wise et al., 2010).

Douglas, Dyson and Foreman (2006) involved their participants in a community leisure programme and found after 6 months there was an increase in social integration and a general improvement in mental health (lowering of depressive symptoms). The research reviewed in this paper suggests the need for such programmes to take account of the barriers and facilitators of participation. Assessing and tackling these on an individual basis could increase the effectiveness of such programmes. For example, Riley et al. (2010) discuss the

value of an individual assessment and formulation of the reasons why someone might be avoiding activities, using their *Avoidance and Threat Appraisals Questionnaire* which asks about the common anxiety-related reasons why people might avoid community participation, and addressing the individual's self-esteem and evaluation of their coping resources. This could then provide the basis for a CBT intervention addressing these appraisals and the avoidance. The person might then be more receptive to participating in programmes such as that used by Douglas et al. (2006). In respect of increasing community integration, other targets for assessment and intervention include finance, accessibility, fatigue and the responses of others in the wider community.

## REFERENCES

- Arango-Lasprilla, J.C., Ketchum, J.M., Dezfulian, T., Reutzer, J.S., O'Neil-Pirozzi, T.M., Hammond, F. & Jha, A. (2008). Predictors of marital stability 2 years following traumatic brain injury. *Brain Injury*, 22(7–8), 565–574. DOI: 10.1080/02699050802172004
- Berkman, L.F. (2001). Social Integration, Social Networks and Health. *International Encyclopedia of the Social and Behavioural Sciences*, 14372-14332, DOI: 10.1016/B0-08-043076-7/03820-1
- Bier, N., Dutil, E, & Couture, M. (2009). Factors affecting leisure participation after traumatic brain injury: An exploratory study. *Journal of Head Trauma Rehabilitation*, 24(3), 187-194.
- Brown, M., Gordon, W. A., & Spielman, L. (2003). Participation in social and recreational activity in the community by individuals with traumatic brain injury. *Rehabilitation Psychology*, 48(4), 266-274.
- Bulinski, L. (2010). Social reintegration of TBI patients: A solution to provide long-term support. *Medical Science Monitor*, 16(1), PH14-PH23.
- Caldwell, K., Henshaw, L., & Taylor, G. (2005). Developing a Framework for Critiquing Health Research. *Journal of Health, Social and Environmental Issues*, 6(1), 45-54.
- Caldwell, K., Henshaw, L., & Taylor, G. (2011). Developing a Framework for Critiquing Health Research: An Early Evaluation. *Nursing Education Today*, 31, e1-e7.

Caldwell, L.L. (2005). Leisure and Health: Why is Leisure Therapeutic? *British Journal of Guidance and Counselling*, 33(1), 7-26.

Carvalho, J.P. & Hopko, D.R. (2011). Behavioral theory of depression: Reinforcement as a mediating variable between avoidance and depression. *Journal of Behavioral Therapy and Experimental Psychiatry*, 42, 154-162, doi:10.1016/j.jbtep.2010.10.001

CASP (2006) 10 questions to help you make sense of qualitative research. Public Health Resource Unit in England.

Chambless, D.L. & Hollon, S.D. (1998). Defining Empirically Supported Therapies. *Journal of Consulting and Clinical Psychology*, 66(1), 7-18.

Conneeley, A. L. (2002). Social integration following traumatic brain injury and rehabilitation. *British Journal of Occupational Therapy*, 65(8), 356-362.

Dikmen, S.S, Machamer, J.E., Miller, B., Doctor, J., & Temkin, N.R. (2001). Functional Status Examination: A New Instrument for Assessing Outcome in Traumatic Brain Injury. *Journal of Neurotrauma*, 18, 127-140.

Dikmen, S.S, Machamer, J.E., Powell, J.M., & Temkin, N.R. (2003). Outcome 3 to 5 Years After Moderate to Severe Traumatic Brain Injury. *Archive of Physical Medicine and Rehabilitation*, 84(10), 1449-1457.

Douglas, J., Dyson, M., & Foreman, P. (2006). Increasing leisure activity following severe traumatic brain injury: Does it make a difference? *Brain Impairment*, 7, 101-118.

- Dumont, C., Gervais, M., Fougereyrollas, P., & Bertrand, R. (2004). Toward an explanatory model of social participation for adults with traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 19*(6), 431-444.
- Dutil, E. & Forget, A. (1991). Le Profil Du Loisir: Version 2.0 [The Leisure Profile: Version 2.0]. Montréal, QC, Canada: Équipe TRAUMA et Société de l'assurance automobile du Québec.
- Fleming, J., Braithwaite, H., Gustafsson, L., Griffin, J., Collier, A. M., & Fletcher, S. (2011). Participation in leisure activities during brain injury rehabilitation. *Brain Injury, 25*(9), 806-818.
- Haggstrom, A., & Larsson, M. (2008). The complexity of participation in daily life: A qualitative study of the experiences of persons with acquired brain injury. *Journal of Rehabilitation Medicine, 40*(2), 89-95.
- Hart, T., Whyte, J., Polansky, M., Kersey-Matusiak, G., & Fidler-Sheppard, R. (2005). Community outcomes following traumatic brain injury: Impact of race and preinjury status. *Journal of Head Trauma Rehabilitation, 20*(2), 158-172.
- Heyvaert, M., Hannes, K., Maes, B., & Onghena, P. (2013). Critical Appraisal of Mixed Methods Studies. *Journal of Mixed Methods Research, 7*(4), 302-327.
- Hoofien, D., Gilboa, A., Vakil, E. & Donovan, P.J. (2001). Traumatic Brain Injury (TBI) 10-20 Years Later: A Comprehensive Outcome Study of Psychiatric Symptomology, Cognitive Abilities and Psychosocial Functioning. *Brain Injury, 15*(3), 189-209.



House, J.S. (2001). Social Isolation Kills, But How and Why? *Psychosomatic Medicine*, 63, 273–274, doi. 0033-3174/01/6302-0273

Huebner, R. A., Johnson, K., Bennett, C. M., & Schneck, C. (2003). Community participation and quality of life outcomes after adult traumatic brain injury. *The American Journal of Occupational Therapy.: Official Publication of the American Occupational Therapy Association*, 57(2), 177-185.

Jacobs, H. E. (1993). Behavior analysis guidelines and brain injury rehabilitation: people, principles, and programs. Gaithersburg, MD: Aspen.

Johnston, M. V., Goverover, Y., & Dijkers, M. (2005). Community activities and individuals' satisfaction with them: Quality of life in the first year after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 86(4), 735-745.

Jorge, R.E., Robinson, R.G., Moser, D., Tateno, A., Crespo-Facorro, B., & Arndt, S. (2004). Major Depression Following Traumatic Brain Injury. *Archives of General Psychiatry*, 61(1), 42-50. DOI:10.1001/archpsyc.61.1.42.

Kersel, D.A., Marsh, N.V., Havill, J.H. & Sleigh, J.W. (2001). Psychosocial Functioning During the Year Following Severe Traumatic Brain Injury. *Brain Injury*, 15(8), 683-696.

Kim, H., Colantonio, A., Dawson, D. R., & Bayley, M. T. (2013). Community integration outcomes after traumatic brain injury due to physical assault. *Canadian Journal of Occupational Therapy.Revue Canadienne d'Ergotherapie*, 80(1), 49-58.

Koskinen, S. (1998). Quality of Life 10 Years After a Very Severe Traumatic Brain Injury (TBI): The Perspective of the Injured and the Closest Relative. *Brain Injury*, 12(8). 631-648

Lamontagne, M., Poncet, F., Careau, E., Sirois, M., & Boucher, N. (2013). Life habits performance of individuals with brain injury in different living environments. *Brain Injury*, 27(2), 135-144.

Lefebvre, H., Cloutier, G., & Levert, M. J. (2008). Perspectives of survivors of traumatic brain injury and their caregivers on long-term social integration. *Brain Injury*, 22(7-8), 535-543. DOI: 10.1080/02699050802158243

Livingston, M.G., Brooks, D.N., & Bond, M.R. (1985)<sup>a</sup>. Three Months after Severe Head Injury: Psychiatric and Social Impact on Relatives. *Journal of Neurology, Neurosurgery, and Psychiatry*, 48, 870-875. DOI: 10.1136/jnnp.48.9.870

Livingston, M.G., Brooks, D.N., & Bond, M.R. (1985)<sup>b</sup>. Patient Outcome in the year Following Severe Head Injury and Relatives' Psychiatric and Social Functioning. *Journal of Neurology, Neurosurgery, and Psychiatry*, 48, 876-881. DOI: 10.1136/jnnp.48.9.876

McColl, M.A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The Definition of Community Integration: Perspectives of People with Brain Injuries. *Brain Injury*, 12(1), 15-30.

McColl, M.A., Davies, D., Carlson, P., Johnston, J., & Minnes, P. (2001). The Community Integration Measure: Development and Preliminary Validation. *Archive of Physical Medicine and Rehabilitation*, 82, 429-434.

Mental Health Foundation, (2010). The Lonely Society?

[http://www.mentalhealth.org.uk/content/assets/PDF/publications/the\\_lonely\\_society\\_report.pdf](http://www.mentalhealth.org.uk/content/assets/PDF/publications/the_lonely_society_report.pdf)

Moher, D., Liberati, A., Tetzlaff, J., & Altman, D.G., The PRISMA Group (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA Statement. *PLOS Medicine*, 6(7), e1000097. DOI:10.1371/journal.pmed.1000097

Morton, M.V. & Wehman, P. (1995). Psychosocial and Emotional Sequelae of Individuals with Traumatic Brain Injury: A Literature Review and Recommendations. *Brain Injury*, 9(1), 81-92.

Noreau, L., Fougere, P., & Vincent, C. (2002). The LIFE-H: Assessment of the Quality of Social Participation. *Technology and Disability*, 14(3), 113-118.

Oddy, M., Coughlan, T., Tyerman, A. & Jenkins, D. (1985). Social Adjustment After Closed Head Injury: A Further Follow-up Seven Years After Injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, 48, 564-568. DOI: 10.1136/jnnp.48.6.564

Oddy, M., Humphrey, M. & Uttley, D. (1978). Subjective Impairment and Social Recovery After Closed Head Injury. *Journal of Neurology, Neurosurgery and Psychiatry*, 41, 611-616.

Pappadis, M. R., Sander, A. M., Leung, P., & Struchen, M. A. (2012). The impact of perceived environmental barriers on community integration in persons with traumatic brain injury. *Acta Neuropsychologica, 10*(3), 385-397.

Parr, M.G. & Lashua, B.D. (2004). What is leisure? The perceptions of recreation practitioners and others. *Leisure Sciences, 26*, 1-17. DOI: 10.1080/01490400490272512.

Reistetter, T.A. & Abreu, B.C. (2005). Appraising Evidence on Community Integration Following Brain Injury: A Systematic Review. *Occupational Therapy International, 12*(4), 196–217. DOI: 10.1002/oti.8

Riley, G. A., Brennan, A.J., & Powell, T. (2004). Threat appraisal and avoidance after traumatic brain injury: Why and how often are activities avoided? *Brain injury, 18*(9), 871-888. DOI: 10.1080/02699050410001671829.

Riley, G. A., Dennis, R. K., & Powell, T. (2010). Evaluation of coping resources and self-esteem as moderators of the relationship between threat appraisals and avoidance of activities after traumatic brain injury. *Neuropsychological Rehabilitation, 20*(6), 869-882.

