# Doctoral Thesis

# Masculine Identity After Traumatic Brain Injury

Ruth M MacQueen BA (Hons)

Primary Supervisor Dr Paul Fisher Secondary Supervisor Dr Deirdre Williams

Submitted on 1<sup>st</sup> March 2016 in partial fulfilment of the Doctorate in Clinical Psychology, Norwich Medical School University of East Anglia

Word Count 37493

© This copy of the thesis has been supplied on condition that anyone who consults it is understood to recognise that its copyright rests with the author and that use of any information derived there from must be in accordance with current UK Copyright Law. In addition, any quotation or extract must include full attribution

#### Abstract

**Background:** Men are twice as likely to experience a Traumatic Brain Injury (TBI) as women suggesting that aspects of masculine identity play an important role in how people acquire their brain injury. Research also suggests that masculine identity influences how people manage their health experiences. Masculine identity may therefore be an important consideration for neuropsychological therapy and rehabilitation more generally particularly because part of the process of rehabilitation concerns helping individuals with their sense of self. This research aimed to explore men's experiences of masculine identity following TBI.

**Method:** Individual interviews were conducted with 10 men age 21-67 who had experienced a TBI who were living in the community. Interpretative phenomenological analysis was used to consider lived experiences and to explore the meaning of the TBI experience in relation to masculine identity.

**Results:** Three superordinate themes emerged from the analysis:

*Doing life and relationships differently*: Participants identified changes in aspects of their role as a man within relationships, family, occupation and social groups.

Self-perceptions and the perceived view of others: Self-perceptions and others perceptions of the ability to perform roles as a man resulted in experiences of shame and loss of self-confidence. The invisibility of the injury appeared to both accentuate and protect from the experience of shame.

*Managing the impact:* Participants identified ways in which they thought about their lives and reformulated their behaviour in order to protect their identity as a man.

**Conclusions**: The findings suggest that men experience changes in masculine identity following TBI, particularly when ideals about independence and roles were challenged. The findings highlight how masculine identity may be a valuable aspect of self in considering threats to and reconstruction of self-identity after TBI. Aspects of gender identity should be considered in order to promote engagement, support adjustment and achieve meaningful outcomes in rehabilitation.

# Table of Contents

| Abstrac  | t                          |  | 1  |  |
|----------|----------------------------|--|----|--|
| Table of | f Con                      | itents   | 2  |  |
| Acknow   | vledg                      | ments  | 5  |  |
| Introdu  | ction.                     |  | 6  |  |
| 1.1      | Ove                        | erview   | 6  |  |
| 1.2      | Tra                        | Traumatic Brain Injury   |    |  |
| 1.2      | 2.1                        | TBI and identity.  | 8  |  |
| 1.2      | 2.2                        | TBI and adjustment   | 12 |  |
| 1.3      | Ger                        | nder Identity and Expression: How do we learn and 'do' gender? | 14 |  |
| 1.3      | 3.1                        | Masculine identities.  | 17 |  |
| 1.3      | 3.2                        | Masculinity and health.  |    |  |
| 1.3      | 3.3                        | Masculine identity and adjustment.                             |    |  |
| 1.4      | Mas                        | sculine Identity and Traumatic Brain Injury                    | 25 |  |
| 1.4      | 1.1                        | Gender differences and TBI                                     |    |  |
| 1.4      | 1.2                        | The need to focus on masculine identity                        |    |  |
| 1.4      | 1.3                        | Critique of existing qualitative research.                     |    |  |
| 1.5      | Sun                        | nmary of Chapter   |    |  |
| 1.6      | Rati                       | ionale for Current Study                                       |    |  |
| 1.7      | Stu                        | dy Aims  |    |  |
| Method   | ology                      | y  |    |  |
| 2.1      | Ove                        | erview   |    |  |
| 2.2      | Qua                        | alitative Methodology  |    |  |
| 2.3      | Inte                       | prpretative Phenomenological Analysis                          |    |  |
| 2.3      | 3.1                        | Epistemological position                                       |    |  |
| 2.3      | 3.2                        | Philosophical underpinnings of IPA.                            |    |  |
| 2.3      | 3.3                        | Rationale for IPA methodology.                                 |    |  |
| 2.4      | Res                        | earch Procedure  | 43 |  |
| 2.4      | 1.1                        | Inclusion criteria.  | 44 |  |
| 2.4.2    |                            | Recruitment process  | 45 |  |
| 2.4      | 1.3                        | Participants   | 46 |  |
| 2.4      | 1.4                        | Topic guide  |    |  |
| 2.4      | 1.5                        | Interview procedure.   | 49 |  |
| 2.5      | The                        | Analytic Procedure   | 51 |  |
| 2.5      | 5.1                        | Reflexivity throughout analysis.                               | 54 |  |
| 2.6      | Qua                        | ality of Research  | 55 |  |
| 2.7      | 2.7 Ethical Considerations |  | 57 |  |

| 2.7.1         | Informed consent, coercion and deception.         | 58  |  |  |  |
|---------------|---|-----|--|--|--|
| 2.7.2         | Confidentiality.                                  | 58  |  |  |  |
| 2.7.3         | Managing risk and distress                        | 59  |  |  |  |
| Analysis      |   | 61  |  |  |  |
| 3.1 Ove       | erview of Chapter                                 | 61  |  |  |  |
| 3.2 Sun       | nmary of Findings                                 | 61  |  |  |  |
| 3.3 Doi       | ng life and Relationships Differently             | 61  |  |  |  |
| 3.3.1         | Loss of individual agency and independence.       | 63  |  |  |  |
| 3.3.2         | Roles and relationships.                          | 68  |  |  |  |
| 3.4 Self      | f-perceptions and the Perceived View of Others    | 77  |  |  |  |
| 3.4.1         | The invisible nature of the injury.               | 78  |  |  |  |
| 3.4.2         | Concern about being judged as less of a man       | 81  |  |  |  |
| 3.4.3         | Shame and loss of self-confidence                 | 85  |  |  |  |
| 3.4.4         | Not feeling safe, feeling vulnerable              |     |  |  |  |
| 3.5 Ma        | naging the Impact as a Man                        | 91  |  |  |  |
| 3.5.1         | Coping with adjustments                           | 92  |  |  |  |
| 3.5.2         | Re-evaluating life and values                     | 97  |  |  |  |
| Discussion    |   | 103 |  |  |  |
| 4.1 Ove       | erview of Discussion                              | 103 |  |  |  |
| 4.2 Rev       | view of Findings and Existing Literature          | 103 |  |  |  |
| 4.2.1         | A discrepancy between ideals and lived experience | 104 |  |  |  |
| 4.2.2         | Loss of ability and fulfilling masculine ideals   | 105 |  |  |  |
| 4.2.3         | Participation in roles as a man.                  | 107 |  |  |  |
| 4.2.4         | The shame of loss of identity as a man            | 112 |  |  |  |
| 4.2.5         | Protecting Masculine Identity.                    | 115 |  |  |  |
| 4.3 Clin      | nical and Rehabilitation Implications             | 120 |  |  |  |
| 4.3.1         | Engagement with the therapy team                  | 120 |  |  |  |
| 4.3.2         | Considering narratives in psychological therapy   | 121 |  |  |  |
| 4.3.3         | Participation in meaningful occupation and roles  | 124 |  |  |  |
| 4.4 Eva       | luation of Strengths and Limitations              | 125 |  |  |  |
| 4.4.1         | Recruitment                                       | 125 |  |  |  |
| 4.4.2         | Interviews  | 126 |  |  |  |
| 4.4.3         | Methodology                                       | 127 |  |  |  |
| 4.5 Imp       | blications for Future Research                    | 128 |  |  |  |
| 4.6 Cor       | nclusions   | 130 |  |  |  |
| References    |   | 133 |  |  |  |
| Appendices157 |   |     |  |  |  |

# List of Tables, Figures and Reflections

# Tables

| Table 1             | Contextual Information About Participants 47  |  |  |  |  |  |
|---------------------|---|--|--|--|--|--|
| Table 2             | Prevalence of Themes Across Data 62   |  |  |  |  |  |
| Figures             |   |  |  |  |  |  |
| Figure 1            | Components and Processes of Self-Identity Threatened by Traumatic Brain Injury <b>9</b> |  |  |  |  |  |
| Figure 2            | The Hermeneutic Cycle 42  |  |  |  |  |  |
| Reflections         |   |  |  |  |  |  |
| <b>Reflection 1</b> | Reflecting on my Starting Position 36   |  |  |  |  |  |
| <b>Reflection 2</b> | Personal Impact on Methodology 60   |  |  |  |  |  |
| <b>Reflection 3</b> | Personal Reflection on Analysis 102   |  |  |  |  |  |
| <b>Reflection 4</b> | Reflection on ending position 132   |  |  |  |  |  |

# List of Appendices

- Appendix A Clinician Information Sheet 157
- Appendix B Participant Information Sheet 158
- Appendix C Consent to Share Information Form 161
- Appendix D Topic Guide 162
- Appendix E Consent to Participate Form 164
- Appendix F Debrief Sheet 165
- Appendix G Example of Reflective Diary: Excerpt Following Interview 166
- Appendix H Example of Initial Analysis: Coding and Emergent themes 167
- Appendix I Example of Master Themes for an Individual 170
- Appendix J Summary of Themes 171
- Appendix K Example of Reflective Diary: Excerpt from Analysis 174
- Appendix L Criteria for Good IPA 175
- Appendix M COREQ (COnsolidated criteria for REporting Qualitative research) Checklist 176
- Appendix N Ethical Approval Documents 178

# Acknowledgments

Firstly, I would like to thank all the participants who took the time to meet with me and share their personal experiences. I hope that I have managed to represent your experiences accurately.

I greatly appreciate the work of all clinicians who reviewed their caseloads and recruited participants. I hope that the findings I share with you are meaningful.

I would like to thank my supervisors who have given so much time and thought to the project. Thank you to Dr Paul Fisher, for your continuous support, guidance and enthusiasm throughout this process. Thank you also to Dr Deirdre Williams, for sharing your valuable thoughts, particularly in developing and interpreting the analysis.

A special thank you to my parents for their endless encouragement and support. To my friends, thank you for always being there and for keeping me strong.

#### Introduction

#### 1.1 Overview

This chapter provides epidemiological information about Traumatic Brain Injury (TBI) and an overview of the existing literature on the impact on self-identity and adjustment. Theoretical perspectives of masculine identity are introduced and consideration is given to how masculine identity has been researched within health literature. Focus is given to the phenomenology of masculine identity in relation to adjustment to changes in health. The relationship between masculine identity and TBI is then considered in relation to clinical relevance and a critique of existing literature. Building on this, a rationale for the current research is presented followed by the aims of the study.

#### **1.2 Traumatic Brain Injury**

TBI occurs when the head is hit by an external mechanical force. This causes the brain to be displaced inside the skull and it can be injured as it makes contact with structures within the skull. The acceleration and deceleration of the force may also cause damage to tissues and vessels of the brain (World Health Organisation [WHO], 2006). The severity of the injury is classified as mild, moderate or severe which is primarily based on the Glasgow Coma Scale score (Teasdale & Jennet, 1974). Individuals with a more severe injury tend to have longer periods of unconsciousness, or post traumatic amnesia.

Head injury (a proxy indicatory of TBI) is the most common cause of death and disability of people age up to 40 years in the UK (National Institute for Clinical Excellence [NICE] 2014). The WHO predicts that TBI will surpass many diseases and will be a major cause of death and disability globally by 2020 (WHO, 2006). Peaks of incidence of brain

injury occur at under 5 years old, between 15-24 years and above age 75 years (United Kingdom Acquired Brain Injury Forum, [ABIF] 2016).

Prevalence in men is two times higher than in women (Key Facts and Statistics, Headway, 2014). A key reason cited for this ratio is that socialisation to masculine ideals encourages risk-taking behaviour in men (Javouhey, Guerin, & Chiron, 2006). This is reflected in causes of TBI as men have more injuries from falls, sporting activities, military service and vehicle collisions at higher speeds (Cassidy et al., 2004; Javouhey et al., 2006; Myeres, 2012; Turner & McClure, 2003).

There were 162,533 admissions to hospitals in England and Wales due to head injury (a proxy indicatory for TBI) in the year 2013-2014 (Headway, 2016). The implications of economic cost of injury include not only hospital admission and any longer health and social care costs, but also lost employment and social security to the state (ABIF, 2016).

The effects of the injury depend on the severity and location of injury as well as the individual's personal context, both pre and post injury. TBI can have a cognitive, emotional, behavioural, social and physical impact which is unique to the individual. Examples of cognitive difficulties experienced include memory difficulties, impairments with executive functioning skills such as planning and regulation, and a lack of insight or awareness into changes in functioning. Receptive and expressive communication difficulties as well as changes to the sensory system can have an impact on an individual's perceptions and experiences of being in the world. Physical difficulties which occur may be a direct result of brain injury, or as a result for associated injury such as spinal cord injury. The consequences of these difficulties can result in changes in functioning and lifestyle. Individuals may experience restrictions in activity and financial strain, as well as changes in social roles and relationships (Segal, 2010; Tyerman, 2009).

Ruth MacQueen 2016

#### **1.2.1** TBI and identity.

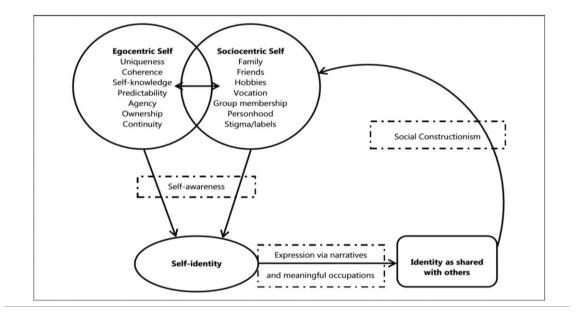
Given the disruptive potential of the consequences of TBI, the day-to-day lived experience of being in the world can be altered for the individual. This disruption has led to consideration of how brain injury impacts on a person's sense of self.

Tyerman and Humphrey (1984) investigated changes in self-concept following TBI and found that individuals tended to rate their pre injury and future self as similar, but rate their current self as different. Evidence consistently demonstrates that following TBI, people experience poor self-concept (Vickery, Gontkovsky & Caroselli, 2005) and that changes to the self tend to be viewed negatively in comparison to the pre-injury self (Carrol & Coetzer, 2011). Ideas about a person's own identity, or sense of self is developed using selfknowledge, interpersonal interaction and activity, all of which may be disrupted by the impact of TBI (Onsworth, 2014).

Qualitative research has provided further understanding about individuals lived experiences of TBI. In a meta-synthesis of qualitative research following TBI Levack, Kayes, & Fadyl (2010) identified eight themes which were prominent in the lived experience of TBI: 1) mind/ body disconnect; 2) disconnect with pre-injury identity; 3) social disconnect; 4) emotional sequelae; 5) internal and external resources; 6) reconstruction of self-identity; 7) reconstruction of a place in the world; 8) reconstruction of personhood. The meta-synthesis concludes that there is a "wealth of research" (p. 996) on the lived experience after TBI. Specifically, the research consistently demonstrates that individuals experience a changed sense of personal identity after TBI and that concept of identity is evident throughout the experience of recovery and outcome. Given the centrality of identity to the experience, it is therefore important to develop a deeper understanding of it in order to support individuals in the process of change.

Thomas, Levack, and Taylor (2014) developed a framework which aimed to draw

together theories present in the literature to explain change of sense of self after TBI. The framework, illustrated in Figure 1, draws on five categories of different theories within the literature including a) self-identity as egocentric self; (b) self-identity as memory; (c) self-identity as sociocentric self and social identity theory; (d) self-identity as meaningful occupation; and (e) self-identity as narrative. This framework provides a way in which to consider the individuality of the experience. In particular, the model suggests that the weighting of various components will differ between individuals, therefore emphasising the importance of a person's context and how the context can influence the construction and meaning a person places on different aspects of their identity.



*Figure 1. Self-reflective meaning making: Components and processes of self-identity threatened by traumatic brain injury (Thomas et al., 2014.)* 

The egocentric self component draws on the importance of continuity of self through autobiographical memory and an integrated sense of one's own past, present and the future which can be disrupted in TBI (Ownsworth 2014). Following TBI, this may be disrupted by periods of amnesia or unconsciousness and individuals may use others to co-construct a continuous narrative (Cloute, Mitchell, & Yates, 2008). In addition, a narrative may be

disrupted by encountering difficulties within an environment, or neuropsychological testing as both may contradict a person's perception of how they function (Gelech & Desjardins, 2011). Therefore a person's egocentric identity may be influenced by these experiences.

The framework suggests an interaction between the egocentric self and the sociocentric self. The sociocentric component represents how social identities and social groups, such as gender, influence and construct identity (Tajfel & Turner, 1979; Jetten, Haslam & Haslam, 2012). The current study considers that gender is one aspect of self-identity through which a person interacts with the social world (Bussey & Bandura, 1999). Given the multiple identities within the egocentric and socio-centric self and the dynamic interaction between them, the self is considered to be plural in nature. Gelech and Desjardins (2011) identified that renegotiating social identity benefited from plural identities, and illustrate an example of a participant who could not return to previous employment therefore "devoted himself to fatherhood" (p. 67). The pluralistic nature of identity is therefore suggested to enable flexibility and development of identities within different contexts and situations.

The framework also proposes that identities are expressed through meaningful occupations and creating narratives. This is suggested to be the process by which meaning and doing are linked. Similarly, Gracey et al.'s (2008) qualitative analysis of group exercises emphasised how participants linked "meaning and doing" (p. 642). Their findings reported a theme described as "experience of self in the world" and the authors highlight how the meaning of activity within social and relational contexts is an important aspect of rehabilitation for clients as this reinforces identity.

In an exploration of how individuals revised their self-narratives after brain injury, Nochi (2000) identified five themes which illustrate how narratives are an expression of selfidentity. The themes included: *'The self better than others'* which was primarily a

Ruth MacQueen 2016

comparison of others perceived as worse off; '*the grown self*' where individuals felt that TBI had contributed positively to their self; '*the recovering self*' in which participants talked about returning to aspects of life as they had been pre-injury; '*the self here and now*' where participants had an acceptance of themselves and of individual differences rather than drawing comparisons. The final theme was '*the protesting self*' in which participants objected to societal perceptions and structures which they had experienced due to the consequences of TBI. These themes highlight the dynamic relationship of the self in the social world and how narratives are constructed in relation to social contexts. The themes identified by Nochi (2000) also illustrate how meaningful occupation can be expressed through different narratives as Thomas et al.'s (2014) framework suggests.

The 'identity as shared with others' component of the framework considers how individuals may differ in how they see themselves compared to how others see them. This includes labelling and stereotyping people with a brain injury rather than recognising the unique individuality. The socially constructed meanings of self then feedback into the developing concept of socicentric self. This dynamic process is considered differently in models such as Douglas' (2013) model of self-concept after severe TBI, where the focus is predominantly on how self-knowledge and self-evaluations form identity. Although this model does not specifically consider the social world of an individual, it supports the idea that self-narratives are developed through social comparisons and that conceptualising self is a dynamic process.

The cyclical and dynamic nature of Thomas et al.'s (2014) model clearly highlights the complexity of the interactions between the self and the social context in the construction of identity after TBI. This interaction has been considered within TBI research in relation to adjustment. For example Muenchberger et al.'s (2008) use of life story interviewing highlighted how social norms constructed expectations about relationship status as one

Ruth MacQueen 2016

participant expresses "everyone's got to have a girl...you feel really inferior without a partner...not good about yourself, frustrated, annoyed, I'd see the other blokes with lovely ladies marching off somewhere" (p. 986). However, this research also identifies how participants valued their own sense of self more than social expectations and that they questioned social norms. The authors suggest that the process of moving between valuing social expectations and sense of self is progressed by the individual making key decisions as a result of the tension between a person's need to redefine themselves, or to expand themselves because of having a sense of difference, reliance on others and lack of continuous sense of self.

This demonstrates the multiple, dynamic and complex nature of identities and also highlights the individual nature of the meanings or importance placed on different social norms. Heller, Mukherjee, Levin, and Reis (2006) consider how plurality of selves may aid adjustment. They suggest that in order to facilitate integration of selves which are unique to the individual in rehabilitation it is important for possible selves to be explored in relation to strengths within the context of the individual.

#### 1.2.2 TBI and adjustment.

The research on identity after TBI has resulted from acknowledgement of the extensive impact of changes on a person's life due to the effects of TBI. The process of adjustment is a way in which individuals endeavour to make sense of their experiences and restore self-esteem through gaining a sense of control (Ownsworth, 2014). Adjusting to a different way of being, and a change in self- identity is a focus for psychological interventions (Tyerman, 2009).

Emotional adjustment after TBI is complex and research consistently demonstrates

Ruth MacQueen 2016

increased risk of negative psychological outcomes following TBI. For example, the prevalence of depression is higher than in the general population (Silver, Kramer, Greenwald & Weissman, 2001). An example of the increasing complexity of these outcomes is that within a veteran population, TBI predicted suicide even when psychiatric comorbidity was accounted for (Brenner, Ignacio, & Blow, 2011). Research suggests that changes to sense of self is central to emotional adjustment following TBI. For example, self-concept has been found to be a mediating variable in the adjustment process (Doering, Conrad, Rief, & Exner, 2011) and research suggests that there is a positive association between perceived changes in identity with depression and grief (Carroll & Coezter, 2011).

In contrast, there is a growing literature around the experience of positive changes as a result of trauma or adversity which is conceptualized as post traumatic growth (O'Leary & Ickovics, 1995). Post traumatic growth has been identified within the experiences of life threatening physical illnesses such as cancer and HIV (Grealy & Heffron, 2009). Research in acquired brain injury, which included TBI, has identified aspects of post traumatic growth following brain injury ( Jones & Curtin, 2011; McGrath, 2004; McGrath & Linley, 2006). Research has identified that the experience of TBI includes narratives of positive growth including identity expansion through personal goals, looking to the future, a desire to give something back and a new sense of self (Freeman, Adams, & Ashworth, 2014; Muenchberger, Kendall, & Neal, 2008). Given these findings, it is important to understand identity after traumatic brain injury not only in relation to the difficulties in adjusting to changes, but also in relation to the development of positive narratives of aspects of identity.

The research discussed illustrates some of the complex factors involved for individuals in making sense of their experiences after TBI in relation to their identity. The literature consistently highlights that identity is a highly important consideration in adjustment and rehabilitation after TBI and there is strong support for the focus of

intervention to enable a person to reconnect with the sense of self (Tyerman, 2009; Ylvisaker, Mcpherson, Kayes, & Pellett, 2008).

The current study considers gender identity as an aspect of sense of self which is changed following TBI. Given the centrality of identity in adjustment following TBI, this study specifically considers masculine identity in order to further understand adjustment. In order to develop an understanding of the relationship between masculine identity and TBI, the literature around gender and masculine identity will now be considered.

#### 1.3 Gender Identity and Expression: How do we learn and 'do' gender?

Gender development has been considered by different developmental theories which have placed variable emphasis on biological, social and psychological factors (Buss, 1995; Freud, 1905; Kohlberg, 1966). A key theory is the 'social cognitive theory of gender development' (Bussey & Bandura, 1999). This theory draws on psychological and social factors of gender development and suggests that observation, modelling and reinforcement shape our learning of gender. For example research demonstrates that parents interact differently with male or female children (Wood, Desmarais & Gugula, 2002). As well as parental influences, wider social interactions including peers, school and media reinforce appropriate gender role behaviours (Blakemore, Berenbaum & Liben, 2008).

The social cognitive theory goes beyond a developmental perspective and proposes that the ways in which people enact gender changes across social contexts and in different phases of life. Gender is therefore continually developed throughout a person's life. This theory can therefore be understood to underpin the framework provided by Thomas et al. (2014) as the meaning of gender identity to an individual is considered by both to interact with and be influenced by the social world.

However, Cohen (2009) criticises that a focus on gender as a social science construct is not inclusive enough and supports an integral theory, emphasising that "gender is not determined by biological sex alone. Nor is Gender determined by psychology, culture, or social interaction alone. It is the combined influence of all of these perspectives" (as cited in Poole, 2014 p. 49).

Poole (2014) expands on Cohen's (2009) view and develops an integral gender theory which considers how biological, cultural, social and psychological factors make up the concept of gender. Poole's framework for studying gender highlights that these different domains of gender interact with each other. For example, biological differences between male and female brains and hormones are examples of biological factors which are suggested to have an influence on our behaviour (Baron-Cohen, 2003). The biology of the brain changes following traumatic brain injury and there is evidence that this process is different in males and females. For example, Wagner et al. (2005) found differences in hormone production and their physiological impact after TBI between male and female participants.

This integral model allows for different disciplines including evolutionary psychology to be drawn on in considering the role of sex differences including how social roles may be advantageous for a society (Poole, 2014; Wilber, 2000). Evolutionary perspectives acknowledge that developmental and environmental factors shape the evolution of gender (Wood & Eagly, 2002). For example, evolutionary psychology suggests that behaviours have evolved due to reproductive pressures as men had to compete for women who were invested in their offspring and therefore invested in choosing a mate who would best support any offspring (Geary, 1998). Existing literature suggests that evolution has fostered that the strong survive and the alternative weakness or vulnerability is dangerous (Gough, 2006).

For men, the need to be strong, self-reliant and healthy has been described as being similar to a Neanderthal man and has also been found to be associated with avoiding health professionals (Farrimond, 2012).

The framework also supports that when studying gender, cultural interactions should be considered as gender is influenced by ethics and customs which shape different ways of thinking and talking about gender. Dominant stereotypes and discourses about the expectations of different genders may be particularly challenged as a consequence of TBI. Within western culture, gender has historically been recognised as a binary concept, male or female. However, this is context specific as other cultures differ, such as Native Americans where a third gender is recognised (Fulton & Anderson, 1992). Within this culture, gender was associated with roles within society and the third gender included individuals who had supernatural roles. The current study is situated in the UK and therefore discusses only masculine and feminine genders, reflecting the dominant discourse of gender within the cultural context.

The influence of social systems are also emphasised in the framework as how a person may perform gender roles is associated with gender discourse & stereotypes (Cohen, 2009). As these change over time, the meaning of what it means to be a man or a woman is also altered (Connell & Messerschmidt, 2005). However, the impact of TBI may mean an individual cannot express their gender identity through participation in activities and roles as they did before their injury (Gerschick, 2000). Therefore, the social context in which an individual is situated in should be considered in order to better understand the impact of these changes in relation to gender identity.

Gender identity is considered to be the individual integration of biological, social and cultural factors and is a subjective experience which changes over time and in different contexts (Pattman, Frosh & Phoenix, 2005; Poole, 2014). Gender identity therefore has

individual phenomenology and meaning. For individuals who have experienced TBI, integrating the biological, cultural and social domains in order to reformulate gender identity may therefore be an important part of the experience of changes to self-identity.

#### **1.3.1** Masculine identities.

The current study aims to focus specifically upon masculine identity and therefore further consideration into masculine identity within western culture will be considered in relation to existing literature.

Socially constructed ideals about what it means to be a man have been identified to include providing for and protecting others, physical strength, emotional toughness, self-reliance, competitiveness, risk taking, aggression, and power (Addis & Mahalik, 2003; Connell, 2005). These dominant masculine ideals which men are expected to enact have been conceptualised as hegemonic masculinity, a social constructionist perspective which is dominant within research and academic literature (Connell, 1995, 2005). This theory acknowledges differences in structural relations of power and the multiplicity of gender. Connell proposes that those who meet these ideals are more privileged in society and that other categories in the hierarchy are complicit, marginalised or subordinate. Men who have had a serious injury may not continue to enact masculinity in the ways in which they did prior to injury and societal discourses about brain injury or disability have been considered to conflict with these dominant ideals of masculinity (Shuttleworth, Wedgwood, & Wilson, 2012).

More recently, Connell's theory has been critiqued as being outdated and in response, a theory of "inclusive masculinities" has been developed by Anderson (2009). This theory draws on studies within the highly traditional masculine context of sport. Anderson suggests that younger men were more likely to be dismissive of implicit and explicit rules of

masculinity which came from older people such as sports coaches. Primarily, Anderson's theory focuses on men's attitudes towards homosexuality and he suggests that homophobia is primary to maintaining "orthodox masculinity." His findings are suggested to indicate that a more inclusive and tolerant way of being a man is now dominant because of a reduction in "homohysteria" and that orthodox masculinity has therefore become outdated. However, Anderson's theory relies heavily on men's attitudes towards homosexuality and this means that there is a lack of consideration of other social factors which influence men's understanding of what it means to be a man. Anderson's research has also been critiqued for drawing conclusions only from data gathered from university students, therefore not representing a range of social backgrounds or contexts (Pringle, 2010).

Research which considers attitudes towards masculinity of different social class and in social contexts supports that there are multiple ways of enacting masculinity and there is evidence in the literature to support both theories of masculine identities (McDowell, 2003; Roberts, 2012; Sánchez, Westefeld, Liu, & Vilain, 2010). For example Roberts (2012) researched young working class men who were employed in the retail sector and found that dominant hegemonic ideals were resisted and that what was considered acceptable masculine identity has changed in nature. However, the dominant discourse of hegemonic masculinity was evident as men drew on things which in the past may have been a threat to masculine ideals and also related to it through rejection of it. The social construction of dominant ideals appears to continue to influence interactions. For example, during interviews with boys in London schools, Pattman et al. (2005) found that boys tended to show more hegemonic characteristics such as confidence, assertiveness, anger and boisterous humour in their discussion in a same sex group in contrast than when they were interviewed individually. This supports the idea that social environments construct the learning of the expectations for how men should behave, or enact masculine identity.

The complexity of a structural hierarchy is evidenced by Peters, Ryan and Haslam (2015) who explore occupations which are traditionally masculine and are associated with macho stereotypes including surgeons and military personnel. They described that trainees who perceived themselves as not fitting in with masculine seniors were discouraged from continuing in the professions and discuss how men identified feeling "not man enough to succeed." (p. 636). The research presents evidence that being a man by biological gender is not enough in itself and that there are values within contexts by which a man is evaluated to measure up to succeeding. The research also suggests that within male dominated environments there may be expectations for male gender roles. The complexity of findings in the research highlight that the construction of gender identity through social roles, activity and behaviour is influenced by the social context and expectations associated with being a man. How men enact masculinity in different aspects of their life is therefore influenced by social expectations.

# 1.3.2 Masculinity and health.

Gender differences in the prevalence of health problems suggest that gender is an important influence on health behaviour. Evidence often suggests that men have poorer health outcomes than women. A prominent example is that suicide rates are three times higher in men than women (Office for National Statistics, 2016), making it the biggest killer of men aged 20-45 years (Campaign Against Living Miserably,2016).

Research considering masculinity and health related behaviours has tended to focus on the idea that adherence to masculine ideals can in some ways be harmful to one's health (Courtenay, 2000a; Galdas, Cheater, & Marshall, 2005) and is supported by research which demonstrates a negative relationship with attitudes towards help-seeking (Berger, Levant, McMillan, Kelleher, & Sellers, 2005; Scott, Morison, John & Killian, 2014; Sullivan, 2011).

Smith, Tran and Thompson (2008) draw on the theory of planned behaviour (Ajzen, 1991), a prominent model used to explain health related behaviours, to consider the relationship between traditional masculine ideology and psychological help-seeking. Support was found for a mediational model where attitudes towards psychological help-seeking mediated between traditional masculine ideology and intentions to seek help.

Courtenay (2000b) identified five barriers specific to men's help seeking, including; the need for control and self-reliance; minimising problems and self-resignation; concrete barriers and distrust of caregivers; privacy; and emotional control. Mahlick, Good and Englar-Carson (2003) argue that there is a gender-specific stigma of seeking help for mental health difficulties and De Visser and Smith (2006) propose that there is a need to consider factors beyond attitudes towards help-seeking by exploring how contextual factors and individual beliefs about masculinity and identity influence health-related behaviour.

In a meta-ethnography, Hoy (2012) reviews research on psychological distress and help-seeking experiences of men. The results illustrate six themes within research. Firstly, men expressed discomfort with the language use of mental illness, such as "depression." The most common interpretation made by authors about this discomfort was that it was associated with feminine rather than masculine traits. Secondly, men tended to endorse social rather than biological explanations of distress. The third theme evidenced that the most reported symptom of loneliness and isolation is least discussed within the literature. The review evidences how hegemonic masculinity influences mental health as men talked about how they felt they had to conceal the reality of their emotions and vulnerabilities. The fourth theme of coping found that avoidance was a dominant maladaptive coping strategy. Adaptive coping strategies were considered to have been given less prominence in the literature but the review identified how roles such as father and husband can be protective. The fifth theme of help seeking was dominated by examples of men's concerns about stigma,

primarily other men's judgements of them and being perceived by others as weak. Finally, the sixth theme considers variability in perspectives from men in diverse communities. The results of the meta-ethnography highlights the difficulties and barriers in help seeking, but also demonstrates the complexity of this relationship and critiques that in much of the research consideration to adaptive behaviour has been lacking. Similarly, it is argued that the focus given to explaining negative aspects of men's health has led to 'problematizing masculinity'\_(Wilson, Shuttleworth, Stancliffe, & Parmenter, 2012).

There is evidence that some masculine ideals such as desire for success encourages help-seeking or health promoting behaviour and that therefore masculine identity can aid men's ability to overcome adversity (Good et al., 2006). An example of this is illustrated in research by O'Brien, Hunt, & Hart (2005) who found a common discourse of "a real man puts up with pain and doesn't complain" (Aiden, p507). However, there were exceptions to this discourse where men perceived the threat to their health as compromising their masculinity and they talked about seeking help as a way of preserving masculine identity. In this way, masculine identity facilitated help-seeking behaviour. When men do engage in helpseeking behaviour, masculine identity therefore continues to be influential.

The dominant discourse within the research appears to portray a negative view of the relationship between masculinity and health. However, not all men engage in unhealthy or unhelpful behaviours and it is important to consider this further in order to identify factors which may influence this. There has been a movement to promote the strengths of men and recognise the problems men may face. Wilson et al. (2012) highlight how this movement emphasises the social influences on the problems which men experience are recognised rather than problematizing masculinity (Addis, Mansfield, & Syzdek, 2010).

What is increasingly emphasised within existing research is not that men need to change their attitudes towards seeking help, but that there is a need to better understand the

relationship between masculine identity and help-seeking in order to offer services which can engage men in a way which does not conflict with their identity (Kingerlee, 2012; Russ, Ellam-Dyson, Seager & Barry, 2014; Wilkins, 2013). Russ et al., (2014) found that although gender differences were identified in interactions within coaching sessions, coaches could be ambivalent about this. They argue that coaches, and similar therapeutic professions, need to recognise gender differences rather than have fear of stereotyping. One way of considering this further is suggested by Kingerlee (2012) who proposes how a cognitive behavioural therapy model can be used to understand male distress and how this can be applied in therapy with men. Beyond individual therapy, Wilkins (2013) suggests in order to address the inequalities in men's health there is a need to ensure that policies provide guidance for practice in relation to men's health. For example, Wilkins and Kemple (2011) have produced a document outlining considerations for effective mental health services for men.