Roscigno, C. I., & Van Liew, K. (2008). Pushed to the margins and pushing back: A case study of one adult's reflections on social interactions after a traumatic brain injury sustained as an adolescent. *The Journal of Neuroscience Nursing : Journal of the American Association of Neuroscience Nurses, 40*(4), 212-221.

Sale, J.E.M. & Brazil, K. (2004). A Strategy to Identify Critical Appraisal Criteria for Primary Mixed-Method Studies. *Quality & Quantity*, 38, 351-365.

Salter, K., Foley, N., Jutal, J., Bayley, M., & Teasell, R. (2008). Assessment of Community Integration Following Traumatic Brain Injury. *Brain Injury*, 22(11), 820–835.

Sander, A.M., Clark, A.N., & Pappadis, M.R. (2010). What is Community Integration Anyway?: Defining Meaning Following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 25(2), 121-127.

Sander, A.M., Krentzer, J.S., Rosenthal, M., Delmonico, R. & Young, M.E. (1996) A Multicenter Longitudinal Investigation of Return to Work and Community Integration Following Traumatic Brain Injury. *Journal of Head Trauma Rehabilitation*, 11(5), 70-84.

Sander, A. M., Pappadis, M. R., Clark, A. N., & Struchen, M. A. (2011). Perceptions of community integration in an ethnically diverse sample. *Journal of Head Trauma Rehabilitation*, 26(2), 158-169.

Schipper, K., Visser-Meily, J. M. A., Hendrikx, A., & Abma, T. A. (2011). Participation of people with acquired brain injury: Insiders perspectives. *Brain Injury*, 25(9), 832-843.

Schretlen, D.J. & Shapiro, A.M. (2003). A Quantitative Review of The Effects of Traumatic Brain Injury on Cognitive Functioning. *International Review of Psychiatry*, 15(4), 341-349. doi:10.1080/09540260310001606728

Seemen, T.C. (1996). Social Ties and Health: The Benefits of Social Integration. *Annals of Epidemiology*, 6(5), 145-157. DOI: 10.1016/S1047-2797(96)00095-6

Shame, J., Treger, I., Ring, H. & Giaquinto, S. (2007). Return to Work Following Traumatic Brain Injury: Trends and Challenges. *Disability and Rehabilitation*, 29(17), 1387-1395. DOI: 10.1080/09638280701315011

Tate R, Hodgkinson A, Veerabangsa A, & Maggiotto S. (1999). Measuring Psychosocial Recovery After Traumatic Brain Injury: Psychometric Properties of a New Scale. *Journal of Head Trauma Rehabilitation*, 14, 543–557.

Tate, R., Simpson, G., Lane-Brown, A., Soo, C., de Wolf, A., & Whiting, D. (2012). Sydney Psychosocial Reintegration Scale (SPRS-2): Meeting the Challenge of Measuring Participation in Neurological Conditions. *Australian Psychologist*, 47, 20-32.

Temkin, N.R., Corrigan, J.D., Dikmen, S.S., & Machamer, J. (2009). Social Functioning After Brain Injury. *Journal of Head Trauma Rehabilitation*, 24(6), 460-467.

Thomsen, I.V. (1984). Late Outcome of very Severe Blunt Head Trauma: a 10-15 Year Second Follow-up. *Journal of Neurology, Neurosurgery & Psychiatry*, 47, 260-268.

Truelle, J., Fayol, P., Montreuil, M. & Chevignard, M. (2010). Community Integration After Severe Traumatic Brain Injury in Adults. *Current Opinion in Neurology*, 23, 688–694. DOI:10.1097/WCO.0b013e3283404258

Veale, D. (2008). Behavioural activation for depression. *Advances in Psychiatric Treatment*, 14, 29–36, doi: 10.1192/apt.bp.107.004051

Weddell, R., Oddy, M. & Jenkins, D. (1980). Social Adjustment after Rehabilitation: A Two Year Follow-up of Patients with Severe Head Injury. *Psychological Medicine*, 10, 257-263. DOI: 0033-2917/80/2828-4860

- Whiteneck, G.G., Charlifue, S.W., Gerhart, K.A., Overholser, J.D., & Richardson, G.N. (1992). Quantifying Handicap: A New Measure of Long-term Rehabilitation Outcomes. *Archives of Physical Medicine and Rehabilitation, 73*, 519–526.
- Willemsse-van Son, A. H., Ribbers, G. M., Hop, W. C., & Stam, H. J. (2009). Community integration following moderate to severe traumatic brain injury: A longitudinal investigation. *Journal of Rehabilitation Medicine : Official Journal of the UEMS European Board of Physical and Rehabilitation Medicine, 41*(7), 521-527.
- Willer, B., Rosenthal, M., & Kreutzer, J.S. Gordon, W.A., & Rempel, R. (1993). Assessment of Community Integration Following Rehabilitation for Traumatic Brain Injury. *The Journal of Head Trauma Rehabilitation, 2* (8), 75-87.
- Winkler, D., Unsworth, C., & Sloan, S. (2006). Factors that lead to successful community integration following severe traumatic brain injury. *The Journal of Head Trauma Rehabilitation, 21*(1), 8-21.
- Wise, E. K., Mathews-Dalton, C., Dikmen, S., Temkin, N., Machamer, J., Bell, K., et al. (2010). Impact of traumatic brain injury on participation in leisure activities. *Archives of Physical Medicine and Rehabilitation, 91*(9), 1357-1362.
- Wood-Daughinee, S.L., Opzoomer, MA., Williams, J.I., Marchand, B., & Spitzer, W.O. (1988). Assessment of global function: The Reintegration to Normal Living Index. *Archive of Physical Medicine and Rehabilitation, 69*, 583-590.

## Social Activity, Community Integration and TBI

- Wood, R. Li., Liossi, C. & Wood, L. (2005). The Impact of Head Injury Neurobehavioural Sequelae on Personal Relationships: Preliminary Findings. *Brain Injury*, 19(10), 845-851. DOI: 10.1080/02699050500058778
- Wood, R. Li. & Yurdakul, L.K. (1997). Change in relationship status following traumatic brain injury. *Brain Injury*, 11(7), 491-502.
- Yates, P.J. (2003). Psychological Adjustment, Social Enablement and Community Integration Following Acquired Brain Injury. *Neuropsychological Rehabilitation*, 13(1/2), 291-306.



**Chapter Two**

**Empirical Paper**

**An Interpretative Phenomenological Analysis of Friendships after Brain  
Injury**

## ABSTRACT

**Background.** It is well documented that friendships often break down after a brain injury, and that new friendships are difficult to establish. However, there is little research into how those with brain injury experience and understand these changes. This was the focus of the current study.

**Method.** Nine people with brain injury were recruited and interviewed with regards to their experiences of friendships both pre and post injury. Interpretative Phenomenological Analysis (IPA) was used to analyse the transcripts.

**Findings.** Four ‘super-ordinate’ themes were found highlighting the *changes in friendships* in terms of a loss/reduction in friends, the possible reasons for change and the strengthening of some key friendships. With these changes *came emotional and coping responses*, as well as an insight into the *nature of friendships* and how these are *formed and maintained*.

**Conclusions.** The experience of loss and change occurred for the majority of the participants, with the exception of one or two key friendships being sustained. The results provide an insight into why these may have been maintained and others lost. The methodological limitations along with the clinical and research implications are also discussed.

Keywords: *Brain injury, friends, friendships, interpretative phenomenological analysis*

## **An Interpretative Phenomenological Analysis of Friendships after Brain Injury**

### **INTRODUCTION**

During adolescence and early adulthood people typically strive to gain independence from their families and use intimate relationships and friendships for support socially, which leads them to highly value their friendships (Callaway, Sloan & Winkler, 2005; Shorland & Douglas, 2010). Brain injury, including Traumatic Brain Injury (TBI) has a major impact on social relationships, with many people reporting breakdowns in intimate relationships, the loss of friendships and social isolation (Callaway et al., 2005; Finset, Dynnes, Krogstads, & Berstads, 1995; Kersel, Marsh, Havill, & Sleight, 2001; Koskinen, 1998, McColl et al., 1998; Morton & Wehman, 1995; Yates, 2003). In a paper by Hoofien, Gilboa, Vakil, and Donovanick (2001) they reported that out of a sample of 78 people with TBI, 31% said that they had no friends at all, with 8% suggesting that they were completely socially isolated. Dawson and Chipman (1995) found that 27% of their sample of 454 TBI sufferers did not socialise with either friends or family. For Thomsen (1984), the reduction in social contact following head trauma was felt to be the 'most disabling handicap in daily life' (p.264). TBI in childhood has also been reported to lead to loss of friendships (Bonhert, Parker, & Warchausky, 1997; Prigatano & Gupta, 2006) and poorer quality friendships (Ross, McMillan, Kelly, Sumpter & Dorris, 2011).

It appears that much of the research focuses on intimate relationships, i.e. marital and romantic relationships (Bowen, Yeates & Palmer, 2010; Dijkers, 2004; Yates, 2003). It is possible that long-term romantic partnerships are yet to be formed during adolescence and early adulthood, leaving friendships as their key relationship. There are a few papers that

## Friendships Following Brain Injury

specifically look into friendships, which would appear to be one of the key relationships for this group of individuals alongside family. Rowlands (2000) reviewed the existing literature around friendship and social support but noted that much of this was linked with physical disabilities due to the lack of literature specifically relating to brain injury. Rowlands felt, however, that there was a strong overlap between the experiences of those with physical disabilities and that of those with brain injury. In addition, much of the research simply reports on the breakdown of friendships and little research has been done into why this may have occurred or how this isolation is experienced. There are two more recent exceptions to this. Two participants interviewed in a qualitative study by Shorland and Douglas (2010) reported a loss of friendships as well as a 'rejection' by existing friends and a sense of not 'belonging' anymore. They linked this to an inability to engage in pre-injury activities with their friends, as well as changes in their ability to communicate following changes in cognitive function. In one qualitative study Frass and Calvert (2009) participant's with brain injury all reported social support networks as being essential when redeveloping a productive life. They went on to discuss that this was not always easy to do, with 71% commenting on or stating that these social networks started to deteriorate following their injury and highlighted emotional distress associated with linguistic, cognitive and physical functioning as a factor in the deterioration of these social networks.

Despite this lack of research, the value of friendships following TBI has often been highlighted. McColl et al. (1998) suggested that for those with brain injuries having close and diffuse relationships was an important part of community reintegration, and stressed the importance of meeting new people and making new friends. Rowlands (2000) highlighted the notion of building and extending social networks as being an important part of rehabilitation following brain injury, and suggested that it is through a personal community that a person

## Friendships Following Brain Injury

will socially participate, and that therefore the development and extension of these networks is needed to help reduce potential isolation.

The basis for this emphasis on the importance of friendships is their contribution to quality of life and mental well-being. Harrick, Kreftings, Johnston, Carlson, and Minnes (1995), Hoofien et al. (2001), and Morten and Wehmen (1995) all reported significant levels of depression within their samples alongside reports of social isolation. Harrick et al. (1995) reported that, on admission to a community-based rehabilitation centre, loneliness and depression were not noted by the participants. However, at 3-year follow-up, both were the most frequently reported concerns for those with brain injury. This association between loneliness and poor well-being has also been noted in the general population. Hirsch (1980), House, Landis and Umberson (1988), and Reisman (1985), all discuss the impact of friendships and social networks on aspects of mental health. They reported friendships helped adaptation to stress, and that the lack of these was linked to psychological difficulties and reduced social competence, particularly in adolescence (Reisman, 1985). As well as the general population, the association between reduced friendships and depressive symptoms has been found in other populations, such as older adults and military veterans (Fiori, Antonucci, & Cortina, 2006; Hatch et al., 2013; Chan & Poulin, 2009; Davila et al., 2012; Ueno, 2005; Nangle, Erdley, Newman, Mason, & Carpenter, 2003; Whitehouse, Durkin, Jaquet, & Ziatas, 2009).