Recent campaigns for men's mental health have considered how gender socialisation may influence help-seeking behaviour and have promoted a preventative approach to target dominant ideals or norms which may be unhelpful (Addis & Cohane, 2005). Examples of social marketing approaches such as the Samaritans "Man on the ropes" (2010) and '#mandictionary' (Campaign Against Living Miserably) have aimed to challenge unhelpful stereotypes and beliefs about men and mental health. In addition, the need for gender sensitive therapeutic support and recommendations for implementing this are increasingly promoted (Kingerlee, Precious, Sullivan & Barry, 2014).

#### **1.3.3** Masculine identity and adjustment.

Life events such as changes to health can mean that individuals have to integrate their new lived experiences to their identity and consequently reconstruct their sense of self (Lennon et al., 2014). Gerschick and Miller (1994) suggest that some men continue to rely

on hegemonic masculine ideals for their sense of self, some reformulate these ideals in line with the changes they have experienced, and others reject hegemonic masculinity, formulating an alternative masculinity. Understanding men's experience of this adjustment has been researched in various health conditions including penile cancer (Bullen, Edwards, Marke, & Matthews, 2010), prostate cancer (Ervik & Asplund, 2012), arthritis (Gibbs, 2005), spinal cord injury (Good et al., 2008) and cardiac health (Robertson, Sheikh, & Moore, 2010). These studies demonstrate that masculine ideals can influence how men make sense of health experiences.

In a systematic review of qualitative research, Nolan (2013) considers studies which examine the phenomenology of gender after spinal injury through men's narratives. Three themes were identified in relation to how men experience masculine identity: 1. "Lost masculinity" where spinal cord injury challenges the dominant ideals of masculinity; 2. "fighting back" which suggests that the challenge to identity and the pursuit of return to hegemonic masculinity is often expressed in terms of war, battle and sport, and 3. "beyond hegemony" where men reject the dominant ideals and redefine masculinity and their experience of spinal cord injury. These themes suggest that masculine ideals influenced how men made sense of their changed experiences and illustrate evidence for both hegemonic and inclusive masculinities.

It is suggested that masculinity and disability are identified as being in conflict with each other because of the differing cultural expectations associated with them. This conflict has been explored and identified as resulting in "a dilemma of disabled masculinity" (Shuttleworth et al., 2012). However, the experience of the conflict between masculinity and disability is also affected depending on impairment type, ethnicity, sexuality and socio-

economic background (Shakespeare, 1999). This highlights the complexity and individualised nature of the experience.

In order to expand understanding of this complexity, research has considered how age and life stage may relate to men's experience of masculine identity and adjustment. Research reports that men in young to middle adulthood (pre-retirement age) experience high levels of conflict (Kvigne, Kirkevold, Martinsen, & Bronken, 2014). At this stage, individuals are completing education, developing careers, forming relationships and families and therefore the impact of illness or injury can directly conflict with these social roles and aspects of identity formation (Kirkevold, 2010; Ownsworth, 2014). This highlights that this age group may therefore be at higher risk for experiencing difficulties adjusting to their sense of self. In addition, this research highlights that it is important to consider an individual's context and that there is a complex relationship between identity and adjustment.

The relationship between masculinity and adjustment is complex because neither masculinity nor disability are singular or definable concepts; they have an individual meaning to a person. Research on masculine identity and adjustment tends to focus on physical disabilities or illnesses but it is proposed that this complexity can therefore be better understood by considering the intersections between masculinities and different types of impairment (Shuttleworth et al., 2012; Wilson et al., 2012).

Going beyond physical disability, research has also explored masculine identity in relation to visual impairments in South African males (Joseph & Lindigger, 2007) and also in men who had intellectual disabilities (Wilson et al., 2012). Wilson et al. (2012) considered how masculinity, the environment, and caring roles might interact in relation to the sexual health needs for men who had an intellectual disability. The authors highlight that masculine

identity includes cognitive and physical experiences but that existing theory and research has tended to overlook the cognitive aspect.

The limited research on older age (Smith, Braunack-Mayer, Wittert, & Warin, 2007) and stroke (Kvigne et al., 2014) are examples of research which has considered cognitive difficulties in relation to masculine identity and in particular, highlights how changes to men's independence conflicts with masculine ideals. Through use of a single case study, Kvigne et al. (2014) illustrate how physical and cognitive impairments had an impact on gender roles and relationships. One of the participants, 'John,' identified concerns about his role as a father, for example he had tried to coach his son's football team but this was difficult due to poor memory. He was also not able to take care of his youngest child by himself because of his poor time perception and became more involved in household running which had previously been his wife's focus. These experiences were identified as conflicting with the characteristics of masculinity such as providing for the family, strength and independence.

There is only a small body of research which explores beyond physical health and there is therefore a limited understanding of men's experiences of adjusting to cognitive, emotional or behavioural difficulties, all of which may be a consequence of traumatic brain injury. Researching men's experiences after TBI could therefore contribute to the understanding of the interactions between masculine identity and different aspects of disability.

#### **1.4 Masculine Identity and Traumatic Brain Injury**

This section draws together research about masculine identity and traumatic brain injury. Existing research is considered and areas where further investigation could contribute to the understanding of the complexities of the intersection of masculine identity and TBI are explored.

#### 1.4.1 Gender differences and TBI.

Current research exploring sex differences in outcomes, such as cognitive and functional outcomes demonstrates conflicting evidence (Farace, & Alves, 2000; Ownsworth & McKenna, 2004; Ratcliff et al., 2007; Thompson, McCormik & Kagan, 2006). For example, Renner et al. (2012) used ratings of independence and disability and found that sex did not have an impact on the course and outcome of TBI, but that age and injury severity were significant factors. Contrary to this, Colantonio, Harris, Ratcliff, Chase and Ellis (2010) reported significant differences in difficulties experienced by men and women. The study assessed symptoms which are commonly experienced following brain injury. The checklist includes physical symptoms, cognitive problems and mood difficulties. They found that significantly more men reported difficulties in setting realistic goals, high sex drive and restlessness. Men also reported that sensitivity to noise and experiencing sleep disturbances had a greater impact on daily functioning compared to women. The variability of the findings may suggest that there is a difference in how men and women experience the impact of TBI, even when objective outcome measures do not demonstrate a clear divide. In line with this, Schopp, Shigaki, Johnstone and Kirkpatrick's (2001) exploration of emotional outcomes suggest that outcomes for men and women differed depending on the measure of psychological distress used and conclude that men and women experience psychological distress following TBI in different ways.

Masculine identity has been recognised as playing an important factor in brain injury rehabilitation. Quantitative studies such as Good et al. 2006, Meyers (2012) and Schopp, Good, Barker, Mazurek and Hathaway (2006) have considered how conformity to masculine norms in beliefs, attitudes and behaviours relate to recovery outcomes after traumatic brain injury. For example, Meyers (2012) study suggested that adherence to a traditional masculine gender role had an inverse relationship with community reintegration, relationships and living skills. These relationships tend to have been considered by examining the relationships between factors on scales such as the conformity to masculinity scale (Mahalik et al., 2003) and rehabilitation outcome measures. Existing literature indicates that adherence to masculine ideals can be negatively associated with rehabilitation outcomes in TBI (Meyers, 2012).

Existing research highlights that the impact of brain injury may be experienced differently because of gender identity. However, the methodologies employed provide a very limited understanding as to what this experience is. Quantitative measures, such as standardised questionnaires cannot adequately capture the uniqueness of lived experience whereas a qualitative methodology allows for differences and contextual factors.

In a study about returning to work after TBI, Stergiou-Kita, Mansfield, Sokoloff and Colantonio (2015) employ qualitative methods to gain more phenomenological understanding of this experience through a "gender lens" (p. 4). The findings illustrate that men tended to talk about their experience of returning to work in relation to their work role, the importance of paid work and being a breadwinner in relation to their self-worth and identity as a man. The traditional masculine role of breadwinner is suggested to be particularly salient, even when men did not adhere to other dominant masculine ideals (Dolan, 2014).

Gender differences were also identified in help-seeking behaviour in the process of returning to work as men were less proactive in seeking help, even when they felt that the medical support was not sufficient. In contrast, women looked for further medical advice and opinion. Men also expressed that they avoided sharing difficulties associated with TBI with others in the workplace. The research suggests that the gendered culture of a workplace also impacts the experience. An environment's ability to be nurturing appeared to be a key

influence in the experiences of participants as those which were more traditionally male dominated tended to be experienced as less supportive by men and women.

These studies highlight ways in which gender can influence the experience and outcomes following TBI. However, research which focusses on gender influences following TBI tends to compare women and men and provides limited understanding into the experience of men in order to further understand the relationship between masculine identity and the experience of TBI. Although the impact on identity is well recognised and evidenced within the literature, the research which draws on comparisons does not allow for consideration of the individual nature of identity and experience of TBI. This means that there is limited scope for this research to further the understanding of the intersection between gender and TBI.

#### **1.4.2** The need to focus on masculine identity.

A key reason cited for the higher male: female ratio is that socialisation to masculine ideals encourages risk-taking behaviour in men (Javouhey, Guerin, and Chiron, 2006). Courtenay (2000b) theorises that through the process of socialisation, men are more likely to engage in risky behaviour such as taking more risks when driving and therefore are more likely to be involved in a road traffic accident. In addition, men are more likely to be employed in occupations which increase the risk of experiencing TBI including being in the military (Meyers, 2012). Men may also be more likely to sustain injury playing high impact sport (Hollis et al, 2009).

As dominant ideals and masculine identity may influence a man acquiring a TBI in the first place, it is particularly important to consider how masculine identity is experienced following injury in order to consider the relationship with rehabilitation engagement, the processes of adjustment and outcomes.

The impact of gender in the experience of TBI and rehabilitation was first considered using qualitative research by Gutman and Napier-Klemic (1996). They interviewed two men and two women six times within two months exploring changes in perceived masculinity or femininity, intimate relationships, gender roles and engagement in activities which support gender roles. The research suggested that men experience greater gender role conflict than women and that men tend to rely more on gender-specific activities pre and post injury to define their gender role. Men described their experience of activity engagement in a dichotomous way , such as either succeeding or failing and the researchers suggest that for men, it was important for activity to be at a standard of past injury performance and that failure to meet the standards resulted in feeling like "less of a man" (p. 542). The research suggests that men experience greater gender role conflict than women and that men tend to rely more on gender-specific activities pre and post injury to define their gender role.

Howes, Benton, and Edwards, (2005) aim to explore women's experiences of TBI through in-depth interviews. Four themes are identified: (1) awareness of change (2) emotional reaction (3) the struggle to make sense and (4) adapting and acceptance. The findings of this study are suggested to indicate that women identified a discrepancy between their past, present and potential future selves as they managed a sense of loss. Women talked about their experiences of change in social functioning and the stigma they felt associated with TBI. The authors suggest that anger and anxiety were emotions which were prominent within the interviews. This research supports themes found across TBI literature in relation to adjustment and changes in identity and provides a more in-depth understanding. Although the research enables some exploration of this experience specifically for women through their

recruitment, the study does not appear to specifically ask or explore women's experiences in relation to their identity as a woman.

Similarly, research which has exclusively considered men's experiences of adjusting to changes has used qualitative methodology but appears to neglect identity in relation to gender. Jones and Curtin (2011) specifically focus on experiences of changed domestic roles such as caring and household duties in relation to reformulation of masculine identity. Participants described either rejecting the reformulation of their masculinity, accepting it for the sake of others, or personally valuing their changed masculinity. The findings illustrate the significance of the change of role from breadwinner to a caring role and how men's perceptions of these changes related to their perceptions of quality of life. However, this paper is part of a study on TBI in rural areas, and interview questions do not directly relate to gender. This therefore limits the interpretations about men's lived experiences in relation to their identity as a man.

Men's lived experiences of perceived changes in personal and social identity have also been considered more broadly by Freeman et al. (2014). This study focusses on the emotional experiences of men and the perceived changes of self in relation to their social world. The emotional experiences identified included 'abnormality', 'the hidden nature of brain injury,' 'others treat me different' and 'the old me- new me,' all of which are suggested to contribute to the emotional threats including loss of self, blame, guilt, shame and loss of pride. It was identified that the response to these emotional experiences included selfcriticism, trying to be how others expected and withdrawal. Strategies such as using humour and also differentiating self from injuries were recognised as being a response to the emotional threat. The interviews also revealed the emotional experience of acceptance and participants talked about this in relation to feeling that others treating them the same. This

led to resolution and the response of positive growth including moving on, making the most of life.

In relation to social identity, participants tended to differentiate themselves from the stigma of being in the "brain injured" group which appeared to be socially unfavourable. The individual nature of the injury was one way which enabled men to create this differentiation. However, the individual nature of injures also appeared to highlight that difficulties were a part of them rather than the injury itself which the authors link to the experiencing of shame. The authors draw attention to how shame and disgust are prominent concepts within mental health literature but less so in brain injury literature. The authors suggest further consideration of gender in TBI experience and how men construct their identity following injury. They also highlight that the concept of stigma may be of particular interest in relation to this.

This research highlights that not only does gender influence a person acquiring a traumatic brain injury but that it can also have an impact on how a person experiences the consequences of TBI and the outcomes following their injury. Qualitative research which has explored experiences following TBI in relation to gender has enabled a more in-depth understanding of this experience. Although some specific research considers women's experiences of TBI, existing research about men's experience in relation to masculine identity is limited.

## **1.4.3** Critique of existing qualitative research.

Qualitative methodology aims to expand understanding through focussing on participant's experiences and the meaning of the experience within their personal context (Yardley, 2000). However, a key limitation of the existing literature of men's experiences of TBI is that the meaning of this experience in relation to masculine identity is not directly considered.

The publications of Gutman (1996, 1999) are based on an occupational therapy intervention with four participants, two male and two female. The research tends to draw comparisons between men and women and as such as limited given that comparisons are made in this small sample size. In addition, by focussing on how males and females compared to each other, there is a lack of depth of understanding of the individual's lived experience. Individuals in this research project were living in supported accommodation, thus limiting findings to a specific context, which was not fully integrated in the community or social world. The threat to identity may be particularly salient in periods of transition such as leaving hospital and returning to the pre-injury environment as individuals are faced with changes including living situation and social roles (Ownsworth, 2014) and those living in their pre-injury community may have different experiences (Tyerman, 2009). Therefore the experiences of men within this study may not reflect the challenges faced by men who return to their pre-injury social context and have to manage the changes. The recommendations which are then made by Gutman et al. (1999) are therefore limited in what they can conclude in relation to men's experiences of adjustment following TBI.

Both Freeman et al. (2014) and Jones and Curtin (2011) expand on the existing literature by focussing more on the lived experience of men in relation to adjustment within their individual contexts. Freeman et al.'s (2014) research is situated within a social context as men reintegrate into their social world. However, in both of the studies there does not appear to be a focus on gender in the methodological approach. Specifically, the studies do not appear to explicitly be seeking to gain understanding of men's experiences. Jones and Curtin's (2011) primary focus in their recruitment was rural identity and interview questions appear to be about rural living rather than gender. Similarly, Freeman et al.'s (2014) research

focusses on the social identity of male participants however the study is not introduced to participants as exploring social identity of only men and interview questions do not highlight gender. Consideration into the phenomenology of masculine identity appears to be something which resulted from the findings, rather than being directly investigated in either of these studies.

The limitations in the methodology and analysis of existing research, in particular the lack of direct investigation into the experience of masculine identity limits the understanding about men's lived experiences after TBI. Further exploration may enable a more in-depth understanding of men's individual experiences of masculine identity after TBI and could further contribute to supporting individuals form a sense of identity in rehabilitation.

#### **1.5** Summary of Chapter

TBI can result in significant changes in aspects of functioning and also have an impact on self-identity. The process of adjustment to these changes is complex and requires consideration of the individual's specific context in order to support a person to develop a sense of self.

Men are twice as likely to experience a TBI as women. This suggests that aspects of masculinity play an important role in how people acquire their brain injury. Research also suggests that masculine identity impacts on how people manage the experience of illness.

Masculine identity is a concept which is unique to the individual. Theories of gender and masculinity highlight the complexity of what it means to be a man. The dominant theory within the literature proposes a hierarchical structure where men strive for masculine ideals. The ideals are socially constructed and are therefore dependent on context. Although

research demonstrates evidence for changing perceptions of what it means to be man, there is also evidence which highlights that dominant ideals continue to be referred to.

There are gender differences in the experience of health issues and health behaviour. The majority of research focusses on how men manage adjustment to physical health difficulties. However, there is increasing focus on engaging men in psychological support. In order to promote men's wellbeing, it is important that an understanding of men's experiences of different aspects of wellbeing such as emotional, cognitive, behavioural, social as well as physical are considered.

The experience of TBI may result in changes to all of these aspects of functioning and therefore impact on masculine identity. Masculine identity is therefore an important consideration for adjustment and rehabilitation particularly because part of the process of rehabilitation concerns helping individuals with their sense of self.

#### **1.6 Rationale for Current Study**

The literature consistently highlights that identity is a highly important consideration in the process of adjustment and rehabilitation after TBI (Levack et al., 2010; Thomas et al., 2014). Masculine identity has been evidenced to influence men's experiences of health and there is a drive to provide services which can engage and support men (Wilkins, 2013). Research which considers masculinity and adjusting to health difficulties primarily focuses on physical health. As well as physical functioning, TBI can involve changes in cognitive, behavioural and emotional functioning but there is limited research which explores masculine identity in relation to how men experience these adjustments. Research involving individuals who have experienced TBI can therefore expand understanding of masculine identity and health experiences. It is also important that research considering masculinity and health goes beyond illustrating the negative relationship between masculine identity and health but also considers adaptive behaviour.

Existing research which has explored men's experiences of TBI is limited in the understanding it can provide about masculine identity. Primarily this is due to the methodology of the research, as the focus has been more broadly on experience, and has not explored the meaning of this experience for participants in relation to their identity as a man (Freeman et al., 2014; Gutman & Napier, 1996; Jones & Curtin 2011).

Masculine identity is complex because the meaning and importance of this is individualised. Similarly the experience of TBI is unique to the individual. In considering how these experiences interact with each other, it is therefore important that the design allows for personal perspectives and situating individuals in their particular contexts.

Further research is therefore needed to consider the lived experience in relation to the individual's personal meaning of masculine identity. Through exploring the internal experience of men, this can enable further understanding of how therapeutic approaches can consider masculine identity in supporting adjustment following TBI.

# 1.7 Study Aims

The current study aimed to explore the experience of masculine identity following TBI. In order to do this, men's experiences of day-to-day life were explored by considering how men made sense of their experiences in relation to their identity as a man. The study aimed to consider the clinical implications for rehabilitation in relation to the findings.

## **Reflection 1: Reflecting on my starting position**

It is important that within this research I am aware of my own experiences and assumptions and that I consider how these may influence the research. As a female researcher investigating masculine identity I am aware that I have developed my own beliefs and assumptions about masculine identity. Whilst some of these expectations have come from my own social and cultural context, I have also developed expectations having investigated the literature. Specifically, I have become interested in the concept of hegemonic masculinity. My interest in this idea largely stems from my personal experience including the structured hierarchy of the military and growing up in a rural part of Scotland where traditional male roles were dominant, and social hierarchy dictates that men are more privileged than women, because they are men. I therefore feel that I can recognise dominant ideals and a hierarchy existing within society.

My professional experience of working with men who have a traumatic brain injury was as an assistant psychologist in a rehabilitation ward and outpatient service. I think that my previous clinical experience will influence how I make sense of the existing literature in my current project as I may focus on aspects which I can relate to in my own experience of working in this population. I look forward to aiming to convey others voices in a meaningful way within my own research.

#### Methodology

#### 2.1 Overview

This chapter employed a qualitative design in line with the study aims. This chapter gives a brief introduction to qualitative methodology and presents the rationale for Interpretive Phenomenological Analysis (IPA) as the chosen approach. The epistemological and ontological positions of the research are outlined. A detailed description of the methodological processes and analysis is presented. A discussion of ethical issues is followed by considerations for quality within the research.

## 2.2 Qualitative Methodology

This study aimed to gain an in-depth understanding of the experience of masculine identity for individuals following traumatic brain injury. Given this, a qualitative design was therefore appropriate as qualitative methodology aims to understand and represent the experiences of people and explores complex phenomena (Elliott, Fischer & Rennie, 1999; Tong, Sainsbury & Craig, 2007). It enables understanding of a phenomena through focusing on the participant's experiences and the meaning of the experience within their context (Yardley, 2000). Qualitative research acknowledges that there is an interaction between the researcher and the research and therefore encourages a reflexive approach (Ortlipp, 2008).

There are different approaches to qualitative designs which have different underlying philosophies and methods of analysis. In considering which approach was most appropriate for the current study, the aims of the current study were carefully considered and IPA was selected. A detailed rationale for employing this methodology is outlined in section 2.2.3 below, following an overview of IPA.

#### 2.3 Interpretative Phenomenological Analysis

IPA can be described as an approach or methodology rather than a set of methodological or analytical steps (Larkin, Watts, & Clifton, 2006). It was developed by Smith (1996), originating within psychology and has been adopted in counselling and occupational research as well as other health and social sciences such as nursing. IPA has predominantly been used to research illness experience (Brocki & Wearden, 2006; Smith, 2011). This is because IPA is concerned with the everyday lived experience as situated in social and cultural contexts, therefore providing insight into patient experiences (Biggerstaff & Thompson, 2008; Larkin et al., 2006)

IPA considers people as meaning makers (Smith, 2011) and is concerned with the lived experience, and how the participant makes sense of their experience. The researcher also interprets data in order to make sense and give an in-depth understanding of the experience and adding insight into clinical understanding.

## 2.3.1 Epistemological position.

IPA does not name its epistemological position, but has epistemological openness (Larkin et al., 2006). The researcher must therefore consider their own epistemological position in order to reflect on how they approach knowledge. However the philosophical underpinnings of IPA promote a position situated between critical realist and social constructionist. This has been referred to as contextual constructivist (Smith, Flowers & Larkin, 2009).

A key principle of contextual constructionism is that knowledge is context specific. The experience of a person therefore becomes meaningful through their interaction with the world. The person is situated within their own context and therefore history, culture and environment contribute to how a person makes sense of their experiences. Interpretations in the current study will therefore draw on information about the context of the interviewee. This approach considers language to reflect meanings and therefore this enables the researcher to interpret the sense making, or meaning of the experience of the participant.

## 2.3.2 Philosophical underpinnings of IPA.

Three key philosophical influences underlie IPA; Phenomenology, the study of lived experience; hermeneutics, the theory of interpretation of the phenomenon; and idiography, how a particular experience is understood from a person's perspective (Smith et al., 2009).

#### 2.3.2.1 Phenomenology.

Phenomenological philosophy originates with Husserl (1927) who considered that as humans we quickly attribute meaning and try to organise our experiences in line with our view of the world. This is known as the natural attitude. As a result we do not pay attention to our experience and it is taken for granted. He proposed a "phenomenological attitude" and argued that we should 'go back to the things themselves' meaning that an experience should be recognised in its own right (Finlay, 2009; Shinebourne, 2011).

In order to adopt the phenomenological attitude, Husserl argues that we need to engage in phenomenological reduction. This process involves bracketing of understandings, or sense making in order to put aside the natural attitude. This means that knowledge and assumptions are suspended by putting aside the 'taken-for-granted world' (Finlay, 2008). This then makes it possible to concentrate on our perception of the world as it is experienced and get close to the essence of the phenomenon (Finlay, 2013). Finlay argues that researchers should engage with this process through continual reflexivity because there will inevitably be an influence of the researcher. In employing IPA methodology, it is therefore important for the researcher to reflect on their own experiences, knowledge and meanings of the phenomenology they are experiencing.

Heidegger (1962/1927), a student of Husserl's, considers that individuals are uniquely situated in the world, and that a person exists within a world of others, language and culture. They are situated in their unique context and therefore it is not possible for a person to gain knowledge separate to their interpretation of it (Laverty, 2008). Therefore phenomenological research can only explore how the world appears to the person through their engagement with it, for example through activities and relationships (Ashworth, 2003). Smith et al. (2009) places importance on this shared and relational nature of a person's engagement with the world, which Heidegger referred to as intersubjectivity. Similarly, the researcher is situated in the world and therefore the findings of the research will be influenced by their own intersubjectevity.

Similarly, Merleau-Ponty (1962) who also had an interest in phenomenology, considers that another's experience can never fully be understood because their position in the world is unique. Therefore research can only aim to get "experience close" (Smith et al., 2009, p. 33). Sartre (1956/1943) also considered how a person is continually developing, rather than a pre-existing entity, and therefore a person's unique position is evolving. These underpinnings of IPA mean that the methodology considers a person as embedded in their world, including their relationships with others, culture and objects and that a person's understanding of their world is unique to them and is changeable. This means that when considering a person's experience following TBI and masculine identity that the phenomenology of the person needs to be understood within their context and that the researcher's context also needs to be considered.

#### 2.3.2.2 Hermeneutics.

Hermeneutics is the theory of interpretation. This theory has particularly been developed by Heidegger (1962/1927) whose work bridges phenomenology and hermeneutics.

He considered that as our experience of something is always through interpretation, therefore we engage in hermeneutic phenomenology.

Gadamer (1990/1960) develops this idea and considers that understanding is dynamic in that what we understand about something is influenced by our previous experiences, and that our past experience will influence new experiences (Finlay, 2009). A cyclical relationship therefore exists between experience and our understanding of the experience (Laverty, 2008). This cyclical process encourages researchers to be open to discovering preconceptions as new experiences are encountered.

IPA therefore engages in a two stage interpretation, or a 'double hermeneutic' where "the participants are trying to make sense of their world; the researcher is trying to make sense of the participants trying to make sense of their world" (Smith et al., 2009, p. 51). The researcher's interpretation is therefore also cyclical in relation to their experiences, including their experiences with the data gathered (Shinebourne, 2011). Research is therefore an iterative process as the researcher's position is constantly changing as their relationship to the data changes as they encounter and interpret new data. An example of this is in the interpretation of one part (e.g. a single word or one interview) of the data within the whole (e.g. the sentence in which the word is embedded, or the research project). The researcher's understanding of the part depends on the understanding of the whole, and the understanding of the whole depends on the researcher's understanding of the parts. This dynamic and iterative cycle is illustrated in Figure 2 below.

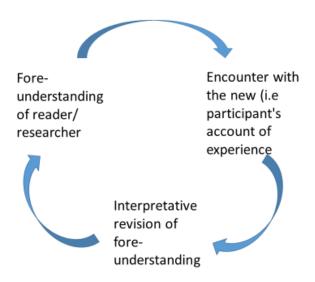


Figure 2. The hermeneutic circle in IPA (Heffron & Gil-Rodriguez, 2014)

## 2.3.2.3 Idiography.

The idiographic approach of IPA means that an in-depth focus on the particular for an individual is prioritised (Shinebourne, 2011). This feature of IPA distinguishes it from other psychological research which tends to be nomothetic and attempts to establish causal laws about human behaviour or claims about a population of people. In contrast, Smith et al. (2009) claims that IPA "does justice to the complexity of human psychology" (p. 38) because it looks at the individual in detail using in-depth, thorough and systematic analysis (Smith et al., 2009). This enables the persons experience to be understood from the perspective of a person in their particular context.

Idiography therefore results in a more cautious way of making claims which generalise across a population (Smith et al., 2009). IPA uses a procedure which allows for consideration of one case to develop more general statements. It looks for convergence and divergence within the data to demonstrate how themes may be shared between individuals relating to an experience and how these themes may be experienced differently between individuals (Smith, 2011). This underpinning of IPA enables a deeper understanding of nomothetic research and can therefore have meaningful implications for clinical practice.

#### 2.3.3 Rationale for IPA methodology.

The research question of the current study focusses on exploring lived experience and finding out about personal meaning. Exploring masculine identity is complex because the meaning and importance of this is unique to the individual. What it means to be a man is unique to the individual and influenced by their particular context. Similarly the experience of TBI is unique to the individual. The question therefore requires a methodology which enables participants to share their experiences, and their sense making of their world with the researcher. The epistemological position of the research question therefore is in line with the philosophical underpinnings of IPA.

The method needs to consider not only the phenomenology, but provide a more indepth understanding of the meaning and the ways in which the individual makes sense of their experiences. IPA allows for situating individuals in their particular contexts, in order to provide a more in-depth understanding of the meaning of experiences. IPA therefore enables a further understanding of how the experiences of masculine identity and experiences after TBI interact with each other.

## 2.4 Research Procedure

This section details the procedures used throughout recruitment and data collection in the current study.

#### 2.4.1 Inclusion criteria.

Participants were recruited from a community specialist neurorehabilitation service in East Anglia. Ten men above the age of 18 years were recruited reflecting a clinically relevant group in adult community neuro-rehabilitation services.

IPA enables individuals lived experience to be explored within an individual's context and exclusion criteria have been considered in line with this. For example, factors such as location and severity of injury were considered to be part of the individual experience rather than as a criteria for participants. In order to aid the researcher to get close to the lived experience and gain rich phenomenological data, as well as recruit an appropriate number of participants, participants had to be within seven years of injury.

Participants were required to have insight into and be able to communicate about their experiences. In order to recruit participants, Clinicians were supported to have a good understanding of the aims of the research and what taking part in the research would involve for participants. It was highlighted that participants would be asked to talk about their day-to-day experiences in relation to masculine identity and clinicians were asked to consider if an individual's ability to reflect on their day-to-day experiences would enable them to engage in this discussion. Participants had to be able to adequately express themselves in English. However, having a communication difficulty did not exclude individuals as support around expressive language difficulties was considered (Lloyd, Gatherer, & Kalsy, 2006).

The Primary Research Supervisor was employed as a Clinical Psychologist at the recruitment site and therefore individuals who were directly working with the supervisor were excluded from participation. This was done in order to ensure that psychological therapy or more general rehabilitation was not affected by participation in research, and that interpretation of research data was not influenced by therapeutic material.

Ruth MacQueen 2016

## **Recruitment process.**

The primary researcher met with the clinical team on several occasions. This included attending team meetings to talk about the aims of the research project and recruitment process. The design and method of the research was also discussed so that clinicians had a full understanding about what participants could expect if they took part. A Clinician Information Sheet (see Appendix A) was also provided to support the clinical team's understanding of the project. By informing clinicians about the nature of the study they were able to use their clinical judgement to consider the suitability of the individual for the study in relation to this.

A clinician within the service who was independent from the project agreed to be the liaison between clinicians and the primary researcher. This role included supporting other members of the clinical team members in recruitment and in consideration of individuals on their caseload who may be appropriate for the project. The primary supervisor was also employed on site to support the staff team in questions relating to the purpose and nature of the research, but had no role in recruitment of individuals.

Clinicians within the service reviewed their caseloads and identified potential participants. They then approached potential participants either during clinical contact, by telephone or by post. Potential participants were provided with the Participant Information Sheet (see Appendix B) and initial information about the study was discussed. If the individual was interested in the research then a consent form was completed for the clinician to share contact information with the primary researcher. This could be completed by the clinician should verbal consent via telephone be given.

The primary researcher then contacted the potential participant using their preferred communication method. This initial contact was made at least 48 hours after the participant had received the information relating to the study and consented to their contact information

being shared. Initial contact by the primary researcher provided the participant with information relating to the research as detailed on the participant information sheet and an opportunity to discuss any questions. A date, time and venue was then agreed with the potential participant if they wished to continue in the process.

Eleven potential participants were identified by the clinical team and gave consent to be contacted by the primary researcher. Following initial contact by the primary researcher one person expressed an interest but postponed the interview and then did not respond to further contact.

## 2.4.3 Participants.

Ten men above the age of 18 years were recruited from a community rehabilitation service, reflecting a clinically relevant group in adult community neuro-rehabilitation services. All participants were open referrals to the community rehabilitation team and had either received or were engaged in support from the community rehabilitation team. A summary of the participant details is provided in table 1. Pseudonyms for all participants have been used throughout.

All participants were of White British ethnicity. They were aged between 21 years and 67 years old. The majority of participants were independently mobile with the exceptions of Gordon who used a wheelchair as a result of spinal cord injuries and amputation and Simon who also used either a wheelchair or walking aid. All participants were able to communicate verbally and only Simon identified that he had some expressive communication difficulties.

| Table 1                                   |
|---|
| Contextual information about participants |

| (years) injury |    |                       | Cause of injury                  | Lives with:   | Post injury employment                                       | education   |  |
|----------------|----|-----------------------|----------------------------------|---|--|---|--|
|                |    | Pedestrian hit by car | Wife & 2<br>daughters            | Left school at 16                                     |  |   |  |
| Luke           | 22 | 2 years               | Single car accident              | Alone   | No   | Left education at 18  |  |
| Gordon         | 42 | 3 years               | Single car accident              | Parents   | No   | Left school at 16 – did<br>further cooking<br>qualifications  |  |
| Jake           | 29 | 1 year                | Physical altercation             | Girlfriend  | No   | Left school at 16 – did<br>qualification I n car<br>mechanics |  |
| Simon          | 35 | 4 1/2 years           | Motorbike RTA                    | Wife & 2 children                                     | No   | Left school at 16   |  |
| Nigel          | 43 | 1 year                | Bicycle RTA                      | Wife, 2 children 1<br>stepchild                       | Has begun to<br>return to<br>different role in<br>same place | left school at 16   |  |
| Chris          | 27 | 2 years               | Driver in road traffic collision | Alone   | Has returned to<br>work in same<br>management<br>role        | Left school at 18 following a-levels                          |  |
| Smith          | 67 | 3 months              | Fall                             | Wife  | Retired  | Left school at 15 – joined the navy                           |  |
| Peter          | 21 | 6 months              | Single car accident              | Parents   | No   | High school (18) then national diploma                        |  |
| George 43 11 r |    | 11 months             | Accident at work with machinery  | Partner and step<br>child (2 children<br>at weekends) | Occasionally on site as owner of business                    | Left school at 16   |  |

#### 2.4.4 Topic guide.

A topic guide (see Appendix D) was developed using guidance on developing an interview (Brinkmann & Kvale, 2014; Smith et al., 2009). The aim of the interview was for participants to be able to communicate their narratives, thoughts and feelings about their experiences in order to obtain rich interview data. The interactive process of the interview and the interviewing skills of the researcher aimed to provide the participant with a safe environment in which to talk at length about the issues which mattered most to them (their phenomenology) and the meaning of their experiences to them (their interpretation).