Friendships are important for our quality of life and psychological well-being. After TBI, old friendships are lost and there are difficulties in forming new friendships. Although this is well documented, few studies have investigated how this loss of friendship is experienced by people with a TBI, or why the loss occurs. It is important to understand more about these issues if we are to develop effective ways of supporting people with a TBI to

## Friendships Following Brain Injury

maintain and develop friendships. In the present study, qualitative methods were used to explore the experience of friendship after TBI, and the participants' perceptions of why old friendships were lost or maintained and of what helped or hindered the development of new friendships.

The present study used Interpretative Phenomenological Analysis (IPA; Smith, Flowers & Larkin, 2009). This approach was chosen because IPA focuses on the meaning participants make of experiences and how they are 'made sense' of by the person, which was consistent with the aims of the study. IPA is also appropriate for the more exploratory stages of investigations because there is no focus on theory development. Using techniques such as grounded theory felt premature because there is insufficient research in this area to permit theory development. Another advantage of IPA is that it requires intensive analysis of each individual participant, and therefore allows exploration of differences across participants. This was important for the present study because there has been little investigation of those with a TBI who do manage to maintain, or make new, friendships after their injury. Another advantage of IPA relates to the anticipation that some participants might struggle at times to express themselves clearly because of their brain injury. As IPA involves an interpretative aspect, it was expected that this might prove useful when meanings may not have been clearly expressed by the participant.

## METHOD

### Participants and recruitment

Male participants between the ages of 18 and 30 were recruited in order to ensure a reasonably homogeneous sample. The participants were a convenience sample of service users who attended a brain injury charity, or a vocational rehabilitation centre. Although as few as five participants may be appropriate for an IPA study (Smith et al., 2009), a higher number was sought for this sample because it was anticipated that difficulties in expressing their experience may have resulted in some participants providing data that were not as rich as one might typically expect. Initially 10 participants were recruited. However, one participant interview was not included as the material was deemed inappropriate due to perceived confabulation throughout the interview. Although the original intention had been to recruit only those with TBI, recruitment difficulties meant that people with other forms of brain injury had to be recruited. However, because these others were young men with moderate-to-severe brain injuries that necessitated attendance at day services or a vocational rehabilitation centre, it was considered that their inclusion would not affect the homogeneity of the sample too greatly.

Nine participants were included in total (two recruited via vocational rehabilitation centre, seven from a brain injury charity centre), all with moderate to severe brain injury (acquired/traumatic) as those who have sustained this level of brain injury were the most likely to have substantial difficulties in the social aspects of their life. The participants were required to have been living in the community for at least 1 year to allow for any possible re-integration into their community and allow for the potential re-establishment of their social network (mean time since injury was 3.7 years). Participants were also required to have

## Friendships Following Brain Injury

sufficient cognitive and communication abilities to reflect on the pre- and post-injury experiences which were essential for the project to help understand any changes that may have occurred. All of the participants had to be able to give informed consent and speak sufficient English, as unfortunately there were no resources to pay for an interpreter. Table 4 provides some demographic information about the participants. It is noted that two of the participants (Robert and Steve) were in employment therefore their experience of brain injury may have been different to the other participants in the sample however they had experiences they wished to share nonetheless.

To recruit the participants, posters and flyers advertising the study were displayed around the services who agreed to take part in the study (for a copy of the poster, see Appendix D). Staff members also helped by identifying potential participants to take part. The participants were invited to an information meeting where they were given the participant information sheet, which included details of how the data would be collected and had the opportunity to ask further questions (see Appendix E for the participant information sheet). At this meeting, it was ensured that they met the inclusion criteria for the study, including their ability to give informed consent (for a copy of the screening form, see Appendix F). Following the meeting, they were given 24 hours to think about whether they wanted to take part in the study. The principal investigator contacted the participants after this period to confirm whether they were willing to take part (see Appendix G, for the consent form).



## Friendships Following Brain Injury

Table 4

### *Descriptive Statistics of the Participants*

| <i>Name</i> | <i>Age</i> | <i>Age at time of injury (Years since injury)</i> | <i>Injury Classification</i> | <i>Employed</i> | <i>Living Status</i> | <i>Children (Number)</i> |
|-------------|------------|---|------------------------------|-----------------|----------------------|--------------------------|
| Tony        | 27         | 25 (2)  | TBI                          | No              | With partner         | Yes (2)                  |
| Steve       | 30         | 23 (7)  | TBI                          | Yes             | With partner         | No                       |
| Nick        | 26         | 24 (2)  | TBI                          | No              | With parents         | Yes (2)                  |
| Clint       | 20         | 15 (5)  | TBI                          | No              | With parents         | No                       |
| Robert      | 23         | 20 (3)  | TBI                          | Yes             | With parents         | No                       |
| Logan       | 18         | 17 (1)  | ABI- Stroke                  | No              | With parents         | No                       |
| Peter       | 22         | 15 (7)  | ABI- Brain Tumour            | No              | With parents         | No                       |
| Charlie     | 22         | 18 (2)  | ABI- Encephalitis            | No              | With parents         | No                       |
| Erik        | 30         | 26 (4)  | ABI- Stroke                  | No              | With parents         | Yes (2)                  |

### **Semi-structured Interviews**

Interviews were conducted face-to-face, and lasted between 15 and 49 minutes. Patterson and Scott-Findlay (2002) investigated the difficulties when interviewing persons with brain injury, discussing issues arising from memory and communication deficits, difficulties with abstract thinking and the challenges around fatigue and distraction leading to more succinct responses and less focus over the course of the interview. The issues highlighted by this paper were considered before the interviews were conducted to ensure the optimal procedure was achieved: Interviews were kept relatively short and the interview schedule (Appendix H) included the option of more concrete and specific questions than might typically be encountered in using IPA. The interview schedule covered topics such as how often they saw pre-injury friends as well as new friends, what they did together in terms of activities, any differences in older friends since injury and also whether there were any newer friendships that didn't work out. The main questions were provided in written form,

## Friendships Following Brain Injury

and timelines were used to gauge pre- and post-injury experiences. Finally participants were encouraged to bring photo graphs of their friends if they felt it would help share their story. As is the case with IPA, the emphasis was on encouraging open and free reflection by the participant, and so the schedule was not used in a rigid way. The interviews were audio-recorded and then transcribed verbatim; all identifiable information was censored for anonymity.

### **Ethical Considerations**

Only those that were able to give informed consent were included in the study. Participants were informed about withdrawal from the study in writing as well as verbally at the screening assessment. The study did raise a potential for distress as the participants were asked to reflect on the changes in their friendships since their brain injury and this could, and did, prove to be emotive. Participants were informed beforehand what topics would be covered in the interview so that they were prepared and were then able to make an informed decision. Participants were provided with an information leaflet with contact information for further support, such as help lines. Finally anonymity was maintained in the write up procedure, changing all names throughout. Ethical approval was obtained from the University of Birmingham Ethics Committee (see Appendix I for email of approval).

### **Researcher**

I have no personal experience of brain injury; however I have previous experience working in this area and an interest in the social experiences of those with brain injury. This previous experience may have influenced how the data was interpreted, something which will be discussed in more detail below. I am a female in my early 30s. Although I am similar in age to the participants, I was aware of potential differences in how males and females

experience friendship, and I tried to avoid imposing a female perspective on the data. During the study my background as a trainee clinical psychologist provided useful experience in identifying and dealing with distress. If a serious degree of distress arose, I was able to halt the interview to provide emotional support. With the consent of the participant, the local collaborator was also informed if the participant had become distressed. The balance of being a clinical psychologist and a researcher was also considered with respect to the conducting of the interviews in order to try to avoid slipping into an interview style that may have been more clinically focused than research focussed.

### **Analysis**

The *phenomenological* aspect of IPA is concerned with a person's subjective perception or experience of a state or event. It looks at the meaning and processes involved in these experiences rather than just an objective account (Larkin & Thompson, 2012). Meaning and process, however, cannot be accessed directly and relies on the researcher's own conceptions that are needed to *interpret* the person's experience. Interpretation occurs during the interview when the interviewer's questions will depend on the researcher's own perceptions and understanding as they explore the meaning and key processes of the participant (Smith et al., 2009). Interpretation also occurs during analysis of the transcripts which focuses on comments made by the participants in terms of descriptive comments (e.g. key words and phrases, descriptions, acronyms, emotional responses), linguistics (e.g. attending to pauses, laughter, pronoun use, tone) and finally conceptual comments.

Each transcript was analysed ideographically – that is, each one was analysed in full before moving on to the next transcript. The purpose of this is to ensure variations between the participants are not lost. This involved reading and re-reading the transcript to gain

familiarity with the material, whilst making some initial notes relating to possible themes (Smith, Jarman and Osborn, 1999). Next an attempt was made to identify patterns within the text and expanding on exploratory notes to gain an idea around the key objects of concern and then the meaning of these to the participant, in essence what their experience of the concepts is *like*. For an example of the coded transcripts, see Appendix J. All of these emergent patterns were then reviewed and classified as potential themes; how they then connected across the transcript. Once this was achieved for each transcript, the slow development of themes and over-arching or 'superordinate' themes was initiated (Smith et al., 2009). This involved comparing the themes derived from each participant, looking for similarities and differences. On this basis the meaning of themes was elaborated, and thought was given to how the different themes were connected with one another.

Several steps were taken to enhance the credibility and trustworthiness of the analysis. Themes arising from the analysis were reviewed by peers in a local IPA group designed for trainees undertaking this methodology and by the research supervisor. Random selections of the transcripts were taken to the group for independent review, with members making interpretations of the data to generate potential themes. In essence evaluating how the researchers themes had been derived, whether any potential themes emerged, how well grounded they were in the data and how clearly they were explained. Quotations are also used to evidence the basis of the analysis in the data. The quotes aim to provide an account of the participants true experience and show that they were not meeting prompts in the interview with a passive agreement (for examples see pages 73 and 74). It was planned to present a summary of the findings to service users to gain their understanding and thoughts around them, however due to time constraints this has not yet occurred. A final summary of the

findings was compiled and given to the managers of the services involved to pass on to the participants for feedback on the findings.

## FINDINGS

Overall, four superordinate themes were developed from the interviews, the details of which can be found in Table 5. In terms of friendships following brain injury, there appeared to be first and foremost a ‘change’ in these, which helped to uncover the nature and function of friendships for those with brain injuries along with how they cope with these changes and their emotional response. Also there were thoughts around how those with brain injuries meet and maintain both new and old friendships.