The topic guide was developed by first giving consideration to the themes which were relevant to the research question. These included the impact of TBI, masculine identity, cultural and social roles, and experiences of rehabilitation and interacting with professionals. As IPA allows for the participant to be situated within their context, the interview also sought to ask about contextual information such as age at the time of injury and current situation.

The final topic guide has fewer questions than had initially been considered. This allowed the questions to be open ended and have a broader focus and therefore provided more of an opportunity for the participant to direct the interview to issues which were pertinent to them. The questions were reviewed and redrafted to ensure that they were open and did not lead participants or make assumptions about their experiences. They were presented in a sequence which aimed to sensitively construct the topics of conversation, for example contextual information was asked first to give opportunity for the participant to feel more at ease before discussing topics which may require more reflection.

Prompts were identified in order to encourage participants to expand on what they were talking about and therefore gain more rich data. These facilitated the researcher to get closer to the experience as the participant spoke. The topic guide was flexible which enabled the participant to lead the interview so that if they raised an issue, the researcher could follow

that up, even if it was not on the interview schedule. This also allowed the researcher to obtain ongoing process consent throughout the interview, for example by asking questions such as "would it be ok to talk more about that?"

Following the first interview, the recording was transcribed, critically reflected on by the researcher and discussed in research supervision. This aided the researcher to consider whether the questions being asked gathered data relevant to the study question and evaluate the topic guide. It was agreed that the topic guide was suitable for exploring the research question. This process also provided an opportunity for the researcher to reflect on and develop interview skills.

## 2.4.5 Interview procedure.

All interviews were carried out by the primary researcher, a Trainee Clinical Psychologist. Participants were interviewed individually either at their rehabilitation service (n=5) or in their own homes (n=5). Lone worker procedure guidance from The University of East Anglia and Cambridge and Peterborough NHS Foundation Trust Working Alone in Safety' were followed to ensure researcher safety.

On meeting with the individual, the researcher gave the participant a copy of the participant information sheet and it was talked through. This enabled the researcher to introduce the study and ensure that participants had a good understanding of what taking part would involve and the aims of the research. This included highlighting the procedure should the participant experience distress during the interview. The research boundaries were established with participants by acknowledging that the interview was a one off meeting and that therefore there were no therapeutic aims for the interview. Participants were encouraged to ask any questions relating to the research. They were also provided with an option to

receive a summary of the results following completion of the project, something which all participants requested.

The Consent to Participate form (see Appendix E) was explained and participants were given further opportunities to ask any questions and any points for clarification were made. When the participant gave written consent to take part in the research an audio recorder was turned on and remained on until the end of the interview.

Prior to the interview beginning, a summary was given to participants to highlight the key aims as stated at the beginning of the topic guide. It was emphasised to participants that the researcher was primarily interested in the persons experience in relation to their identity as a man and there were no right or wrong answers. They were encouraged to talk about what was important for them.

Interviews aimed to last around one hour and duration ranged from 52 to 71 minutes. Flexibility with regards to duration and opportunity for breaks was offered to support interviewees in challenges to the interview such as fatigue and distraction (Paterson & Scott-Findlay, 2002). The topic guide was memorised by the researcher in order to try to provide a more natural and comfortable interview. It also enabled the researcher to respond to what the participant was talking about and engage in empathic listening (Finlay, 2005).

At the end of the interview, participants were offered an opportunity to feedback about their experience of participating. They were asked if there was anything which they had expected to discuss which they hadn't done or anything that they wished to add. Participants were reminded of what would happen to the results and data and reminded of who to contact if they have any concerns or questions regarding their participation. This debrief also enabled the researcher to consider any cause for concern about the participant and provide an opportunity to discuss this together. A written debrief sheet was also provided (see Appendix F).

After the interview, the researcher used a reflective diary to reflect on the interaction. This aimed to aid the researcher to identify their feelings and thoughts during the interview and any themes which stood out. It was also used to consider the inter-subjective dynamics and think about what the researcher brought to the interview and how they may have influenced the data. An example of an extract following an interview can be found in Appendix G. The personal reflection section at the end of this chapter also considers the researchers experience of the interviews in relation to the how this may have influenced the data collected.

## 2.5 The Analytic Procedure

The Primary Researcher transcribed audio recordings of the interviews. Individuals were assigned a pseudonym to protect their identity. Listening to and transcribing all of the interviews enabled the researcher to become familiar with the data and become immersed in it (Rodham, Fox, & Doran, 2015). This provided a high level of engagement with individual's data. Transcription included making notes about the interaction such as significant pauses, hesitations, laughter, and indication of tone of voice.

IPA does not prescribe a specific method for analysis but encourages flexibility in developing a method which aids analysis. However, there are "common processes" (Smith et al., 2009 p. 79) which underlie this flexible method of analysis. Smith et al. (2009) outline a framework for analysis and a description of these stages in the current study will be described. As this was the researcher's first project employing IPA, these guidelines were referred to throughout the project with the aim of closely adhering to them.

The first stage was reading and re-reading of a single transcript. This facilitated the researcher to engage with the data and become familiar with the transcript. This stage involves the participant being the focus and the researcher entering into their lifeworld. During this stage, the researcher aimed to remain open to the new data and respond to the data as it was encountered.

The second stage involved the researcher making initial notes about the transcript through considering the semantic content and use of language within the transcript. Coding was exploratory and the notes tended to be descriptive comments which stays close to the participant's experience. The researcher also made interpretive comments by considering the language use and the content to make sense of their account. In addition, comments about the researcher's reactions were recorded as a means of reflexivity.

The data was further examined by considering the underlying meaning of what was being said and how this related to other things which the participant may have said. This also involved personal reflection so that the researcher could consider how they may be interpreting the data to develop conceptual comments. Conceptual comments were grounded in the data however also moved away from the data in order to enable reflexivity and interpretation. Coding was carried out on a column to the right hand side of the transcript.

Moving beyond initial coding, the comments made in this initial exploration were used to develop emerging themes. This process was written to the left hand column of the transcript. An annotated transcript which illustrates coding and emergent themes is provided in Appendix H.

Emergent themes were then listed. Each individual transcript had between around 40 to 100 emergent themes. The emergent themes for an individual transcript were printed and manually considered and clustered together through searching for connections across themes.

This process reduces the volume of detail and maps out relationships between the comments made. Smith et al. (2009) highlight that this reflects the hermeneutic cycle as patterns between emerging themes are grouped under an umbrella term. For example, emergent themes such as "reliance on others, loss of freedom and needing to be watched" could be clustered and given the heading of "loss of independence." The clusters were given a descriptive label, or master theme, which the researcher felt captured the nature of the themes within it. This process continually involved checking against the transcript to ensure the connection between quotes and the cluster or theme. This process was repeated for each individual transcript. Each individual had between four and twelve master themes. An example of individual master themes can be found in Appendix I.

The final stage of analysis involved identifying patterns across the master themes of participants. This way of organising the data was dynamic and the researcher rearranged themes multiple times. The master themes for each participant were printed using different coloured ink. The researcher then looked for links between the themes in a similar way in which had been done in developing clusters within individual transcripts. The researcher was able to consider themes which were common and also how participants may live the theme differently. Eight master themes identified were then grouped into three superordinate themes (see Appendix J). Throughout the process, each theme was reviewed in relation to the evidence from the transcript in order to ensure that the interpretation remained grounded in the data. The analysis was led by the Primary Researcher, with each stage being reviewed with the Primary Supervisor.

The iterative nature of the methodology means that reaching data saturation is not achieved as the cyclical process could continue as the researcher's relationship to the data continually changes. Therefore the analysis can never reach saturation. Given this, in order to ensure the rigour of the current study the analysis was conducted systematically. Each of

the three superordinate themes were present in all of the participant interviews. This is the most stringent criteria to establish these. In line with guidance for rigour in the analysis appropriate to the sample size, illustrations from at least three to four participants per theme are evidenced in the analysis (Smith, 2011).

## 2.5.1 Reflexivity throughout analysis.

As data analysis in qualitative research is inevitably linked to the epistemological, ontological and theoretical assumptions of the researcher who conducted the analysis (Mauthner & Doucet, 2003), it is important to consider how these may influence the analytic process as reflexivity is an important part for ethical research (Houghton, Casey, Shaw & Murphy, 2010).

Using reflexivity to consider preconceptions and intersubjectivity enabled the researcher to critically evaluate the interpretations about the data. In addition, the researcher may only get to know what preconceptions they hold once interpretation begins (Etherington, 2007; Smith, 2007). The researcher used supervision and qualitative research peer groups to develop reflexive skills and consider the personal impact on analysis. A reflection of the personal impact on different aspects of the project have therefore been included in the final write up of the study.

In addition, the reflexive journal was used to explore self-reflections and to examine assumptions and preconceptions in order to explore reflections and interpretations. An example excerpt of the journal can be found in Appendix K. Keeping this journal also increases the transparency of the research (Ortlipp, 2008).

Ruth MacQueen 2016

## 2.6 Quality of Research

It is important that research is of good quality in order to make it a worthwhile use of resources, which can make a valid contribution to knowledge. IPA methodology considers the credibility and trustworthiness of the data at all stages.

Smith (2011) outlines features of high quality IPA research and develops guidelines for evaluating quality in IPA (see Appendix L). These guides were developed through independent reviews of existing IPA research which was then discussed and a guide developed based on the evaluations. This project aimed to adhere to Smith's guidance on what makes a good IPA paper. The criteria include that the paper should have a clear focus, have strong data, should be rigorous, sufficient space must be given to the elaboration of each theme. The analysis should be interpretative not just descriptive, and should demonstrate convergence and divergence.

In order to adhere to these criteria, supervision was used throughout the project as a way of improving the quality of the research. This included the researcher and primary supervisor regularly discussing different aspects of the research throughout the project. The initial design and IPA methodology has been considered in supervision from the initial stages of this project. This project was being supervised by two supervisors who had an overview of the research process.

After the first interview, the transcript was reviewed giving consideration to IPA and the quality of the interview skills of the researcher. At the data analysis stage, the themes were considered by the supervisor and discussed as required to reach consensus. When identifying themes, each transcript was referred back to in order to ensure that theme was warrantable within the data. This ensured that the conclusions drawn from the research were sufficiently embedded in the participant's data as was suggested in the guidance (Smith, 2011).

In addition to the primary research supervisor, verification of themes also involved the secondary supervisor, and another Trainee Clinical Psychologist at the University of East Anglia who was independent of this research study. Both Trainees shared the supervisory team. Whilst being independent of the research process, the trainee was also undertaking a (completely separate) qualitative research project using IPA and was therefore in a good position to assess the credibility and trustworthiness of the themes. The researcher also invested time in attending IPA training as well as a qualitative research group in order to develop the skills required to carry out good IPA research.

The use of reflective diary and reflexivity throughout the research process contributes to the quality of the research and is consequently has important ethical considerations. This enabled the researcher to maintain openness rather than only considering data in which pre-existing assumptions were supported (Guillemin & Gillam, 2004; Ortlipp, 2008). In addition to this, a detailed record of the analysis process was mapped so that the data can be traced throughout (Yardley, 2008). This process of analysis is illustrated in Appendices H-J.

In addition to guidelines for high quality IPA research, criteria for quality within qualitative research were also considered including Yardley (2000, 2008) and Tracy (2010). Exploring these criteria at an early stage of design supported the researcher's qualitative research skills and developed understanding of important issues for quality.

The Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, Sainsbury, & Craig, 2007) is a 32 item checklist for researchers reporting qualitative studies. The checklist covers three domains: research team and reflexivity; study design; and analysis and findings. The checklist was reviewed regularly to ensure that the methodology would enable the criteria to be met and was then reviewed as a tool to reflect on the quality and ensure that all relevant factors were reported. A completed checklist for the current study can be found in Appendix M.

The key purpose of research is to provide evidence that informs clinical practice and it is ethically important that the findings are shared. This ensures that the participant's contributions and the resources used in this study are used in a meaningful and effective way. A dissemination plan was therefore developed as part of the research proposal. The research development was disseminated using a poster presentation at the National Brain Injury Symposium, (2015). The findings of the research will be submitted to a relevant journal for publication. The findings of the research will also be shared with the clinical team from whom participants were recruited through a training workshop within the setting which will facilitate the findings to be applied to clinical rehabilitation.

## 2.7 Ethical Considerations

Ethical approval for this project was obtained from the Research Ethics Committee of the National Health Service Research Authority. Approval was also obtained from the Research and Development committees of the Trust where the research took place. In addition, the research project proposal was approved by the University Of East Anglia, Clinical Psychology Doctoral Programme. See Appendix N for approval documents.

It is recognised that ethical considerations are crucial though all stages of research and ethical considerations are therefore woven throughout this chapter in relation to the relevant section. However, some more general points will be addressed in this section. The Code of Human Research Ethics (British Psychological Society, 2010), guidance on ethical interviewing (Brinkmann & Kvale 2015 ) and ethical issues specific to qualitative research (Orb, Eisenhauer, & Wynaden, 2001; Richards & Schwartz, 2002) have been drawn upon for this research. Consideration has been particularly given to issues of consent, coercion, confidentiality, deception, distress and debriefing.

#### 2.7.1 Informed consent, coercion and deception.

Participants were provided with detailed written and verbal information about the purpose and nature of the research so that they had an understanding of what to expect if they decided to take part as detailed in the recruitment process section of this chapter. It was emphasised that participating in the research was voluntary and would not have an impact on treatment received. Participants were encouraged to ask any questions.

In setting up the interview, it was emphasised that participants should only share that which they felt comfortable to. Guidance on ethical interviewing (Allmark et al., 2009) was considered. During the interview clinical judgement was used to enable the researcher to respond sensitively within the interaction and gain a balance of obtaining rich data, whilst respecting the participants wishes about what they wished to share (Orb et al., 2001; Brinkmann & Kvale, 2015).

#### 2.7.2 Confidentiality.

All confidential information relating to the research was stored securely. Electronic information, including audio recordings were stored on an encrypted memory stick. Paper documents were stored in a locked cabinet at the University of East Anglia in accordance with the Data Protection Act (1998). Data was destroyed for participants who had consented to share contact information with the researcher, but had decided not to take part.

Only the researcher listened to the audio recordings. Pseudonyms have been used throughout transcription and analysis in order to protect interviewees' confidentiality. Reporting of analysis required careful anonymising as participants may have been identifiable by particular language use or specific information (Richards & Schwartz, 2002). All participants were made aware of the boundaries of confidentiality in relation to risk of harm. This meant that should any risk be highlighted during the interview, the researcher could openly discuss with the participant the need to share this information with others for safety. This was not required for any interviews.

#### 2.7.3 Managing risk and distress.

Gathering in-depth data using an interview may result in participants experiencing anxiety and distress (Richards & Schwartz, 2002). This aspect of the nature of qualitative study was considered throughout the recruitment process. Clinicians were given sufficient information to enable them to make informed judgments about the suitability of potential participants in relation to participants being able to talk about their experiences.

The researcher's clinical skills enabled a continual responsiveness to the changing needs of the participant. If participants experienced distress the researcher responded to this by tentatively reminding the participant that they could choose to continue, take a break, or stop the interview. All participants engaged throughout the interviews and the termination of an interview due to emotional distress was not required.

The ending of the interview allowed further opportunity for any risk or distress to be discussed. However, it was recognised that participants may not express their anxiety and distress explicitly to the researcher, or that they may become distressed following the interview. The debrief sheet was discussed with the participant and a copy provided so that they were informed of some options for support available to them following the interview.

## **Reflection 2: Personal impact on methodology**

The experience of conducting the interviews varied between each participant. A prominent reflection was about how explicitly men related their experiences to masculine identity or not, even although the study and questions were directly focussed on this aspect of experience. When men less explicitly related their experience to masculine identity, at times, particularly in the initial interview I felt more tentative in exploring this, and it was tempting to remain talking about issues which may have felt safer for myself and the participant. However, in subsequent interviews I felt more able to ask about this aspect of experience and this appeared to enable men to feel that they had permission to talk about difficult experiences.

As a female interviewer, I wondered about how this dynamic may influence what men talked about. At times men apologised for swearing, and I wonder if this may have been less of a concern to them if talking to another male. In addition, only two participants talked directly about sexual experiences. This was a topic which I had expected to be of importance but it was not often discussed. It may be that men felt they could not talk about this with me and that therefore this aspect of the lived experience is lacking in richness in the current study. However, I felt that it was important to maintain a balance between encouraging men to share difficult experiences whilst maintaining ethical and respectful interview practice.

#### Analysis

#### **3.1 Overview of Chapter**

This chapter begins by providing a summary of the analysis and giving an overview of the themes identified. Each theme is then described in detail and illustrated by the data to support the analysis.

#### **3.2 Summary of Findings**

Three superordinate themes emerged from the analysis: doing life and relationships differently, self-perceptions and the perceived view of others, and managing the impact. Each of the three superordinate themes were present in all of the participant interviews. Within each superordinate theme there are two to four master themes which are evidenced by at least half of the participant's individual main themes. A summary of superordinate themes and a detailed hierarchical representation of the organisation of themes can be found in Appendix J. Table 2 below illustrates the occurrence of themes across participants.

## **3.3 Doing life and Relationships Differently**

All participants talked about how the injury had impacted on different aspects of their lives and about the losses of pre-injury. Day-to-day ways of living independently had changed and many participants identified how their changed life was childlike in comparison to the man they had been. Participants also identified how the impact of TBI changed and often limited different aspects of their roles as a man within their relationships, family, work and social groups. Each master theme is now described in turn using the supporting data from the interviews.