Table 5

*Study Themes*

| <i>Superordinate Theme</i>          | <i>Theme</i>                                     | <i>Content</i>  |
|-------------------------------------|--|---|
| Changes in Friendships              | Loss and change                                  | Experience of a loss or reduction of friendships and experience of isolation or loneliness, as well as a change in the quality of friendships |
|                                     | Reasons for change                               | The possible reasons for this change given by participants, including changes in how friends see them now.                                    |
|                                     | Fortified friendships                            | The strengthening of some friendships   |
| Nature and Function of Friendships  | What type of friend are you?                     | The categorisation of friendships- different types of friendships   |
|                                     | What are friends for?                            | What these friendships provide, what friends do.  |
| Emotional and Coping Responses      | Emotional responses                              | How the participant responded to the changes in friendships emotionally   |
|                                     | Coping Responses                                 | Coping strategies used to possibly help cope with these changes   |
| Forming and Maintaining Friendships | Maintaining old and establishing new friendships | How old friendships are maintained and new ones are established, including thoughts around reciprocity  |
|                                     | The shared experience as a basis for friendship  | How the shared experience is a basis for friendships with others with brain injury  |

### **Changes in Friendships**

*Loss and Change.* A loss or change in friendships was reported by all the participants except Robert. For example Erik lost contact with all his friends following his stroke:

Interviewer: ...any of these people you're still in touch with?

Erik: None of them...

Interviewer: ...so those people that you're not in contact with....

Erik: None have never, never, never, never been in touch, ever.

Erik went on to describe particular friends that he was close to, and one in particular that he played with in the same band; "I used to have loads of gigs everywhere with him...and then he doesn't want to know, he's not, doesn't want to know now, no. Since I've had a stroke, no."

Even when friendships had been maintained, the quality of those friendships seemed reduced. Participants described how they would see these friends less often than they did pre-injury or would do fewer or different activities with them. For example, Logan still had contact with some friends from before his injury, but, whereas he would see them every day prior to the injury, now he only saw them a few times each month. Similarly, Steve had maintained contact with a 'close' friend but saw him only a couple of times a month, and their contact tended to be more via playing computer games on-line rather than direct contact.

The loss of friendships was particularly marked for Peter and Clint whose injuries happened whilst they were at school, around the age of 15. They both experienced a complete

## Friendships Following Brain Injury

loss of friendships at that time. During the interview process Peter became upset whilst recounting his story of his return to school, which sounded isolated and lonely he explained:

I had about two, three months off...that's when I, that's when I found things had changed...Um, didn't really want to know me, didn't want to, didn't want me, not, not, not didn't want me to hang around with them but...like I say I think they'd found other things to do...and other people to hang around with.

This sense of friends moving on during this period was echoed by Clint, feeling left behind:

Before my accident I was friends with a lot of people from school and everything and after my accident, they all went through year nine...[Be]cause when I had my accident, like it took a big chunk out [me] life. I missed all year nine and I missed out part of year ten. So they saw me, [be]cause they were all palling up in year nine, altogether and I was away from them like...

This sense of loneliness and isolation from their friends was further confounded with powerful statements from Clint such as; "...they sectioned me off in that way [the brain injured person]" and "cause this guy...I used to knock around quite a lot with him but now he just doesn't want have nothing to do with me like". The sense of isolation was compounded by the experience of bullying; "...when you were doing something they would take the 'mickey' out of me like, stuff like that..." .

Of all the participants, Robert was the only one not to report any loss of friendships. He talked in a very positive way about his experience of his friendships since his injury; "my...erm family friend, school friend, footy friends like Paul and Simon...absolutely amazing", "[friends] are still there...absolutely fantastic..." .

*Reasons for loss or change.* Participants offered various reasons to explain why they lost friendships, or their friendships had diminished in terms of frequency and quality of contact. These explanations could be broadly divided into those which offered an explanation in terms of how the injury had affected them and those which offered an explanation in terms of characteristics of their friends and the general nature of friendships.

In terms of the first category the majority commented on physical disabilities getting in the way of their friendships, which appeared to be particularly poignant for Clint and Peter who had their injuries at school age (“...when I first went back to school [me] ability weren’t right...and I had to walk around with a walker so I think that the other reasons, cause I couldn’t do what all [me] friends at school could do like”- Clint). Erik talked of his friendship with one member of a musical band he played in that had ended once he was no longer able to play. Some of the participants were members of sporting teams (Nick and Steve) or played sport regularly (Tony), and this had provided the basis for a number of their friendships (“...active stuff like...I can’t play football as well as I used to...[made him feel like]...crap...You know when you see someone try and run and you can’t run the best...” - Tony).

For Steve, this was more challenging as he belonged to a semi-professional football team membership of which had been the basis for many of his friendships:

Like I say, I think it’s just...I mean I think if I still played sports now I’d still be doing the same things with the same people, but obviously with not playing sports then I don’t...all the other people are like interested in what I used to do before my accident. I mean that’s why I was close to them.



## Friendships Following Brain Injury

Indeed, Steve actively distanced himself from the team because of the upset caused by thinking about what he used to be able to do:

If I can't play then I'm not really interested in going there with people...I mean I can go there and watch and meet other people but I'm not really interested in that [be]cause it would get me down probably...because I'd look on the pitch and I think I used to be able to do that, I used to play here, but now I can't.

This was echoed in other comments Steve made such as, "I mean I have their numbers in my phone, but I don't really talk to them". More generally, Steve had distanced himself from others. He was aware of being different to his old self, felt embarrassed about this and stopped friends visiting: "I'd been this person who could do most things and then...I was this person who could do nothing for myself...at the time I didn't want no one coming to see me because it was embarrassing".

Robert similarly talked about how difficult it was to return to a sporting activity he had previously excelled in, but, in contrast to Steve, he persisted in maintaining participation:

It wasn't very nice at all to be honest. If I had the choice I wouldn't have gone, but I'm glad I did though because it made me hungrier if you know what I mean...I'm no longer on the first team cricket, it's the third team cricket, but it's making me hungrier and hungrier to get back where I was.

Other reasons suggested by the participants as to why they thought they had experienced these changes in friendships centred on cognitive changes following injury. For Charlie and Clint in particular it was difficult interacting with others, "I found it really hard to interact with them. I don't know why...just the surroundings, like loads of people were like all over the place, I just found it difficult" (Charlie). This was similar for Clint, "some people

## Friendships Following Brain Injury

who knew me would talk to me and I would like have a chat with them, but after a while I would just like...I couldn't think like". Communication difficulties were also an issue; "like when I was talking after my accident [me] head wasn't correct and I would sometimes say something that had no value. So they wouldn't take that into the fact that, that wasn't me talking, that was me injury" (Clint). Sometimes, the impact of cognitive difficulties on friendships was more subtle. Nick, for example, mentioned that he had had to change his phone number because his phone got broken in the crash; "...so I had a different number and I didn't have their numbers so..." It could be that initiation or problem-solving deficits prevented Nick from contacting them by some other means.

Cognitive difficulties may also have interfered with establishing new friendships. Clint had met new friends at college and even started to do a regular activity (swimming) with one particular person. However, once his friend had finished his course and left college, this activity ended abruptly and Clint was unable to explain why the friendship had ended. Possibly, difficulties with initiation and planning prevented Clint from maintaining contact. However, it is also possible that the diminished quality of this relationship was the reason; "It [contact with the friend] was alright but it was like, like me mum used to say, it was something to get me out of the house."

Sometimes, more indirect consequences of the injury had interfered with the maintenance of friendships. Clint also spoke of parental restrictions following his injury, around certain activities that would restrict his contact with friends, such as going to the pub for a drink. Lack of money as a result of the injury was also an obstacle for some participants. Not having money for phone credit to contact friends hindered them from contacting friends, and also going out and doing activities; "After [my] injury there's no money and benefits are no good, so just money wise that's why I couldn't go out and have a

## Friendships Following Brain Injury

drink with the lads...” (Tony); “been contacted once [by friend]...the phone, that was a, a phone call, see and didn’t have any money at the time, that’s why [I couldn’t get back in contact]...I’ve gone from quite comfortable to nothing.” (Erik).

Other explanations offered by participants for the loss or change in friendships focused on characteristics of their friends or the general nature of friendships. With reference to the latter, the natural changes in friendship that occur as we get older was commented on by six of the participants. Steve stated; “everyone moves on don’t they? They get their own lives and have children and everything. So that’s the main reason I think...” Clint’s parents used a similar explanation to reassure him following the dissolution of his friendship with Jacob; “...[my] mum and dad always said that some of their friends that they had at school and stuff they hadn’t seen for years, so it swings both ways.”

An explanation offered for reduced contact by some participants was that their friends were too busy with their own lives to maintain more frequent contact. Despite wanting to see his friends more, Charlie explained that; “they’ve got, they’re doing things like jobs and courses and stuff like that”. Similarly when asked if seeing his friends twice a month was enough he responded with “I understand that they’re busy”. Charlie stated his closest friend was Jim, whom he saw all the time prior to injury and during the early stages of recovery, but now will only see him occasionally at gigs when Jim is performing:

...at the time he was coming to the hospital quite a lot, he visited me loads and brought others to visit me as well. Since then, since I came out of hospital, I haven’t I haven’t really, I’ve only seen him at gigs....I haven’t seen him outside of that. I don’t know why that is, he’s just been...been busy I suppose.

## Friendships Following Brain Injury

A reason offered for lost friendships was that these friends from before the injury were not 'true' friends. This was associated with anger at being abandoned, Nick stated "Yeah there was a lot of people, loads of people from back then. Loads of people I knew...you know who your true friends are! Yeah I don't speak to them, they ain't rang me or nothing so..."; "...I just think after me accident like, most of [me] friends I used to know they aren't genuine, else they'd come down and visit" (Clint). For Nick, in particular, there was great emphasis on the theme of 'true' friendships, which was apparent with his repetition of the phrase, 'you know who your true friends are', throughout the interview. Steve reflected on these lost friendships and suggested that they were superficial and not really friends in the first place; "...the quality of the friends before my accident were like...they weren't...I don't suppose they were really friends...nothing deep, no."

Some participants felt that their friends now see them as 'different' and not who they used to be. This was perceived as another barrier to the quality of their friendships: Even when friends maintained contact, the sense of friends perceiving them as being different had an effect on the relationship. Clint described his experience of this:

Clint: I do wish that I did never had this accident, and we'd [old friend] be a bit closer and he'd see me different.

Interviewer: so you think he sees you as different now?

Clint: Yeah

Interviewer: In what ways...?

Clint: I think....it's the same with all the people I used to knock around with I think they see me different as I can't, they know that I can't cause me injury [join in on

## Friendships Following Brain Injury

activities]...I mean most of them, like spoke to me and everything, but you can see it in their faces. [Be]cause I had this accident...you know when you're talking to people and they see you different than what you actually are...

Tony also reported a difference to the quality of his contact with friends; "it felt different in a way [be]cause I thought they were looking at me cause look...I don't...well I don't look different, I just act differently".

Logan's experience was one of being treated differently by his closest friends because they were more sensitive around him, holding back to avoid offending or upsetting him:

Logan: Feels a bit strange sometimes...Um, they seem to act differently around me...

Interviewer: Mm-hmm, in what ways?

Logan: Just say different things than they used to.

Interviewer: They'll say different things, is it, I mean, when you say they say different things, is that kind of, do you know if, bit more careful what they say or...?

Logan: Yeah, kind of a bit more careful.

Interviewer: So do you think they're kind of a bit worried about they might upset you if they say the wrong thing?

Logan: Yeah, like insulting me or upsetting me.... Yeah, feels different.

For some participants, their sense of being different in the context of social interactions with friends appeared to be based more on their own sense of shame and embarrassment, rather than on the reactions of their friends. For example, Steve commented

## Friendships Following Brain Injury

on not wanting his friends to see him when he was in hospital as he was embarrassed that he could not look after himself:

...it was a bit embarrassing for me [be]cause I'd been like a kind of sporty person and then I used to sit on the bed and then I used to slide down and I couldn't get myself back up so I used to have to ask people...it was a bit embarrassing...

***Fortified Friendships.*** Two of the participants reported that some of their friendships had been strengthened by the brain injury. This strengthening was based on the support these friends gave and the contrast with other friends who had failed to stand by them; “they stood by me like...I think I'm closer to them two and then I find that some people who I used to be friends with didn't give a crap...” (Nick). For Steve it felt as though the interview process itself provided him with the time to reflect on his main friendship with William; “I think we've got closer really”, followed up by “It's like...I suppose a closer friendship than I thought it was and it was much closer than the other friendships that I had.”

### **Nature and Function of Friendships**

***What type of friend are you?*** Friends appear to be categorised by the majority of the participants into work friends, school friends and new friends (who were mainly other people with brain injuries). The participants' close friends or 'best friends' appeared to be those that had developed in childhood or adolescence at school. In the case of those participants who reported that they had maintained one or two close friendships from before the injury, these friendships had also begun at school (“Craig who is someone I went to school with and the other is Mark I went to school with him as well yeah...they were two good friends... think I'm closer to them two”-Nick; “Names Albert...[know from school], yeah my best friend”- Tony). Erik spoke of his old school friend as his “best friend ever” who comes to see him every

## Friendships Following Brain Injury

week, taking him out and sharing special events with him (“when it gets to birthdays or something like that...or Christmas, he’ll just do stuff, yeah”).

Not all the participants had ‘work friends’; four were too young at the time of injury to have established these. With the exception of Robert, the experience of work friendships after the injury was generally negative. Erik described how contact with his work colleagues stopped suddenly; “when I was a bit poorly, like, I didn’t have a card or nothing”. Steve had similar experiences to Erik. He did not see these people much after injury. He commented that their friendship was probably always more superficial relationship; “I don’t suppose they were really friends, they were more like drinking partners and work mates...”.

New friendships were primarily with other people with a brain injury that participants had met at services for people with a brain injury. Even in the case of those reporting new friends from other sources (Peter and Charlie), they had met these friends in the context of charities providing services for people with medical or psychiatric conditions. The quality of these new friendships were different in terms of what they provided (see next theme), but also in how they were experienced by the participant (“...most of the friends you make now aren’t genuine...like me mum used to say it was something to get me out the house [going swimming with a friend]”-Clint). A marker of the superficiality of these friendships was that the participants would only see these friends in the setting in which they had originally met them, in other words never outside of the service and service hours. However, both Peter and Charlie, whose new friends came from different services, would socialise with them outside of this, for example go for meals, or go to the pub.

***What are friends for?*** Friendships offered a range of things that the participants valued. One was about having fun, a ‘laugh’ and being able to have ‘banter’ with their

## Friendships Following Brain Injury

friends; “he was the same age as me and he was a good laugh” (Nick). Banter appeared to be a way in which friends showed their care and acknowledgement of their friends experiences.

Robert sums this up:

I like having the michael taking out of me cause it shows that they have obviously looked into what you’ve been up to and stuff like that...weird stuff but yeah...it always coming back to me with them taking the michael out of me, but in their own very strange way that’s their way of saying they understand.

Another valued aspect of friendships was spending time in shared activities and interests (“...[computer games] well it’s what you’ve got in common ain’t it...- Logan; “I’m back cricketing, drinking and watching football, having a laugh with them”- Robert). Talking together was also highlighted by some participants as something they valued in their friendships. Erik explained that he and his friend Colin talked; “talk like, all different sorts of things, what we used to do before and after and all sorts”.

Missing from the accounts of most participants was any sense of obtaining emotional support from their friends or sharing personal issues or difficulties. When asked if he talked to his friends about difficult issues, Robert said, “yeah...a little bit [laughs]”. It felt as though, even though he was close to his friends, he found it difficult to share his problems with them.

Nick offered a different perspective:

Interviewer: Do you talk to your other friends, Craig and Mark about problems if you have problems?

Nick: Yeah I speak to them all the time....

Interviewer: Yeah. Who do you prefer to talk to about your problems?



## Friendships Following Brain Injury

Nick: Erm...my friends like Craig and Mark really...

Interviewer: So it's easier to talk to them about your problems?

Nick: Yeah...cause they probably know all about [inaudible] my kids and....whereas at [centre name] they don't really know what I'm on about so....

### **Emotional and Coping Responses**

*Emotional Responses.* For several of the participants, a sense of anger and frustration towards their pre-injury friends was evident. Erik and Nick were particularly angry at how they had been abandoned by them in their time of need. Erik's description appeared to be about them not visiting, they should be coming to him as he's the one who suffered an injury, not them:

Erik: They're not as good friends as I think, are they?

Interviewer: Yeah, so you kind of don't want to see them, in a sense?

Erik: Yeah, that's right, yeah, yeah...I've had a stroke and it should be me that's ill...not the other way around.

Interviewer: Yeah, so it's, I don't, I [hesitates], don't want to kind of put words in your mouth, but it sounds like they've hurt you in a way and it's...

Erik: Yeah, yeah.

Interviewer: And it's kind of like why should I?

Erik: Yeah, that's right, yeah...exactly, arr.

Interviewer: They should be coming to you.

Erik: Well, they should be really, shouldn't they?

Like Erik, anger was also evident from Nick stating that his friends "...didn't give a crap about me".

## Friendships Following Brain Injury

In other participants' accounts, there was a sense of grief and sadness when reflecting on their loss of friendships. As noted earlier, during his interview Peter became upset whilst recounting his story of his return to school, which sounded isolated and lonely. Even after seven years, his experiences have stayed with him and felt quite raw. Like Peter, Clint's time at school following his injury had an overwhelming sense of separation from others. Although he did not directly express upset over his experiences, there was an 'atmosphere' of sadness during the interview.

***Coping Responses.*** Several participants reflected on how they coped with the upset of being abandoned by friends. There was a sense of resignation and a feeling that they just had to get on with life despite what had happened; "I don't want to, do-don't want to see them now...but I'm not bothered anyway." (Erik), "It [not seeing friends] made me feel bad at first, but I've learnt to live with it, you get on with your life don't you" (Tony), "They've moved on with their lives and I've moved on with mine..." (Steve), "It's their loss not mine. You got to think of the brighter side," (Nick).

It was noted earlier that some of the reasons given by participants for the loss or change in their friendships related to the general nature of friendships (that it is natural that friends drift apart) or to characteristics of their friends (that they have busy lives, or that they were never true friends in the first place), as opposed to changes in themselves as a result of the brain injury. Explanations of this kind did seem to provide comfort for some of the participants, and a means of coming to terms with their sense of loss and anger.

### **Forming and Maintaining Friendships**

***Maintaining old and establishing new friendships.*** It appeared that there are certain elements that are needed to both make and maintain friendships. Shared interests and

## Friendships Following Brain Injury

activities were an important means of bonding. When asked what he got up to with new friends when he attended the centre, Clint responded “just like sitting and chatting and like having a game of pool...”, for Nick it was similar; “...play pool...go in the gym...”. In the case of maintaining older friendships, it seemed important that old friends kept the participant involved in activities, sometimes by adapting those activities so that the participant could be included. For example, Robert’s physical and cognitive difficulties made participation with his friends difficult in the earlier stages of his recovery, but his friends adapted to this so that they could continue to include him in their activities:

When I weren’t well and recovering they involved me in everything still...it was a little weird because my talking wasn’t the best anyway so we just...spent time, most of the time when they came to see me in hospital or at home just watching something...if I couldn’t go or anything like that they would just find somewhere else to go...

Charlie also continued to be included by friends in activities he did before despite not fully being able to participate; “We go drinking and that...or, well I can’t drink but they do”.

Some of the participants had adapted their own interests in a way that allowed them to maintain participation with old friends. For example, Steve, whose main focus pre-injury was on sport, had developed an interest in cars, which had allowed him to become closer to his friend William: “...cause he’s not really a sports kind of person...with me not being able to do sports now, erm...we kind of become closer and stuff and I do the things he does more...”

Similarly, Erik, was no longer able to play the drums because of his physical disability, but had developed alternative interests that helped maintain his friendships; “He does football and I didn’t go football, I used to do the drums all the time, until I had the stroke...Well I go [to the] football now...”

## Friendships Following Brain Injury

Keeping in touch was also seen as important to maintaining friendships. Robert, for example, made a point of sending birthday greetings to his friends. For some this contact was maintained using newer technologies such as Facebook and texting (Peter), and online gaming (Steve, Logan and Nick),

***The shared experience as a basis for friendship.*** An important aspect of new friendships was having a shared understanding of what the other has been through in terms of their brain injury. Tony's experience of meeting new people in the service he attended highlighted this:

It's ok meeting other people, cause they've all been through a similar thing that you've been through or had different brain injuries, but we've all been in the same boat, so it's ok...when you talk to them it's ok. They understand a bit better than what other people do.

Nick and Erik also shared with their new friends from the centre their experiences and problems; "He was talking about; he was in a car accident...so I tell him my story and he tells me about his." (Erik). For Clint it was easier to talk to his friends at the brain injury service than the people he met at college; "all the people here have had similar things to what I have had so...so it's easier to get in a conversation with them, than my friends at college like". It does seem that this shared experience as such helps to build a relationship with the other.

## DISCUSSION

### Summary of Findings

The participants' accounts of their experiences of friendship following brain injury were varied, yet the themes generated appeared to express a similarity of these experiences for the majority. The main superordinate themes of *changes in friendships, the nature and functioning of friendships, emotional and coping responses, and the forming and maintaining of friendships* highlight the challenges and nature of this relationship faced by those who have suffered this injury. Although changes appeared on the whole to suggest more of a loss or reduction in contact with friends, for some there was an actual strengthening or *fortifying* of certain friendships.

From the nine participants, Robert was the only one not to experience the loss of any friendships; instead he labelled his friends as 'amazing' and 'fantastic'. For Nick and Steve, there was a strengthening of the relationships with one or two particular friends who 'stood by' them in their time of crisis. It is worth noting that Steve and Robert were both in employment, and so their experience of brain injury may have been different from others in the sample. This positive change in friendships is something that has not been reported or explored in the literature on friendships after brain injury. In a large survey (N=630), Jones et al. (2011) asked participants to indicate which relationships from a list (partner/spouse, family, friends, employer and work colleagues) had 'improved since the injury'. Although participants were allowed to indicate as many from the list as appropriate, the mean number indicated was only 1.1 (SD=1.1). Jones et al. also commented that these reported improvements were usually in the relationship with the partner/spouse or family. This implies

that few reported improvements in their friendships, though Jones et al. did not provide exact figures.

In line with the outcome studies into life after brain injury (Callaway et al., 2005; Finset et al., 1995; Hoofien et al., 2010; Kersel et al., 2001; Koskinen, 1998, McColl et al., 1998; Morton & Wehman, 1995; Yates, 2003), for the majority of the participants there did appear to be a *loss* or reduction in friendships and social contact. There was a sense of rejection by those they once considered to be good friends, people that they had grown up with. Unlike the others, the two participants that had their injuries at a young age (Peter and Clint) did not retain any friends at all. Theirs felt like a true experience of isolation and loneliness, when, on returning to school, they discovered that people had ‘moved on’ establishing new friends with others in their absence. As discussed in the Introduction, this finding has often been noted in the literature exploring TBI in school children (Bonhert et al., 1997; Prigatano & Gupta, 2006; Ross et al., 2011).