# Table 2

# Prevalence of Themes

|             | Doing life and relationships<br>differently |                         | Self-perceptions and the perceived view of others |   |  |   | Managing the impact     |                                |
|-------------|---|-------------------------|---|---|--|---|-------------------------|--------------------------------|
| Participant | Loss of<br>individual<br>agency             | Roles and relationships | The<br>invisible<br>nature of the<br>injury       | Concern about<br>being judged as<br>less of a man | Shame and<br>loss of self-<br>confidence | Not feeling<br>safe - feeling<br>vulnerable | Coping with adjustments | Re-evaluating<br>life / values |
| John        | $\checkmark$                                | $\checkmark$            | <u>√</u>  |   | $\checkmark$                             | $\checkmark$                                | $\checkmark$            | $\checkmark$                   |
| Luke        |   | $\checkmark$            | $\checkmark$                                      | $\checkmark$                                      | $\checkmark$                             |   | $\checkmark$            |                                |
| Gordon      | $\checkmark$                                | $\checkmark$            | $\checkmark$                                      | $\checkmark$                                      | $\checkmark$                             | $\checkmark$                                | $\checkmark$            |                                |
| Jake        | $\checkmark$                                | $\checkmark$            |   | $\checkmark$                                      |  |   | $\checkmark$            | $\checkmark$                   |
| Simon       |   | $\checkmark$            |   |   |  | $\checkmark$                                | $\checkmark$            |                                |
| Nigel       |   | $\checkmark$            | $\checkmark$                                      |   | $\checkmark$                             |   |                         | $\checkmark$                   |
| Chris       | $\checkmark$                                | $\checkmark$            | $\checkmark$                                      | $\checkmark$                                      |  |   | $\checkmark$            | $\checkmark$                   |
| Smith       | $\checkmark$                                | $\checkmark$            |   |   |  | $\checkmark$                                |                         | $\checkmark$                   |
| Peter       | $\checkmark$                                | $\checkmark$            |   | $\checkmark$                                      |  |   |                         | $\checkmark$                   |
| George      | $\checkmark$                                | $\checkmark$            | $\checkmark$                                      |   | $\checkmark$                             | $\checkmark$                                |                         | $\checkmark$                   |

3.3.1 Loss of individual agency and independence. "I just don't feel adequate as a man in any way now. It just feels [I] always have to be babied or watched." (Gordon)

The participants talked about experiences of loss of independence and loss of the freedom to make their own choices. This loss was experienced as not being in control of their own lives and their bodies. Their loss of control and agency was the most important factor for some and related to their expectations of how a man should be.

Chris: A man should be in charge and organised and know what they're doing but now I have to rely on a bit of pen and paper. ... It makes you feel, again, it makes you feel like a child, it makes you feel like you can't control your own life because you're having to rely on looking at something to remind you (p.6, 195-196; p8, 236-238).

Chris's comparison of his experience as childlike highlights the difficulties of experiencing reliance. Similarly for Peter reliance on others is difficult:

Yeh it's pretty rubbish cause I was independent before, I get up and go to work and that'd be it, Mum and Dad wouldn't have to do anything for me during the day sort of thing...It just feels like being a kid again. Like Mum, Dad, can we go here, can we go there. Like whereas before I'd be like I'm going here and that'd be it, I'd be gone sort of thing (p.8-9, 228-261).

For some participants, the cognitive losses were identified as having an impact on their identity and their felt sense of independence as for Chris above and also for Jake and Gordon.

Jake: Like ...a man.... cause I know what I was like before d'you know what I mean, and that's what, like I weren't like this before, I was very like decisive and like, on it. Like if I did something it was done, you couldn't ever say "oh you forgot that, you forgot that." It would never be like that, I was always on the ball. It's hard 'cause I know what I was like before and I'm not that now. I have to rely on (partner) to do a lot of things, I get angry 'cause I can't work things out (p.5-6, 164-169).

Gordon: Cooking as well now, I just can't get my head round what I could do, I just can't produce the food in any rush you know it takes ages, it takes hours now.... It's frustrating because you know you can do it, your body's willing but your brain just won't, it just won't go into action, everything takes so long, it just doesn't all come together right (p. 13, 397-402)

Participants also felt that the loss of control over their bodies was a salient factor. This is described emotively by Chris:

I felt weak, and I felt worthless because I couldn't control my body essentially. Yeh this is all linked in then with feeling depressed (p. 12,368-369).

Smith: as I mentioned before, it, it is the tiredness, you know, ... I feel I've still got the get up and go but it sort of runs out quicker (laughs) you know, you think you get up and start doing things and then, ok, let's have a cup of tea (p. 9, 277-280

These examples from Chris, Jake, Peter, Smith and Gordon highlight different ways in which they no longer felt that their mind or body was co-operating with how they wished to live their lives. These reflections on the experience of the injury were directly prompted by questions about what it was like to experience this as a man. The responses given by participants therefore suggests that their experience contrasts with masculine ideals about being in control, being able to take charge of your body and override challenges.

Discomfort with reliance on others was also expressed throughout some of these sections of transcript, and some participants, such as Chris and Peter above, feel in a very childlike position. Although throughout the interview, Peter doesn't tend to explicitly relate his experience to his identity as a man, his repeated childlike comparisons throughout his interview highlights that his experience of loss of independence appears to leave him feeling restricted. Following his injury, others tell him what to do because of what they think might be good or safe for him rather than Peter being able to follow through his own needs and wants:

Just having to go like to bed early and not being able to just do what I want sort of thing, but cause like I can't cause I get fatigued, so everybody reckons, and I'm not allowed to go to bed as late in the evenings, it's like being a kid again really (p.15, 482-486).

In contrast, Gordon is explicit about how his experience of being "babied or watched" impacts on his identity as a man:

I don't feel like a man, I feel like a young lad... who hasn't had the experience in life. I've lost something along, you know in the last few years, I've lost the last 3 years, I've lost who I actually am.... I suppose I just don't feel... very manly. You know, I suppose I don't feel as if, people see a man as a strong person that can keep up you know and do things and it just, I just, I just don't feel adequate as a man in any way now. It just feels always have to be babied or watched and you know I just don't feel you know, I don't feel, I just don't feel my age. You know and I just can't take the responsibility that I used to. That's hard to take in (p. 6 177-180; p.7, 213-218).

For Jake, restrictions on his independence of movement and agency seem to be the things which particularly affect him, and he feels restricted because of his reliance on others:

Having your own car you've got the freedom to go anywhere, like it (not being able to drive) stopped me going out places cause if I got fatigued I can't, I was relying on everybody else to give me lifts home and give me lifts everywhere so you're then working on other people's times, you can't just expect them to get up and go when you want them to so yeh my life just sort of come to a halt, know what I mean like I couldn't go out to places (p. 4, 99-104).

By having to rely on others, Jake is dependent on other people's wishes. Jake also indicates that the impact of fatigue is likely to mean that how he wishes to spend his time may be different from others. However, because he is not able to be independent in pacing social activity this has resulted in him stopping engaging in certain activity. Jake highlights how this also resulted in his initial reluctance to seek help from professionals:

(rejecting help), yeh that was like so I felt like a man so I felt like I was still in control, like with all these appointments my dad had to have time off for getting here now he doesn't that's changed, that's only been the last 2 weeks, this whole year he's had to take every Thursday off to bring me here. Accepting help is horrible, cause I knew by accepting the help, other people would have to drop things to then help me do you know what I mean, so accepting the help, was sort of accepting defeat, I was accepting the fact that I need help. (p. 21, 661-667) Many of the participants highlighted loss of control over their finances and major life decisions as one of the most significant ways of being in charge and doing what they want which was now lost to them. John and Jake explicitly relate this to their identity as a man.

John: I'm not allowed to control my own money. Oh Christ that's a hugely emasculating thing actually! I'm not allowed to look after my own money anymore because I had impulse buys and done stupid stuff (p. 16, 513-515)

Jake: I'm not really getting money and like all my important bills that need paying are being paid and so it's just things like that like I'm not in charge, I'm not seeing what's what, cause like me going in, my Dad's now on a joint bank account with me and that definitely makes me feel like less of man cause I've ever needed that, I've never needed support like I've always dealt with things on my own like if I want money I can earn money, money's never been an issue to me. Like, so it's just like all responsibility's taken away from me really (p.6, 191-197).

Being able to make important decisions is also highlighted by Chris who talks about the things he has achieved which has helped him to feel in control and more of a man.

Chris: I'm a man I can buy a house, I can do these things, I can do what I want because I can... and that's what men do (laughs) they do what they want. But yeh I wanted to buy a house, I went out and bought a house. and it's not just buying a house it's everything around it, it's the lawyers, its everything, its organising the money, getting to a point where you can save enough money and do it. So yeh that was a big proving point (p. 17, 527-532).

It seems that being able to buy a house is part of Chris demonstrating that he can do what he wants, to take charge of his own life. In this way, the process of buying a house appears to be evidence to him and others of his ability to be a man.

# **3.3.2** Roles and relationships. *"I'm married, a father and my main problems are around filling them positions."* (Simon)

All of the participants talked about how the injury had an impact on their roles and relationships in their lives. This included work, social, family and other relationships. All four men who were fathers of younger children, (John, Simon, Nigel and George) talked about the impact on their role as a father when asked about roles in their lives. John and Simon discuss how within their family, their roles such as provider and protector have been affected.

John: I wasn't doing anything that I felt contributed to my family. I felt like an embarrassment, I felt that my kids, or my kid at that time would grow up to be so ashamed like when people at school say oh what does your daddy do? I mean I remember (daughter) asking me for the first time "Daddy what do you do for a job?" I was like erm, I didn't know how to answer it. Erm, yeh I didn't really, I mean what was my purpose, my existence revolved around medical appointments, medical assessments and being a burden to everyone around me. It was horrible. I didn't provide anything for anyone yeh there was a roof over our heads and all the rest of it, but I wasn't the breadwinner in any respect (p. 7-8, 223-231).

John later goes on to say:

And I mean there's no doubt that if I needed to for myself or my family I would put myself in harms way, but I just don't feel as, I don't feel that I can offer my family the security that I want for my family, and that might *just be completely in my head, I still have strong legs – I could still probably kick somebody if they tried to rob me (p. 15, 480-484).* 

The above extracts demonstrate the loss of roles within family which appears to reduce their sense of purpose in comparison to the roles they fulfilled prior to injury. Participants attributed this loss of role to different things, varying from the ability to physically defend the family to the ability to provide a certain lifestyle. John considers how he might try to defend his family and his query about whether it is "in (his) head" suggests uncertainty about his ability to meet expectations. He also highlights that by being protective, he is putting himself at risk. This may be considered more by John following his brain injury because of the increased risk of harm which he later refers to.

Simon illustrates how what he does now is different to pre-injury, but that his activity may continue to be part of enacting the roles he feels he has lost. He appears to consider ways in which he can continue to fulfil roles in his behaviour:

I can't provide for family like did. Money is not as easy as (it) was. That's my biggest, being the breadwinner or being the strong one ...or protect....I think that's where (growing) fruit (and) veg comes in, providing something. Plus being the man or protecting, I'm always the one to lock all doors at night. Car, garage, makes sure everything is off or locked. So whether subconscious that is for that, I don't know. But yeh it's... (I) don't feel like the man of the house (as) such (p.5, 134-141).

Both George and Nigel talk about how the impact of their injury on their emotional regulation has directly affected their role as a father. George talks about how his difficulty in controlling emotions impacts on his ability to respond to his daughter as a father, which is an upsetting experience for him:

I know I've done wrong by how I've reacted but I just do it anyway you know. Where (OT) has said you gotta try, you know if you, if you try not just fly off the handle if you know what I mean. And just the littlest things as well. Nothing major or nothing like that, I just sorta haven't got the patience I used to have basically....It's upsetting, because I've upset my daughter and I've seen her get upset over it (p. 8, 241-249).

George's response appears to cause him guilt and he indicates that he feels this is not in line with the kind of father he wishes to be. At other times, George tries to leave a room in order to avoid reacting and causing upset. Nigel similarly explains his response to situations such as arguments, or busy environments:

There was times where I would have to just remove myself and just go upstairs out the way and just you know, just keep out of it cause you know, you get a lot more irritable with them than you know, if they were messing about or playing up or something I would have to remove myself ... you know, they were really annoying me. But I thought it was good in a way cause at least I recognised it and I didn't just go (blows raspberry) and just launch at them or shout at them or anything. So you know I did recognise that. But that's a lot better so I feel like I've been a better father the last 3 or 4 months (p. 6-7, 193-201)

For Nigel, removing himself from the environment seems to protect his role as a father because he is not losing his temper with his children. However, it may also indicate that he can't cope or manage the situation as he explains that now that he is not having to do this so often, he feels more able to fulfil the role. Some participants explicitly related their role as a father as having an impact on their masculine identity. For others, such as George and Nigel, this link did not appear directly but was referred to indirectly by the impact on masculine roles such as father. For example, whilst the extract above highlights that George provided material which clearly relates to his role as a father, he initially rejected the idea of an impact on his sense of self as a man:

Interviewer: can you think of any times or examples of things where you've felt like the injury might have had an impact on your sense of yourself as a man?

George: erm, not really, no, off my head at the moment, no, no, no, not as a man, no. Sex is totally normal (laughs) so, no, no (p. 5-6 160-163).

Participants talked about how their role as husbands or partners had changed. Simon talks about how the division of household labour has changed:

I can't cut the (lawn), so my wife does. Putting out the bins my wife does. And that saddens me as (it's something a) husband should do (p. 4, 103-106).

For John, the change in roles at home appears to be directly experienced as "emasculating" reflecting how life together as a couple and family is different from how he had hoped it would be.

And as far as being emasculating, I was like the one at home pottering about, doing little houseworkey chores, but (wife) was having to tell me what to do....I was stopping my wife from being able to earn as well because she had to be at home because of me. In an ideal world I'd have been at work, (wife) could have been a stay at home mum, which is what she wanted to be when we had (child) and had she wanted to go back to work part time or anything or just have time to herself, (child) could've gone to nursery (p.7, 221-223; p8, 231-236).

In talking about the role he now has at home, John appears to find these tasks demeaning as he seems to belittle the kind of jobs he is doing which is further intensified by the sense that he may have restricted his wife's choices too.

Similarly, Jake talks about how his role in the relationship has had to change and adjust and, like Simon and John above, he feels the loss of the breadwinning role:

I couldn't work so I couldn't bring money into the house, couldn't support my partner so it made me feel less of a man....I was earning so it was like, you have the lifestyle to match that money d'you know what I mean, you've got bills to pay cause you have Sky and things like that. And then you go onto benefits and it's like Woooah, like all of a sudden everything's like, like I'm very old fashioned, that's no thing to put on a woman in my eyes. I'm pretty old fashioned, a man should bring the money home, a women's money's a woman's. I'm, very like I pay all the bills, I make sure everything's like all cushty like I'm the only one who drives, my partner doesn't. Like she hasn't even got a license so like just everything really, the whole household just got turned upside down (p.3 87-89; p. 4, 115-124).

Jake's loss of employment has resulted in a change in lifestyle that he had provided for his partner which conflicts with his expectations of himself in a relationship. His sense of the house being "turned upside down" may reflect the gender role reversal he experiences as well as the feeling of chaos.

Feelings of being a burden to others were common amongst participants:

Simon: my wife has to get out of the car, get chair out of car plus any bags she has to. so I feel I erm am hassle to my wife....She never signed up for what she got (p. 4, 107 – 108; p. 4, 114-115).

Gordon has begun a new relationship following his injury. He considers how his role in this relationship is the opposite of how he thinks it should be:

I always remember that, he (his father) was able to provide and always been there, the strong one and doing everything for my mum. But I just feel with (partner) it's role reversal, she's doing it all because she knows I can't do it and I want to do it, I just can't (p. 11, 354-357).

Gordon goes on to talk about how his difficulties can result in him feeling he does not meet a standard in comparison to others:

She wants to be perhaps doing, you know sitting in the garden or doing things which I just physically or mentally can't do.

Interviewer: and does that have an impact in you in relation to your identity as a man?

Gordon: Yes, I don't feel as if I'm, I always say, you should go and find someone who can do, and this is it, I always go back to, well you can do a lot better than me (p.6 170- 174).

The extract from Gordon suggests that as the man in the relationship, he experiences a degree of insecurity where he compares himself unfavourably to other men.

Others talk about the emotional support they can provide for their partners and feel this is important. Nigel talks about how he feels it is his role to support his wife with the impact his injury has had on her: At one stage I couldn't even recognise my wife, but I didn't recognise my wife or the children or anything, it was like, yeh that's been really tough on her, she's sort of been you know, she gets a lot more upset than I do, and that, it's weird because I'll say but I'm fine, I'm still here, he didn't kill me (reassuring warm tone) you know and she says that's not the point you know....I just have to support my wife whenever I can (laughs) cause it still gets to her (p. 3, 87-92; p. 20, 621-624).

During the interview Nigel places emphasis on how different stages of the incident and recovery have had an impact on his wife. The extract above highlights how he appears to view himself as resilient and that it is his role to support and reassure his wife, acknowledging the impact of the traumatic nature of his injury on others.

When couples remained together following the injury, as was the case for George, John and Simon, the support from their partners also appeared to be identified as a demonstration of strength within the relationship. These extracts indicate how the reliance on a partner was also perhaps experienced as a demonstration of a partner's commitment and also as a sign of resilience as a couple.

George: And I don't know realistically where I'd have been if she hadn't been about. So I've realised that she does love me (laughs) you know (p. 18, 433)

Smith: I think I would be lost without the wife (p.7, 200).