For the remaining participants, their friendships appeared to significantly reduce in number, frequency of contact and quality post-injury. The participants provided a number of *reasons for change* in their friendships, including being unable to take part in shared physical activities such as sports, difficulty interacting with others due to cognitive change and the natural changes in friendships over time. Although cognitive impairments have often been highlighted as a consequence of brain injury and a potential barrier to social participation (Callaway et al., 2005; Finset et al., 1995; Fraas & Calvert, 2009; Hoofien et al., 2010; Kersel et al., 2001; Koskinen, 1998, Mazaux et al., 1997; McColl et al., 1998; Morton & Wehman, 1995; Shorland & Douglas, 2010), they were not often mentioned by the participants as a barrier to friendship. Only three spoke of difficulties in following conversations or broader difficulties such as fatigue (e.g. becoming confused and ‘not making sense’-Clint). For the

majority of the participants, being unable to take part in their old shared activities due to physical disability appeared to be more of an issue.

With regards to the ‘natural changes’ in friendships, evidence from the general population suggests that this is something that most people experience over the lifespan (Hartup, 1995, 1996; Hartup & Stevens, 1997). Wrzus et al.’s (2013) meta-analysis described an increase in friendships up until young adulthood, plateauing in the mid twenties - early thirties, before steadily declining. For many of the participants in this study, the brain injury appeared to accelerate this natural decline, but the participants were able to take some comfort from the recognition that friendships often do come to a natural end as adulthood progresses. Exceptions to this pattern were the two participants who suffered a brain injury in adolescence (Peter and Clint, who both suffered their brain injury at the age of 15). Their experience was of a wealth of friendships pre-injury that came to a sudden and abrupt end. Related to the idea of a natural loss of friendships was the explanation given by some participants in terms of both parties being too ‘busy’ with other aspects of life such as courses, jobs, family and children. Not having the time for friends appeared to get in the way of meeting up.

*Emotional response* to change included a sense of anger towards those friends who ‘abandoned’ or rejected them. Being treated differently by friends could also be experienced as unnecessary and frustrating (Logan). Some of the participants’ stories (Clint, Erik and Peter) portrayed loneliness and isolation, and suggested a sense of sadness. Most of the participants, however, did not seem too distressed by the loss of friendships. Some of the participants’ *copings responses* may have helped with this. Their coping was often geared around ‘getting on’ with things as best they can. As suggested earlier, explaining the loss of friendships as a natural process may also have helped in this respect; as may the labelling of lost friends as not really being ‘true’ friends in the first place. The emotional and coping

## Friendships Following Brain Injury

responses to the loss of friendship after brain injury are not issues that have received much attention in previous literature.

Despite the challenges, all but two of the participants, Clint and Peter, had maintained at least one friendship that predated their injury, or had formed newer ones. The *nature and function of these friendships* were varied but generally they reflected what Moore & Boldero (1991) highlighted as the essentials of friendships - reciprocity, commitment and common interests – as well as a simple enjoyment of one another's company. There were comments around friends 'being there' for them (commitment), and being there for each other (reciprocity) which literature suggests are important element of friendship (Hartup, 1995, 1996; Hartup & Stevens, 1996; Rowlands, 2000).

The importance of common or shared activities/interests is supported by much of the general friendship literature (Adams & Blieszner, 1994; Bogan, Livingston, Parry-Jones, Buston & Wood, 1997; Bonhert et al., 1997; Hartup, 1995, 1996; Hartup & Stevens, 1997; Moore & Boldero, 1991; Mulderji, 1997; Niffenegger & Willer, 1998; Schaefer, Simpkins, Vest & Price, 2011), more so for male friendships (Aries & Johnson, 1983; Booth, 1972; Caldwell & Peplau, 1982; Chu, 2005; Hartup & Steven, 1997). The importance of shared interests, particularly sporting interests, was prominent in this study. An important aspect of friendships formed after the injury with other people with a brain injury was the *shared experience* of having the injury. This may have served to establish a sense of an emotional or empathic connection, which is another aspect considered important to friendships in both the general literature (e.g. Adams & Blieszner, 1994; Hartup, 1995, 1996; Hartup & Stevens, 1997) and literature specific to acquired brain injury (e.g. Rowlands, 2000).



### **Methodological Considerations**

Patterson and Scott-Findlay (2002) discussed some of the challenges of interviewing persons with brain injury that might be expected to limit the quantity and quality of the data. These included difficulty recalling events due to memory deficits and communication problems inhibiting their response to questions. One might also add difficulties in reflecting on their situation at a more abstract level, and problems with poor concentration and fatigue.

Precautions were taken to enhance their ability to recall information such as having the main questions in written format for them to look at, using a timeline to piece together the pre- and post-injury experiences, and encouraging them to use photos of friends to help with recall. To address potential problems with poor concentration and fatigue, interviews were kept relatively short. With regards to potential limitations on the ability to reflect on experience at a more general level, the interview schedule included the option of more concrete and specific questions than might typically be encountered in using IPA.

Despite these precautions, cognitive difficulties did appear to have an impact on the quality and quantity of data. Participants sometimes struggled to recall specific friends and events. Responses to questions were sometimes rather brief and unelaborated, and sometimes quite specific and concrete, and did not evidence a deeper or more abstract level of reflection on the participant's experience of friendship.

Another potential issue highlighted by Patterson and Scott-Findlay (2002) is the concept of 'image management'. It is suggested that some people with brain injury may try to present themselves as one who has 'recovered', desiring to give an image of 'normalcy', and just 'getting on with life', which is a phrase that several of participants used. There is a possibility that some of their accounts may have been limited due to this process. Gender

## Friendships Following Brain Injury

issues may have contributed to this. For example, participants may have covered over some of their feelings about the ending of their friendships due to wanting not to be thought of as un-masculine. The fact that the interviewer was female may have contributed to this.

Gender issues may also have had an impact on the process of analysis. Some research suggests that there is a tendency for men to value the shared activity/interest elements of friendship, whereas women value a more talking-based, shared experience relationship; that women value their friendships more than men; and that women find it easier to establish close friendships than men (Aries & Johnson, 1983; Caldwell & Peplau, 1982; Chu, 2005). Although the researcher was aware of this potential bias, it may have influenced her selection and interpretation of interview data.

Other issues about the methodology that should be noted are those common to qualitative approaches in general. There are issues about the credibility and trustworthiness of the analysis, given the subjective nature of the interpretation and the vagueness about the process of analysis and interpretation (Brocki & Wearden, 2006). To address this issue the themes were reviewed by peers in a local IPA group and by the research supervisor, along with using quotations to evidence the basis of the analysis in the data. Improving the credibility and in essence the trustworthiness may have been further achieved by having more frequent peer reviews and having participants check that their transcripts provided an accurate reflection of the interview (Shenton, 2004). Finally, consultation with the participants about the interview schedule or procedures would have been ideal; however time constraints and the limited participant pool restricted the ability to take these approaches. Another issue is that the small and self-selected nature of the sample means that generalization of the findings is limited. To address this, a fairly homogenous sample was selected, and information about their circumstances was provided. This allows others to consider the similarity of the present

participants to other people with a brain injury, and therefore whether the present findings might have application to these other people.

### **Future Research and Clinical Implications**

In terms of future research there are a variety of investigative leads produced by the current study. As highlighted, gender appears to be relevant to the nature of the friendships. It would be interesting to replicate the current study with an all female sample and to explore potential differences in the male and female experience of friendships after brain injury – for example, whether female friendships are more robust in the aftermath of brain injury, and whether women find it easier to establish new friendships. Although touched on by some participants in the current study, the impact of cognitive difficulties on the experience of being in social situations and on friendships merits further investigation. Understanding this impact may assist us in developing rehabilitation strategies to help people to maintain and develop friendships after brain injury. Finally, interviewing the friends (or ex-friends) of those with brain injuries may provide insight into their experiences, why they may have decided to end friendships, and what elements were important to them in keeping the friendship going.

In terms of clinical implications, the results suggest that, for young men at least, it may be important to support the person with a brain injury to identify and engage in interests and activities that they can share with existing and new friends. At times, they may need help to overcome cognitive, physical and other disabilities so that they can engage in these activities as fully as they can. This may require rehabilitation services to involve friends of the person with the brain injury more fully in the rehabilitation process (Callaway et al., 2005). Friends may need educating about the effects of brain injury; advice about dealing with the

## Friendships Following Brain Injury

effects of cognitive difficulties on friendship-related activities and interactions; and support in thinking about how they help maintain the friendship through, amongst other things, shared activity.

Friendships are important to people. Gracey et al. (2008) discussed the importance of ‘feeling part of things’ to the sense of self. Friends give us a sense of who we are as people and who we want to be, and more to the point it is nice to have friends:

Um, just, just the fact that, to have friends, it’s just nice to know that I, I have got a friend... I have got friends, I've only got a few...but they are there... (Peter).

## REFERENCES

- Adams, R.G. & Blieszner, R. (1994). An integrative conceptual framework for friendship research. *Journal of Social and Personal Relationships, 11*, 163-184. DOI: 10.1177/0265407594112001.
- Aries, E.J. & Johnson, F.L. (1983). Close friendship in adulthood: Conversational content between same-sex friends. *Sex Roles, 9(12)*, 1183-1196.
- Bogan, A.M., Livingston, M.G., Parry-Jones, W.L., Buston, K.M. & Wood, S.F. (1997). The experiential impact of head injury on adolescents: Individual perspectives on long-term outcome. *Brain injury, 11(6)*, 431-443.
- Bohnert, A.M., Parker, W., J.G. & Warschausky, S.A. (1997). Friendship and social adjustment of children following a TBI: An exploratory investigation. *Developmental Neuropsychology, 13(4)*, 477-486.
- Booth, A. (1972). Sex and social participation. *American Sociological Review, 37(2)*, 183-193.
- Bowen, C., Yeates, G. & Palmer, S. (2010). *A relational approach to rehabilitation: Thinking about relationships after brain injury*. London: Karnac.
- Brocki, J.M. & Wearden, A.J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21(1)*, 87-108. DOI: 10.1080/14768320500230185.
- Caldwell, M.A. & Peplau, L.A. (1982). Sex differences in same-sex friendship. *Sex Roles, 8(7)*, 721-732.

## Friendships Following Brain Injury

- Callaway, L., Sloan, E., & Winkler, D. (2005). Maintaining and developing friendships following severe traumatic brain injury: Principles of occupational therapy practice. *Australian Occupational Therapy Journal*, *52*, 257-260. DOI: 10.1111/j.14401630200500492.
- Chan, A. & Poulin, F. (2009). Monthly instability in early adolescent friendship networks and depressive symptoms. *Social Development*, *18*(1), 1-23.
- Chu, J.Y. (2005). Adolescent boys' friendships and peer group culture. *New Directions for Child and Adolescent Development*, *107*, 7-22.
- Davila, J., Hershenberg, R., Feinstein, B., Gorman, K., Bhatia, V., & Starr, L.R. (2012). Frequency and quality of social networking among young adults: Associations with depressive symptoms, rumination, and corumination. *Psychology of Popular Media Culture*, *1*(2), 72-86.
- Dawson, D.R. & Chipman, M. (1995). The disablement experienced by traumatically brain-injured adults living in the community. *Brain Injury*, *9*(4), 339-353.
- Dijkers, M.P. (2004). Quality of life after traumatic brain injury: A review of research approaches and findings. *Archives of Physical Medicine and Rehabilitation*, *85*(2), S21-S35. DOI: 10.1016/j.ampr.2003.08.119.
- Finset, A., Dynes, S., Krogstads, J.M., & Berstads, J. (1995). Self-reported social networks and interpersonal support 2 years after severe traumatic brain injury. *Brain Injury*, *9*(2), 141-150.