Simon: We spend lot of time together but where some would eh falter, or would find difficult, we, it's worked well for us, we both enjoy each other's

company so been lucky in that way. I know when therapy first started (wife) looked at the average (time) for married couples to stay together after head injury – it's not long. So we've done well. Yeh it works well (p. 5-6, 158-163).

Simon had clearly previously been made aware that relationships often did not survive after head injury and felt a degree of pride in how he and his wife had managed as a couple.

Changes in work roles and relationships at work were also highlighted by participants in relation to identity as a man. This appeared to overlap with roles within the family as provider. Particularly, there was a sense of status as a man being threatened at times within the work context, and this was the case for Nigel and Chris who had returned to work.

Interviewer: Do you think that getting back to normal and back to work, for you does that have any meaning in relation to your identity as a man? Nigel: it probably does because you know, you know my job is in the control room manager, you know, you've got, 'cause I said to (wife) I'm a bit worried now that I get redeployed cause I can't do night shifts they might redeploy me to a job or whatever and I don't wanna lose the respect that I've sort of built up the last 20 odd years, you know working my way up and because of someone ran me over I'm back down there again. So it's not all you know, financial, although that's important cause you know the job that I do, they might offer me a job that's a lot less money but they're not night shifts type thing so I'll have to see what they can offer really (p. 17-18, 550-560). In addition to needing some help rehabilitating at work, and needing to ask for this help from very junior staff member, Chris talks about how difficulties and reliance on others can result in him questioning his capability and his deservedness of his role as manager:

So for example it was busy summer lunch time a really simple drink, and I had to ask a new starter, actually, I don't even know what I'm doing can you just show me how to do it cause I have no idea I've done it a hundred, well probably a thousand times before but I had no clue what to do so they had to do it for me....I felt like, like people had lost a little bit of respect for me.... I'm only there on merit, like I don't deserve it, well this is how I felt at the time, I don't deserve to be store manager cause I can't do the job kind of thing (p. 4, 116-126; p. 15, 483-485).

Chris draws comparisons with his pre-injury ability. These extracts appear to overlap with feeling dependent on others and feeling out of control of his own body and mind which he had contrasted with how he thought a man should be. Another crucial part of Nigel and Chris's responses was their felt sense that others had lost respect for them. This theme will be developed in section 1.3 below.

Luke and Peter are the youngest participants at age 21 and 22 years. Both of them explicitly say at different points during the interview that they do not relate changes in their life to masculine identity. However, as young men in their early twenties, their interviews suggest that they both identify with peer group expectations about how they should be living their life and they appear to feel isolated from their pre-injury peer groups.

A large part of Luke's life pre-injury was playing football. His team have encouraged him to remain part of the team through supporting with activities. This appears to present a dilemma as, whilst maintaining aspects of this social role, he is also confronted with a loss: It's frustrating just standing there and watching and not getting my boots on and playing (165-166)... And it makes me think yes I'd love to, and I mostly will but it's not the same. It's never the same and that's what's frustrating for me. 'Cause I think well I'm only 22, like, I should be playing at least until I'm a good 35ish (p. 6, 164-170).

Peter also compares himself to others in his peer group where the expectations are to work long hours during the week and go out at the weekend.

Peter: Like, where I used to work, Friday night would be going down the pub for a few pints then Saturday would be going into town and getting a bit more than a few pints but yeh that's a bit rubbish cause now you're sort of at home, sat in, with not really much to do. ... You think like I'm 21, I should be out making the most of it, whereas I'm just sat here watching TV, it's not great (p. 10, 301-307).

## 3.4 Self-perceptions and the Perceived View of Others

All participants talked about different aspects of their internal emotional and cognitive experiences. Participants talked about how they felt their own lived experience was different from how others saw them. The invisible nature of brain injury was considered in comparison to a visible physical injury or disability and this appeared to result in both positive and negative experiences in relation to masculine identity. Participant's talked about their own self-perceptions and the ways in which they thought others perceived them. This often related to activities which they felt they should be doing as a man but were not. When this was identified either by themselves or it was felt that others identified that an individual was not meeting the expectations of a man, participants experienced shame and embarrassment. Each master theme will now be described in turn.

# **3.4.1** The invisible nature of the injury. "Oh you look fine, you look no different" (Nigel)

The invisible nature of the injury meant that participants had interactions with others in which their individual experience was not understood. John states:

like if I'd lost my arm, you can see it's gone, you can understand it and other people can see it (p.2, 38-39).

Similarly, Nigel talks about how the outer shell of normality hides his internal experience:

Cause I mean a lot of it, it's difficult for a lot of people, cause they look at me "oh you look fine" "you look no different." You look like, you know (laughs) you look you know just the same and but you know, that's just the outer shell, they can't see obviously what's in there (gestures to head) so you know (p. 16, 505-508).

The invisibility of the injury for Nigel and the ability for the "outer shell" to appear the same may suggest that he feels others do not understand his experience, or certainly will not immediately understand about his injury and its effects. However, this may also be a protective shell in some ways and he later talks about how he prefers to keep internal emotions to himself:

I've never been one of these people that expresses my feelings to everyone who cares to listen type thing, I've always sort of been quite a closed book really (p. 10, 302-305).

Similarly, George indicates that he prefers his internal experience to be private:

*Cause you don't obviously go and tell everyone down there (the local pub) what's going on in your head you know, well I don't anyway (p.10, 316-317).* 

Gordon also highlights how he feels others recognise that he uses a wheelchair but that they do not recognise the impact of the invisible injury:

They couldn't see it, they said well surely he's only in a wheelchair he can sit here, but they couldn't, because I don't sort of talk to people about my brain injury, a lot of people just see physical disability, they don't actually realise that I'm trying to deal with things (p. 7, 200-204).

It may be that Gordon also finds some protection in the invisibility as he chooses not to share with others. However, he also indicates that he feels this maintains others lack of understanding which appears to be distressing for him.

For Chris, the invisibility of the injury causes frustration and he talks about how at work he tries to convey his experience to others:

it's not visible, especially my boss at work, like they think I'm fine, but I try and get across to them how much harder I have to try to get the same results (p.14, 446-448).

John and Luke gave examples of times when they felt their own lived experience was valuable and important, which they identify as positive.

Luke: my doctor has asked me to come off my tablets. I come off them for a week or 2, I was, well, I put myself back on cause the shakes were that bad, I felt really off balance if I was walking about and stuff. So I didn't feel the need to come off it. I know he obviously says different but he's not in my body right now, he's not experiencing what I'm experiencing. He can only *judge by what I'm telling him. So any doctor, like with brain injury for instance, you can only imagine (p. 5-6, 191-195).* 

Luke appears to have made his own decisions about medication in response to what he felt was right for himself. His rationale indicates he feels empowered through recognition that only he can know what it is like to be him and that he is therefore best informed to make decisions about himself. Similarly, when the value of his experience was acknowledged by a professional, John recalls this as hugely positive and acknowledged his personhood and humanity:

That's why that Dr (name) character, I loved to bits 'cause I remember the first time I met him and he said, anything I say is based on the theory and the studies, he said, I have not got a clue what it's like to be in your shoes. He says every person I see in your situation isn't in your situation because you've all got different backgrounds and history he said and all I can do is help you and maybe understand some of the theory and all the rest of it and I will learn more from you than you will from me. And that was like Wow! I mean, honestly, I remember it for one thing, it was one of the most ground breaking things for me, because it made me feel like I wasn't just a number, I was an individual and had a purpose (p. 12, 376-384).

This experience has been powerful for John. John feels that not only is he being considered as an important and unique person, perhaps in contrast to being viewed as a passive receiver of services. It seems that having a purpose may also refer to having something to contribute to working with this doctor in the sense of being of value to him in promoting his learning. In other extracts, John has related "having a purpose" to his sense of identity as a man and it appears that that this interaction with a professional has been protective of his masculine identity.

# **3.4.2** Concern about being judged as less of a man *"You then think, do other people look at you differently?"* (Jake)

Participants expressed concern that they would be viewed negatively by others because of their injury and that others would judge them negatively as a man. The data suggests that sometimes this was based on actual experiences of stigma or of negative stereotypes about head injury and sometimes on anticipation of these. Gordon talks about an upsetting experience of others having negative stereotypes about brain injury:

But it's very difficult to try and explain cause if you say a brain injury to people they just think you're daft you know that is the... That's the way... Cause I go to headway you see and people say oh that's, you know, that's for idiots I said no, no, they've had a brain injury but people always think the worst with it.( ...)I mean I said to someone, it was on the bus, he said what you up to the weekend? and I was talking to him, he said how about next week? I said I go to headway Monday. He said what the hell do you go there for then? He said that's... I don't know what he said now, he said that's... I dunno he said something horrible you know about it, and I said cause I've had a.. he said oh you're one of them are you? I said what's that? He said not quite there, a sandwich less a picnic this sort of thing. Cruel isn't it! And I said well you don't really... And then people judge me (p. 5, 143-157).

It seems that for Gordon, the concern about being viewed negatively means that he feels he has to put on a front, to try and be the man expected within society. However, within social groups with others who have experienced a brain injury he does feel accepted as a man:

I feel more manly there (in brain injury social group), I feel as if I'm a lot more brighter there and I never feel so bad, I do feel, I feel more myself there because I can let myself erm just be myself, who I am. But on the outside world trying to act as though, I suppose I put a front on in the real world as a man my age, and there you can just be yourself, and everyone accepts you as what you are (p.9, 281-285).

For other participants, the stigma may not have been so explicitly expressed by others, however they talked about how they thought others might judge them because of brain injury. Luke gives an example about when he went to meet his new girlfriend's family:

I was scared but I was more worried in the sense of how they'd then take me as a person. Would they look at me any different as such? And it do make you think, like would that person actually look at me any different, just because I had a serious car accident and a brain injury? Like would they sit there and think, for instance, I don't want my daughter to be with this person (p. 14, 437-442).

Luke appears to feel nervous about being judged as not good enough, and he goes on to talk about his attributions of a previous relationship breakdown including that as a consequence of TBI, his girlfriend didn't have the patience to deal with him and that his loss of financial earning ability and status changed her desire to be in the relationship.

Jake also identifies similar concerns about how others view his role in his relationship:

It do worry you at the same time, cause like you then think do other people look at you differently cause you can't support in a way that like, cause obviously she was used to living the life style (p. 7, 227-230).

Jake goes on to talk about his concerns that his peer group view him differently and that they may underestimate his ability to join in activities:

I didn't want people thinking oh we can't do that cause of Jake. There are things like day to day life like that. And everywhere I go someone will suggest something and oh no – Jake can't do that (p. 10, 308-310).

Jake also considers the changes to his identity as a man in terms of how others may see him differently:

Well I've always been a tough boy do you know what I mean, – people can rely on me to do anything. I'd always be the first one there do you know what I mean, and now it's different (p. 15, 481-482).

Similarly, Chris expresses concern about how others view the support he has received:

cause in the negative side of it I feel like they see me as this little boy who needed all this help to get back together, these nothing wrong with him really, he broke his arm, broke some bones and a bash on the head and he needed this much help to get back to normal (p. 14, 438-431).

Both Jake and Chris indicate that they feel they have to convince others that their negative perceptions are not true. For Jake, this tends to be convincing peers that he can join in activities and persuade them that he is not fragile:

It's like yes! I'm not joking, like they think I'm mad sometimes (p. 16, 502).

Chris highlights that this is intensified by the invisibility of his injury and goes on to describe his experiences at family social gatherings:

"you had to be like look at me, look at me, I'm normal, I'm normal, I'm normal and point out everything that you're doing that's normal whereas before you just done it and no one cared" (p. 16, 501-503).

Peter also considers how the impact of his injury changes his outward appearance and how others might view him. For example he talks about how he feels his desirability as a man may be different because of reliance on his parents:

like you're going through a car park or something, and like a 21 year old in the car with their mum is a bit rubbish really. It does, yeh you're not quite as, you're not as independent or you see like you might see a nice young lady in the carpark for example and she might be like oh he's all right and then like oh he's in the car with his mum, it's a bit gay (p. 9, 287-291)

Peter's use of language may reflect the colloquial use of "gay" to mean something is negative or undesirable as being seen with his mum is not how he would like others to see him (Postic, & Prough, 2014). Alternatively, Peter's use of the word "gay" may indicate that he feels he is no longer seen as a heterosexual man, and this may have a subordinate or diminished interpretation (Connell & Messerschmidt, 2005). Peter also considers how other people may view him as not living up to physical expectations of being a man. He gives an example of when he was not allowed to life a heavy bag of compost into a car and a female member of support staff was doing it instead, and of avoiding activity in the gym as he is worried about how it looks to other people: I'm thinking everybody looking at me thinking "why is he not doing that" sort of thing....You see again, that's (lifting weights) like a bit of a masculinity thing as well, like we go to the gym and we do weights in front of mirrors and I'm doing like 3kg weights cause of my left arm's pretty crap and that's all I can really lift which is a bit rubbish really. And like I don't do that on me own, when I went on me own a couple of times. When I went with the physio I'd do it cause I'd happy got an excuse then to do it, but on me own I don't wanna sit there and do 3kg weights, 3kg weights cause it just looks rubbish sort of thing. (p. 5, 144-145; p. 14, 438-444)

Peter indicates that when he is with a physiotherapist he feel less judged by others because he has an excuse. The use of the word excuse suggests that Peter feels he needs to provide a reason to others which might protect him from being viewed as less of a man by others. The extent to which this relates to Peter's internal experience or to his experience of interactions and responses from others is unclear. In many of these extracts it is not always clear whether participants' concern about being viewed negatively by others is influenced as much by their own judgments of themselves as a man as by the responses of others that they have experienced.

## 3.4.3 Shame and loss of self-confidence. *"I certainly felt too ashamed to even try that"* (John)

Participants expressed that they experienced shame and loss of self-confidence in themselves which was related to how they saw themselves and how they thought that others viewed them as a man. For John, losing roles such as being able to look after his children, where he is trusted to be responsible and where he feels he has become dependent on his wife is shameful for him, describing this as "humiliating" (p. 7, 221). John: (Wife) had to help me shower for a couple of weeks after the accident and I mean like how is she going to find me attractive and sexy (he laughs) if she's got to basically wipe my arse for me? ....I doubt (wife) could have fancied me or found me attractive because she was my carer and I certainly felt too ashamed to even try that (sex)(p. 5,159-161; p. 8, 248-250).

These extracts from John's interview illustrate how he experienced care as shameful and the impact that this had how he feels as the man in his relationship. There is also a sense in which a different kind of physical intimacy, being physically cared for at an intimate level, might be an anathema to his own sense of himself as a sexual person. This may be considered a particularly personal topic and in general, participants did not discuss sex during interviews. There was a sense that these intimate discussions were avoided, perhaps due to embarrassment or potential shame.

A change in physical appearance and ability is also identified as having a diminishing effect on self-esteem for participants.

Luke: you gain that confidence in yourself cause, when I was in hospital I lost 3 stone and I used to like working out before and I used to be at work and playing football so I was very active. My job was very active so I was enjoying life as such. And then I'm 3 stones lighter and just not having no confidence whatsoever (p. 8, 241-245).

John: I put a fair bit of pudding on....And the first few weeks I hated every second of training, in fact I hated every second of 9k of the 10k! (laughs) it was horrible. I felt so shit and so unfit compared to what I'd been prior to the accident. (p. 8, 260; p. 9, 268-270) In the extracts above, Luke suggests that he had gained confidence in the past through physical health and that this had been part of his work and leisure which has been lost. John's change in physical appearance suggests that he felt disgusted with himself when he begins to train for a running race. Appearing physically strong and achieving physically appears to facilitate an increase in self-confidence and promote strength in contrast to being viewed as weak.

Loss of confidence and embarrassment in social situations as a result of the injury, was also highlighted by participants:

*Jake; it just made me all shy and that. And men shouldn't be shy should they (p. 13, 427).* 

Nigel talks about experiencing difficulties in managing money in a pub and describes

Things do happen when you just feel, a bit silly really (p. 4, 127).

Similarly, Gordon talks about an occasion where he left a social evening which he attributed to fatigue and having difficulty in managing the noise:

That night it was embarrassing cause I just, I couldn't stop you see and I felt bad because I let her down, must have made a laughing stock of myself and I just couldn't cope and erm, I just, couldn't cope then that makes you think there's other people our age, and their husbands, boyfriends they're all fine they get on with it and that puts me back, that sets me back socially, not going out you see and that's why I ended up stopping doing anything.... it makes me feel silly again, it doesn't make me feel grown up, erm yes it's when other people my age, other men, they wouldn't do that, you know (p. 7, 204–209; p. 8, 231-232) Gordon directly compares himself to other men and appears to evaluate himself as not fulfilling the social expectations of men, husbands, or boyfriends. His description of feeling "a laughing stock" speaks to the degree of shame and embarrassment he felt about not being able to cope with social situations and commitments.

Participants identified feeling shame and guilt about their feelings related to their own lives when they compared themselves to others. George describes himself as "whingeing" (p. 16, 507) about his injury when he considers himself in comparison to those with more severe injuries. In situations where Chris and John have been in groups for people who have had a brain injury they both talk about how they compared themselves to others and how this made them feel guilty.

Chris: we had group sessions where other people with brain injuries would go and just discuss tactics, how to get around problems and stuff, which was really beneficial but at the same time it made me feel really, really guilty that I was complaining and moaning about the state I was in when people across the room from me were in such a worse state than me. I just felt like I was wasting peoples time asking for help and I didn't really deserve the help 'cause that person across the room from me was a lot worse. So I felt a bit guilty then, for quite a while I felt guilty. Yeh. 'Cause I didn't feel like I needed this sort of help but I was being given it (p. 6, 167-168).