## Friendships Following Brain Injury

- Fiori, K.L., Antonucci, T.C., & Cortina, K.S. (2006). Social network typologies and mental health among older adults. *The Journals of Gerontology: Series B: Psychological Sciences and Social Sciences*, *61B(1)*, P25-P32.
- Frass, M.R. & Calvert, M. (2009). The use of narratives to identify characteristics leading to a productive life following acquired brain injury. *American Journal of Speech-Language Pathology*, *18*, 315-328. DOI: 10.1044/1058-03602009/08-0008.
- Gracey, F., Palmer, S., Rous, B., Psaila, K., Shaw, K., O'Dell, J.,...Mohamed, S. (2008). "Feeling part of things": Personal construction of self after brain injury. *Neuropsychological Rehabilitation*, *18(5/6)*, 627-650. DOI: 10.1080/09602010802041238.
- Harrick, L., Kreftings, L., Johnston, J., Carlson, P., & Minnes, P. (1994). Stability of functional outcomes following transitional living programme participation: 3-year follow-up. *Brain Injury*, *8(5)*, 439-447.
- Hartup, W.W. (1995). The three faces of friendship. *The Journal of Social and Personal Relationships*, *12*, 569-574.
- Hartup, W.W. (1996). The company they keep: Friendships and their developmental significance. *Child Development*, *67*, 1-13.
- Hartup, W.W. & Stevens, N. (1997). Friendships and adaptation in the life course. *Psychological Bulletin*, *121(3)*, 355-370.
- Hatch, S., Harvey, S.B., Dandeker, C., Burdett, H., Greenberg, N., Fear, N.T., & Wessely, S. (2013). Life in and after the armed forces: Social networks and mental health in the UK military. *Sociology of Health & Illness*, *35(7)*, 1045-1064.

## Friendships Following Brain Injury

Hirsch, B.J. (1980). Natural support systems and coping with major life changes. *American Journal of Community Psychology*, 8(2), 159-172.

Hoofien, D., Gilboa, A., Vakil, E. & Donovick, P.J. (2001). Traumatic Brain Injury (TBI) 10-20 Years Later: A Comprehensive Outcome Study of Psychiatric Symptomology, Cognitive Abilities and Psychosocial Functioning. *Brain Injury*, 15(3), 189-209.

House, J.S., Landis, R., & Umberson, D. (1988). Social relationships and health. *Science*, 241(4865), 540-545.

Jones, J.M., Haslam, S.A., Jetten, J., Williams, W.H., Morris, R., & Saryan, S. (2011). That which doesn't kill us can make us stronger (and more satisfied with life): The contribution of personal and social changes to well-being after acquired brain injury. *Psychology and Health*, 26(3), 353-369. DOI: 10.1080/08870440903440699.

Kersel, D.A., Marsh, N.V., Havill, J.H. & Sleigh, J.W. (2001). Psychosocial Functioning During the Year Following Severe Traumatic Brain Injury. *Brain Injury*, 15(8), 683-696.

Koskinen, S. (1998). Quality of Life 10 Years After a Very Severe Traumatic Brain Injury (TBI): The Perspective of the Injured and the Closest Relative. *Brain Injury*, 12(8), 631-648.

Larkin, M. & Thompson, A.R. (2012). Interpretative Phenomenological Analysis in Mental Health and Psychotherapy Research. In D. Harper & A.R. Thompson (Eds.), *Qualitative research methods in mental health and psychotherapy: A guide for students and practitioners* (pp. 101-116). Wiley, West Sussex: UK.



## Friendships Following Brain Injury

- Mazaux, J.M., Masson, F., Levin, H.S., Alaoui, P., Maurette, & Barat, M. (1997). Long-term neuropsychological outcome and loss of social autonomy after traumatic brain injury. *Archive of Physical and Medical Rehabilitation*, 78, 1316-1320.
- McColl, M.A., Carlson, P., Johnston, J., Minnes, P., Shue, K., Davies, D., & Karlovits, T. (1998). The Definition of Community Integration: Perspectives of People with Brain Injuries. *Brain Injury*, 12(1), 15-30.
- Moore, S. & Boldero, J. (1991). Psychosocial development and friendship functions in adolescence. *Sex Roles*, 25(9-10), 521-536.
- Morton, M.V. & Wehman, P. (1995). Psychosocial and Emotional Sequelae of Individuals with Traumatic Brain Injury: A Literature Review and Recommendations. *Brain Injury*, 9(1), 81-92.
- Mulderij, K.J. (1997). Peer relations and friendship in physically disabled children. *Child: Care, Health and Development*, 23(5), 379-389.
- Nangle, D.W., Erdley, C.A., Newman, J.E., Mason, C.A. & Carpenter, E.M. (2003). Popularity, Friendship Quantity, and Friendship Quality: Interactive Influences on Children's Loneliness and Depression. *Journal of Clinical Child and Adolescent Psychology*, 32(4), 546-555.
- Niffenegger, J. P. & Willer, L.R. (1998). Friendship Behaviors in Early Childhood and Beyond. *Early Childhood Education Journal*, 28(2), 95- 99.

## Friendships Following Brain Injury

- Paterson, B. & Scott-Findlay, S. (2002). Critical issues in interviewing people with traumatic brain injury. *Qualitative Health Research, 12* (3), 399-409. DOI: 10.1177/104973202129119973.
- Prigatano G.P. & Gupta S. (2006). Friends after traumatic brain injury in children. *Journal of Head Trauma Rehabilitation, 21*(6), 505-513.
- Reisman, J.M. (1985). Friendship and its implications for mental health or social competence. *Journal of Early Adolescents, 5*(3), 383-391. DOI: 10.1177/0272431685053010.
- Ross K., McMillan T., Kelly T., Sumpter R. & Dorris L. (2011). Friendship, loneliness and psychosocial functioning in children with traumatic brain injury. *Brain Injury, 25*(12), 1206–1211. DOI: 10.3109/02699052.2011.609519.
- Rowlands, A. (2000). Understanding social support and friendship: Implications for intervention after acquired brain injury. *Brain Impairment, 1*(2), 151-164.
- Schaefer, D.R., Simpkins, S.D., Vest, A.E. & Price, C.D. (2011). The contribution of extracurricular activities to adolescent friendships: New insights through social network analysis. *Developmental Psychology, 47*(4), 1141-1152.  
DOI:10.1037/a0024091.
- Shenton, A.K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information, 22*, 63–75.
- Shorland, J. & Douglas, J.M. (2010). Understanding the role of communication in maintaining and forming friendships following traumatic brain injury. *Brain injury, 24*(4), 569-580. DOI: 10.3109/02699051003610441.

## Friendships Following Brain Injury

Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory, Method and Research*. London: Sage

Smith, J.A., Jarman, M., & Osborn, M. (1999). Doing interpretative phenomenological analysis. In M. Murray and K. Chamberlin (Eds.), *Qualitative Health Psychology: Theories and Methods* (pp. 218-240). London: Sage.

Thomsen, I.V. (1984). Late outcome of very severe blunt head trauma: A 10-15 year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry*, 47, 260-268.

Ueno, K. (2005). The effects of friendship networks on adolescent depressive symptoms. *Social Science Research*, 34(3), 484-510.

Whitehouse, A.J.O., Durkin, K., Jaquet, E., & Ziatas, K. (2009). Friendship, loneliness and depression in adolescents with Asperger's syndrome. *Journal of Adolescence*, 32(2), 309-322.

Wrzus, C., Hänel, M., Wagner, R., & Neyer, F.J. (2013). Social Network Changes and Life Events Across the Lifespan: A Meta-Analysis. *Psychological Bulletin*, 139(1), 53-80.  
DOI: 10.1037/a0028601

Yates, P.J. (2003). Psychological Adjustment, Social Enablement and Community Integration Following Acquired Brain Injury. *Neuropsychological Rehabilitation*, 13(1/2), 291-306.

**Chapter 3**  
**Public Domain Briefing Document**

## Overview

The current document provides a summary of a research project that has been submitted as partial fulfilment for the qualification of Doctorate of Clinical Psychology (Clin.Psy.D.) at the University of Birmingham.

**Title: An Interpretative Phenomenological Analysis of Friendships after Brain Injury.**

**Background.** It has been documented that friendships often break down after a brain injury, and that new friendships are difficult to establish. Much of the research into relationships focuses on more intimate relationships, i.e. marital and romantic relationships. There is little research into how those with brain injury experience friendships and understand the changes that may happen to friendships following a brain injury.

**Aim.** The aim of the study was to use qualitative methods to explore the experience of friendship after brain injury, and the participants' perceptions of why old friendships were lost or maintained and of what helped or hindered the development of new friendships. More understanding about these issues may help to develop effective ways of supporting people with a brain injury to maintain and develop friendships.

**Method.** Nine male participants between the ages of 18-30 years old were recruited from a brain injury charity, and a vocational rehabilitation centre. They were interviewed with regards to their experiences of friendships both pre and post injury. Consent to take part in the study was gained from all of the participants. In order to protect the participants identity anonymity was assured by removing or changing all names and locations that could lead to identification.

## Friendships Following Brain Injury

The present study used a method known as Interpretative Phenomenological Analysis (IPA) to analyse the interview transcripts. This approach was chosen as IPA focuses on how each participant understands and makes sense of their experience. From the interviews, themes were developed that expressed the participants' experiences and the challenges they faced in their friendships following brain injury.

**Findings.** Table 6 below gives a brief description of the themes generated.

Table 6

*Study Themes for the Empirical Paper*

| <i>Main Themes</i>                 | <i>Sub-theme</i>             | <i>Description</i>  |
|------------------------------------|------------------------------|---|
| Changes in Friendships             | Loss and change              | Following brain injury the majority of participants experienced a loss or reduction of friendships, isolation and loneliness, as well as a change in the quality of friendships.  |
|                                    | Reasons for change           | The participants gave possible reasons for this change, including changes in how friends see them now, cognitive difficulties impacting on their ability to communicate effectively, and the natural decline of friendships when getting older. The most prevalent reason given was the physical disabilities preventing them from joining in pre-injury activities with their friends. |
|                                    | Fortified friendships        | For some of the participants there appeared to be an actual strengthening of some key friendships that they had retained from before the injury.  |
| Nature and Function of Friendships | What type of friend are you? | There was a tendency for the participants to describe their friendships in terms of different categories, e.g. work friends, new friends and school friends. Key friendships that had survived the brain injury had generally been formed at school.  |
|                                    | What are friends for?        | The participants offered descriptions as to what they got out of friendships. There were mentions of 'having a laugh', enjoying shared activities and 'being there' for one and other.  |
| Emotional and Coping Responses     | Emotional responses          | There appeared to be anger towards those former friends whose friendship had been lost following the injury, along with frustration. For two of the participants who were still at school when they had their injury, there was an overwhelming sense of sadness and isolation  |

## Friendships Following Brain Injury

---

|                                     |  |   |
|-------------------------------------|--|---|
|                                     | Coping Responses                                 | over the loss of their friendships during this period.<br>The participants described a sense of resignation and a feeling that they just had to get on with life despite what had happened. |
| Forming and Maintaining Friendships | Maintaining old and establishing new friendships | For the participants, it appeared that shared activities or interests were the best way to maintain old friendships and establish new ones.   |
|                                     | The shared experience as a basis for friendship  | The majority of the participants only established new friendships with other persons with brain injury. Having a shared experience of injury was a basis for friendships.                   |

---

**Conclusions.** The experience of loss and change occurred for the majority of the participants, with the exception of one or two key friendships being sustained. There were a variety of reasons posed for these changes; however a clear finding was the importance of shared activities or interests. It was highlighted as a reason why friendships were lost, why some friendships survived, and why participants were able to establish some new friendships. In terms of working with person with brain injury, the results suggest that, for young men at least, it may be important to support the person to identify and engage in interests and activities that they can share with existing and new friends. At times, they may need help to overcome cognitive, physical and other disabilities so that they can engage in these activities as fully as they can. This may require rehabilitation services to involve friends of the person with the brain injury more fully in the rehabilitation process. Friends may need educating about the effects of brain injury; advice about dealing with the effects of cognitive difficulties on friendship-related activities and interactions; and support in thinking about how they help maintain the friendship through, amongst other things, shared activity.

## Appendix A: Critical Appraisal Skills Programme (CASP) Tool

### Screening questions

---

- 1 Was there a clear statement of the aims of the research?

*Consider:*

- *what the goal of the research was*
  - *why it is important*
  - *its relevance*
- 

- 2 Is a qualitative methodology appropriate?

*Consider:*

- *if the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants*
- 

### Detailed questions

---

#### *Appropriate research design*

- 3 Was the research design appropriate to address the aims of the research? Write comments here

*Consider:*

- *if the researcher has justified the research design (e.g. have they discussed how they decided which methods to use?)*
- 

#### *Sampling*

- 4 Was the recruitment strategy appropriate to the aims of the research? Write comments here

*Consider:*

- *if the researcher has explained how the participants were selected*
  - *if they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study*
  - *if there are any discussions around recruitment (e.g. why some people chose not to take part)*
- 

#### *Data collection*

- 5 Were the data collected in a way that addressed the research issue? Write comments here

*Consider:*

- *if the setting for data collection was justified*
  - *if it is clear how data were collected (e.g. focus group, semi-structured interview etc)*
  - *if the researcher has justified the methods chosen*
  - *if the researcher has made the methods*
-



## Appendices

*explicit (e.g. for interview method, is there an indication of how interviews were conducted, did they use a topic guide?)*  
– *if methods were modified during the study. If so, has the researcher explained how and why?*  
– *if the form of data is clear (e.g. tape recordings, video material, notes etc)*  
– *if the researcher has discussed saturation of data*

---

### Reflexivity

- 6 Has the relationship between researcher and participants been adequately considered? Write comments here
- Consider whether it is clear:*  
– *if the researcher critically examined their own role, potential bias and influence during:*
- *formulation of research questions*  
– *data collection, including sample recruitment and choice of location*
- *how the researcher responded to events during the study and whether they considered the implications of any changes in the research design*
- 

### Ethical Issues

- 7 Have ethical issues been taken into consideration? Write comments here
- Consider:*  
– *if there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained*
- *if the researcher has discussed issues raised by the study (e. g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)*
- *if approval has been sought from the ethics committee*
- 

### Data Analysis

- 8 Was the data analysis sufficiently rigorous? Write comments here
-

## Appendices

### *Consider:*

- *if there is an in-depth description of the analysis process*
  - *if thematic analysis is used. If so, is it clear how the categories/themes were derived from the data?*
  - *whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process*
  - *if sufficient data are presented to support the findings*
  - *to what extent contradictory data are taken into account*
  - *whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation*
- 

### *Findings*

- 9 Is there a clear statement of findings? Write comments here

### *Consider:*

- *if the findings are explicit*
  - *if there is adequate discussion of the evidence both for and against the researcher's arguments*
  - *if the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst.)*
  - *if the findings are discussed in relation to the original research questions*
- 

### *Value of the research*

- 10 How valuable is the research? Write comments here

### *Consider:*

- *if the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature?)*
  - *if they identify new areas where research is necessary*
  - *if the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used*
-

**Appendix B: Participant Information Sheet**

**PARTICIPANT INFORMATION SHEET**

***Title of Project:*** An Interpretative Phenomenological Analysis  
of Friendships Following Traumatic Brain Injury

***Researchers:*** Nicola Baker and Gerry Riley

My name is Nicola Baker and I am a student at the University of Birmingham. I am conducting a research project that is asking people who have suffered a traumatic brain injury about their past and present friendships. Some people find that after brain injury their friendships change. I would like to know more about these changes.

• **What is the purpose of this research?**

Through knowing more about what happens to friendships after brain injury, researchers will hopefully be able to develop better ways of helping people with a brain injury to maintain old friendships and establish new ones.

• **Why have I been invited to take part?**

You have been invited to take part because you have sustained a traumatic brain injury in the past.

- **What will happen to me if I agree to take part?**

If you agree to take part you will be interviewed by myself. The interviews will last for around an hour and I will be asking questions about your friendships both past and present. You have the option to bring in photographs of your friends if it will help you to explain who people are.

The interview may ask some sensitive questions that may be upsetting for some people. If at any point during the interview you find it too difficult to continue or do not wish to answer a particular question, you have the right to do so. Also if I feel at any time that you are becoming distressed I will stop the interview.

- **What will happen if I do not want to carry on with the study?**

You can stop at any time without giving me an explanation. At the end of the interview, I will ask you whether you are happy for me still to include your interview in the research. If you want to withdraw your whole interview, or part of it, I will make sure that it is not included in the study. After the interview, you will have a further 7 days during which you can contact me if you decide later than you want to withdraw your interview.

Withdrawing from the study will not affect the services you receive in any way.

- **Expenses and payments**

It is hoped that the interviews will be held at the service you currently attend. However, if you have to make an additional journey to take part in the interviews the cost of your transport will be covered by the University of Birmingham.

- **What will happen to the information you give me?**

An audio-recording will be made of the interview. As soon as possible after the interview, I will make a copy of the recording and put this on a password-protected computer account at the University. I will then destroy the recording on the audio-recorder. I will then type out a written account of what we both said in the interview. I will not use your name in this written account, or any other personal information that might allow you to be identified. This written account will also be stored on a password-protected computer account at the University. The consent form and a record of your name and contact details will be kept in locked filing cabinets at the University.

No one will see any of this information apart from myself, my supervisor and anyone appointed by the University to check

that the research is being carried out properly. However, if you reveal information that indicates that you or another person is at significant risk of injury or harm, I am obliged to pass on this information to relevant authorities concerned with the protection of yourself and others.

I will write up the results of the research as part of the thesis I need to submit for my degree. The results may also be written up for publication in an academic journal, and presented at an academic conference. These accounts of the research may contain direct quotations from your interview, but at no point whatsoever will your name or other identifying information be given. Your confidentiality is guaranteed.

I will also write a brief summary of the results that I will send you and the other participants. I will also send a copy of this to the service where you were attending at the time you took part in the research. I also intend to return to this service and present the results in a talk to people within the service. This summary and the talk will not contain any quotations from your interview or any other information that might identify you. No one will know from this summary or the talk that you took part in the study.

- **What happens if I have any further concerns?**

If you have any further concerns you can contact either myself on the details below, my research supervisor (see below), or you can discuss it further with a member of staff at the centre you attend.

### **Support Services**

Headway            0808 800 22 44            [www.headway.org.uk](http://www.headway.org.uk)

Samaritans        08457 90 90 90            [www.samaritans.org](http://www.samaritans.org)

Or contact your GP

**Appendix C: Screening Form**

**SCREENING ASSESSMENT FORM**

**Participant Number:** \_\_\_\_\_

**Demographics**

Male  Female

Age \_\_\_\_\_

Ethnicity \_\_\_\_\_

Language \_\_\_\_\_

**Information About Injury**

Injury classification: mild  moderate  severe

Acquired  Traumatic

How was the injury caused? \_\_\_\_\_

Time since injury (> 1 year) \_\_\_\_\_

Do they have capacity to give informed consent? Yes  No

Do they have any existing mental health difficulties? Yes  No

Do they misuse any substances (drugs/alcohol)? Yes  No

Do they have a learning disability? Yes  No

**Questions**

Could you tell me what you will have to do if you agree to take part?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Are you able to tell me a bit about how your injury has affected you? (Give an example of how something has changed /Tell a story about what it was like before the injury? What usually happens now?)

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Do you have any photos of old friends or friends you had around the time of your brain injury? And if you willing to take part in the project would you like to bring them along with you to the interview?



**Appendix D: Consent Form**

Research site: .....

Participant Identification Number:.....

**CONSENT FORM**

*Title of Project:* An Interpretative Phenomenological Analysis of Friendships Following Traumatic Brain Injury

*Researcher:* Nicola Baker

Please initial box

- 1. I confirm that I have understood the information sheet dated 17/10/12 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time during the research interview, without giving any reason, without my own social care or legal rights being affected.
- 3. I understand that the research interview will be audio-recorded
- 4. I understand that following the research interview I will have seven days for reflection. The researcher will then contact me at which point I may withdraw my interview entirely or in part, without giving any reason, without my social care or legal rights being affected.
- 5. I understand that the data collected during this study will be looked at by the researcher and relevant others at the University of Birmingham to ensure that the analysis is a fair and reasonable representation of the data. Parts of the data may also be made available to the staff team responsible for my care but only if any previously undisclosed issues of risk to me or others should be disclosed.
- 6. I understand that direct quotes from my interview may be published in any write-up of the data, but that my name will not be attributed to any such quotes and that I will not be identifiable by my comments.
- 7. I agree to take part in the above study.

.....  
Name of participant                      Date                      Signature

.....  
Name of researcher                      Date                      Signature

## Appendix E: Interview Schedule

### Interview Schedule

#### Opening

Interview will open with asking whether they have brought any photos of their friends with them.

Any photos will be discussed in terms of who's who and a pictorial 'timeline' will be created. If they have not brought any photos the 'timeline' will be generated from their memory.

The timeline will help to establish pre and post injury friends and the current status of these friendships. They will also be used as a way of illustrating the questions.

All of the questions will be written down on a piece of paper so that they can refer to it if needed.

#### Questions

- Experiences of pre-morbid friendships that are still ongoing
  - If we think about your old friends from before your injury that are still in your life such as.....?
  - How often do you see your friends (is that too much or too little)?
  - What do you do together? Are you satisfied with what you do together?
  - What do you enjoy about each other's company?
  - Do you feel that there are differences in this friendship before and after your injury?  
How do you feel about these differences?
  - Have you experienced any difficulty maintaining this friendship?  
Why do you think that this friendship is still there, but other friendships have been lost?
- Experiences of pre-morbid friendships that have ended
  - Why do you think this friendship ended?
  - How do you feel about this?
- Experiences of any unsuccessful attempts to make new friendships since the TBI
  - What happened?
  - Why didn't it work out?
- Experiences of successful attempts to form new friendships
  - Nature of relationship: How often do you see them? What do you do together?  
What do you enjoy about each other's company?
  - What was the difference between this and the friendship that didn't work out?