Similarly, John states:

I ain't got the brain space to listen to anyone else's problems to be honest erm it just drives me mad hearing other people's. And then I feel guilty that mine aren't as severe as theirs, or if theirs seem lesser for any reason I get angry about it. (p.4, 126-129).

88

It seems that the comparison to others can mean that participants feel they are nondeserving of support and can also result in feelings of guilt in relation to how they judge their difficulties in relation to others. It therefore seems as if participants experience self-to-other comparisons as negative, regardless of the comparison group. If comparing themselves to non brain-injured men, this brings up feelings of loss, shame, embarrassment and inadequacy, but if comparing themselves to other brain injured men, they feel guilty, undeserving and unworthy.

# 3.4.4 Not feeling safe, feeling vulnerable. *"I find myself being a lot more cautious."* (George)

The participants talked about how having the injury meant that they tended to behave in a more cautious way and that they were more aware of risk. This appeared to be related to their own sense of how further injury may potentially affect them, or cause death. John talks about a time when he was punched by a friend out of the blue which made him consider how at risk he was from others unpredictable actions:

and that kind of brought home as well how frail, I suppose, I feel which is again emasculating (p. 15, 478-480).

Smith talks about how his sense of caution impacts daily life:

As you progress with your everyday living, you're now more aware of what you're doing and you'll think twice before you do something foolish or erratic. You think ohh, you know (p. 10, 301-302).

Participants mainly talked about an awareness of the risk of further physical injury particularly being a victim of a physical attack or getting involved in a fight. Some participants had clearly experienced these kinds of physical risks and encounters very differently pre-injury, and would have responded in a different way to the way they do now. George explicitly relates his cautious behaviour to the potential for further injury to be fatal which contrasts with his comparisons to himself before his injury as being confident in how he physically moved and interacted with others.

George : it's knocked me in a way where is someone say have a go at me, I'd go straight back at them cause, I know it sounds horrible but I know I could look after myself if you know what I mean, as in with fists, where now I've got a broken finger, I can't clench my fist and I haven't got the confidence so much to argue back either (p. 6, 167-171).

He later says:

I mean another thing about the nerves, I've still got about 25 fractures on my skull so I think if I fell over or I got hit or anything got knocked again, it's goodbye Vienna if you know what I mean. So I find myself being a lot more cautious (p. 12-13, 389-392).

George's extracts suggest that he now feel more vulnerable and less able to protect himself and others. He describes himself pre-injury as "*a rouge*" (p. 6, 166) with the implication that he had been involved in physical altercations previously. However he no longer maintains this identity.

The vulnerability which Gordon experiences appears to be linked with his lack of confidence as a man in the "real world" in contrast to feeling "more manly" within the brain injury community. Gordon uses a wheelchair and therefore his adjustment to experiencing life differently due to this may also impact on his sense of vulnerability.

Gordon: but it's just you know you go to these, you do these a couple of times a week these clubs but then when you leave them it just feels it all comes crumbling down, you don't feel safe. And another thing, I feel safe when I'm at these places, I feel safe and secure, I don't feel in harm, but when I'm out and going round the city I just feel very vulnerable and disorientated and just not, not very positive (p. 10, 297-301).

This excerpt illustrates how vulnerable and unprotected Gordon feels. It is unclear what he is referring to when he describes that it "*all comes crumbling down*" but clearly his sense of safety, vulnerability and orientation is affected as soon as he leaves his brain injury club.

John and Simon also suggest that they gain a sense of safety from professional services and that being discharged from professional services left them feeling unsafe.

John: I've been really scared of being cut loose into the general population cause like who have I got to turn to when the shit hits the fan (p. 12, 369-370).

Simon: I like, worried, (about the) thought about not having the support. And if I felt low then there wasn't anyone there. But since they said just phone and they'll see me so that's ok (p. 2, 32-33).

Participants appeared to be concerned with a number of kinds of safety in these extracts but predominantly with their physical safety and with the safety provided by the group, whether this was a peer group or a service that was providing professional support.

### 3.5 Managing the Impact as a Man

Participants differed in how they managed the impact of living with a TBI in relation to their identity as a man. Participants talked about coping strategies such as reformulation of roles, compensating, denial and avoidance. For some, the impact had resulted in reevaluating their life and values and they felt that the impact of the injury had had some positive influences.

91

### 3.5.1 Coping with adjustments. "Yesss! I've reclaimed some manliness!" (John)

Participants acknowledged that aspects of their life had changed and described differing responses. A prominent part of this experience appeared to be that participants drew on ideals of strength and resilience to cope with making adjustments. For example, Jake visits the rehabilitation centre weekly and is asked what it is like as a man to gain this support. Jake talks about how he has become more accepting of receiving therapeutic support and how this relates to his ideas about how a man should cope:

*I used to just think you're depressed you need to just give yourself a kick up the arse and get out of it, I've always been that type of person, nothing can bring me down no matter what (p. 8-9, 262-265).* 

Gaining professional support in relation to mental wellbeing appears to be made more acceptable for Jake because of the brain injury. Jake also appears to have reformulated help seeking as protective as his identity as a man and he expresses that his resilience in life is part of what it means to be a man:

Like a man should be someone who's powerful, someone that can't be knocked down, can't be brought down by what's happened, make the bright side of anything, like someone that can support people, show people that there is like there's no point in giving up and that cause at times I felt like giving up, can't be bothered with it anymore cause I'd get stressed and depressed about it but there aint no point in being like that, I've got the rest of my life to live....it (having help) doesn't make you any less of a man, if anything it makes you stronger cause you learn new things (p. 18, 584-589; p. 21, 686-687) Others also identified that their view of seeking help in coping with adjustments demonstrated strength as a man.

Gordon: I suppose it takes a very strong person to get over it as well, a man. A lot of men I don't think would be able to cope with it.... I don't know what they'd do but they just wouldn't want to carry on in that situation....But you have to have a lot of go in you and a lot of erm erm, what's it called, sort of, courage to push on, you have to get over it...yeh, Strength,, it takes strength (p. 17-18, 549 – 561).

Chris: I feel like it actually did take a little bit to be a man to be like, yeh you have got a bit of problem you need to sort yourself out, you need to bite the bullet and do it rather than mope at home and be a little baby by yourself, just go out and try and fix yourself, so yeh (p. 13, 399-402).

Similarly, having resilience to manage changes and view changes as being a short term impact appears to be helpful for Luke who seems to have interpreted the uncertainty about his recovery as possibility and potential. Luke's desire to progress and develop is prominent. Luke also expresses the importance of this drive and changes for improvement coming from himself rather than others:

I managed to rebuild it up as such and I've done that all off my own back. Only me that's done it so I feel like I don't need anyone to help me out (p. 8, 252-254).

Luke's drive to be independent appears to have enabled him to implement changes to his dayto-day life through reformulating use of strategies to maintain independence. Luke: It's not too bad actually (using memory aids such as lists) I in a way prefer it cause at least then I'm not 'oh should have done this, should have got this today', I prefer it like that (p. 11, 324-325).

This contrasts with Gordon's initial reluctance to adopt compensatory strategies:

I just want to go back to how, you know try to be myself, but it's not gonna be and it's trying to adjust make adjustments, and change, turn your life and do it all in a different way....to do things differently when I didn't want to but realising now getting to the stage after 3 years that I'm going to have to start writing things down (p. 14, 445-4447; p. 16, 503-504).

It appears that Luke has reformulated the use of strategies as promoting independence which consequently means he feels more able to use compensatory strategies than Gordon, who viewed strategies as being reliant.

Participants discussed how they coped with adjustments through adapting activities, making compromises or thinking about things differently. Simon appears to aim to compensate:

It's little things like teaching my children to ride bikes, normal Dad's hold the seat and run and then let go and they ride so I couldn't do that erm which found ways of getting round it. We went, found a hill (laughs) and sat them off (laughs) on the bike and pushed them down (laughs), that worked, they now can ride the bikes (p. 2, 45-49).

Again where some parents go on governors for school, I can't do that for because reading and all, I can do other stuff to make up for it. So yeh. It's you can see it's still raw, upsetting to think of stuff I can't do, but then think of ways I can make up for it....(I'm) finding other ways of trying to make up for the way I am. So I erm grow a lot of flowers or veg or fruit, so it tries to outweigh the grass (p. 3, 89-90; p.4, 113-114).

The above extracts from Simon suggests that he considers what "normal" (p. 2, 46) activity is as a man and that he feels there is a difference between this ideal and his own experience. He demonstrates how he has tried to be creative and use the skills he does have to fulfil roles within the school community and within his family. For example as he cannot do some physical things such as playing football, he takes his son to archery as this is something they can do together. Simon identifies that through doing this he gains pleasure and pride. Whilst this is positive for Simon, he seems to suggest that his compensatory strategies only partially make up for some of the losses he is adjusting to:

It makes up for some of the bad points (p. 3, 81).

For John, compromising some of his values in order to protect roles which are part of his identity can be illustrated in the impact of fatigue:

I call it a siesta because it makes it feel cool and continental. When it's referred to as a nap, I feel like a baby.... It took (wife) basically 2 years to argue with me to get me to nap, cause if I don't recharge my batteries I'm no use as a father in the evenings which is even more humiliating. So me having an hours rest before (child) comes home from school, I can contribute as a parent (p. 8, 240 - 246).

In the above extract, John appears to compromise his reluctance to have a rest during the day in order to protect his ability to be a father which would be more damaging or threatening to his identity as a man. John's changed activity also appears to have been reformulated as something which contributes to his identity as a man in his family:

But in the last few weeks I have kind of regained some manliness...

Researcher: what do you mean by regaining manliness?

John: started gardening....And I think that the running and the gardening stuff has made (wife) find me attractive again 'cause I'm the man in her life and instead of me being dependent on her, I suppose I'm doing things that I should be doing. Sorry I sound like such a cliché. (p. 11, 336-348).

Despite the significance of this activity for him, John appears embarrassed by his suggestion of male stereotypes. He initially talks about gardening in a humorous way, describing himself as an *"old man"* (p. 11, 338). However, reformulating his view of gardening means that he has a meaningful activity as a man:

when I do gardening and I come in and I've got mud under my nails and I've been sweating, I've earned the right to be tired. Cause that's the crap thing when you're tired all the time for no reason, if I'm going to be tired I want to have earned the right to be tired (p. 16, 507-510).

These extracts from John contrast with his earlier accounts of how he managed the impact of TBI. He describes his initial denial and avoidance:

The first two years I drank quite a lot, I was constantly going out, I was trying to be the old me, I wouldn't accept there was anything wrong, it took me a long time to accept there was anything wrong (p. 5, 162-164).

Nigel expressed that he did not identify his experience as having an impact on his identity as a man:

I don't feel any less of a man having a brain injury. I still, you know, I still feel, I still feel like me most of the time (p. 5, 146-147).

Nigel's interview illustrates differences in how he feels he has a supportive group of friends and does not feel excluded. It seems that Nigel has been able to maintain some pre injury activities which has been protective for him.

I still do eh, you know I still do the blokey things you know go down the pub, meet friends, I don't drink much now cause I have to be careful with the brain injury and alcohol and stuff so you know I still do that, go to the football (p. 18, 565-568).

## 3.5.2 Re-evaluating life and values. *"I'm very, very lucky to, on all accounts, to still be alive"* (Smith)

Participants talked about how they felt that they had been given a second chance and often considered how much more severe the impact of their injury may have been.

Smith: It makes you more aware of who you are or what you're doing because you... you sometimes, when you, now on the bus you know, you see a lot more people and you, you know, you get seeing people with disabilities, you think, hey, at least I can walk, you know, I don't need help (p. 12, 371-374).

However, explicitly referring to feeling lucky often appears to be contrasted with the reality of difficulties in day-to-day life and how they are not leading a lucky life.

John: apparently I should have been dead or in a wheelchair for the rest of my life. So its's weird cause I feel like the luckiest unlucky person (p. 1, 19)

Similarly, throughout Nigel's interview he refers to potential difficulties which are not a problem he experiences and in this way appears to minimalize his difficulties. For example he feels he has not had difficulties with crowds, anxiety about leaving the house or losing friends, all of which he identifies as being possible outcomes of TBI. Although "luck" is a

prominent feature in Nigel's interview, he does indicate that he finds some of his "luck" exists within a bigger context of being unlucky. For example, this can be seen when he talks about how the circumstances of the incident meant that he had opportunities for legal support and privately funded health care:

Luckily, well I say luckily, but luckily I was hit by, it was white transit van, so erm and he was insured luckily and as soon as I was in (specialist regional hospital) erm, I can't remember anything about it but my wife was given some numbers to try for like sort of compensation claim type thing (p.4, 103-106)

Nigel's view on luck appears to enable him to minimalize the impact and promotes acceptance:

I think you just have to sort of be happy with who you are, I think you do, I think you have to be happy with you are because you can't go back you can never go back you can't turn the clock back (p. 19, 605-607).

Nigel's view of luck may be a protective factor in making sense of the impact of his injuries. However, his frequent reference to luck may indicate that he feels his life has been able to continue as it was pre-injury.

When participants considered their current ability and compared it to others this appeared to promote the belief that they should feel lucky. However, the reality which was talked about in the content of the interviews suggested that they tended not to feel lucky. This seems to link to feeling ashamed or embarrassed by their own difficulties and a guilt for not being more strong or resilient when compared to others.

George: I looked at some people in there and I thought, my god, I'm lucky to be how I am. You know. Because there was some people in there who

98

you know, who had injury and would never be able to walk again in their life. You know, so realistically I sit here winging like I have been for the last hour to yourself, I'm bloody lucky to still be here (p. 16, 504-508)

Participants reflected on their current situation and how their experiences so far had contributed to their learning about themselves and had positive outcomes about the kind of values they had in their lives. For Chris, learning mindfulness had added value to his life for others it was about the way they lived their life and the values they placed on family.

Chris: You know who your friends are. Not that I was distant, I was close with my family but it's brought us closer even still so that's really good. Erm, appreciate the good things in life. Appreciate when you achieve something and I know what I had to do to get that. Erm... it's introduced me to mindfulness I would not have got involved in that. (p. 9, 291-295)

George: I've got no idea what I'm gonna do but at least I'll spend some more time with my kids. You know so at least. After having this happen I think family's a very big thing for you. You know. It's all very nice to have money, which I have a bit of money, done all right for myself, but it puts a different perspective to what's important and in my eyes family is (p. 13, 412-416)

John: I used to be all about me, living for the moment, all the things that were priorities in my life were things which are irrelevant now, I didn't value family and all the rest of it and I didn't really have any compassion for anyone and I'd say now it's kind of been a moral reversal (laughs) in that the only thing that comes first is my family... (I'm a) much better person because I suppose it's made me revaluate my life, what actually matters erm that I'd wasted, well I didn't waste it cause I had fun but 10 years of kind of living for the day which I suppose is a good thing, but not actually having any respect or values for myself or anyone else around me. (p. 16, 493-502)

John and George reflect on how their values have changed. It seems that their values about what it means to be a man have changed. George had talked about prioritising working and providing materialistic things for his family before his injury and John described himself as being a man about town. However, for them both, the injury appears to have contributed to changing the values they hold about what is important for their identity.

Similarly, both John and Simon discuss how they have found new values in community roles. For both of them this has related partly to their children's school community. Simon talks about various woodwork and creative projects he has developed for use in his children's school and reflects on this:

Where others may only get pleasure from their own children's thanks, which I do (he laughs) but with the things I'm doing I get thanks from, pleasure from helping all the kids and they all thank me which is nice (p.4, 96-99).

*John: I've joined the PA (Parents Association) at my daughter's school, because I've got the time to do it and I want to contribute (p. 16, 503-504).* 

John also talks about how his change in lifestyle, not only has enabled him to find value and meaning, but also means that he can help others:

Whereas before I probably would have drunk myself into a stupor, smoked myself until my lungs fell apart and not be available on my phone at all to the people who were worried about me and not give a shit about it, instead I'd bugger off and do a 10 mile run off in the countryside somewhere. So yeh, running saved my life....It feels great, to feel, I guess to inspire other people because a lot of people inspire me... I'm actually hoping to do a course, like a couch to 5k coaching course, cause I really wanna help other people now (p. 10, 299-302; p. 10, 323-238).

These extracts suggest that participants in this study re-evaluated their life and values and that this related to negotiating their roles and values as a man.

## **Reflection 3: Personal reflection on analysis**

There are a range of influences shaping the analysis and interpretative processes which are important to consider as the process of analysis involved many choices which were informed by my own perspective.

This is the first qualitative analysis which I have undertaken. Given this, it may be likely that there is a closer alignment to the epistemological position of Smith, the developer of IPA, rather than a critical perspective. In addition this meant that during initial coding, I found that descriptive and linguistic coding was initially was easier to identify. However, through use of supervision of initial coding, conceptual level coding became more prominent and confidence in the analysis increased.

Dilemmas were encountered when it was felt that analysis was either too interpretative or not interpretative enough. At times this appeared to be due to giving consideration to existing literature and making claims which were not obviously evident in the data. At other times, I was perhaps making interpretations based on the sense gained from an individual's interview, and the data used to support this needed to be reconsidered in order to ensure that interpretations were founded on data.

It was difficult at times to reduce the amount of data, as this could feel like leaving behind data which a participant had contributed. This became easier as the process went on as I was able to use the reflective diary and supervision to explore this. In addition, as skills in analysis developed, I felt more able to capture the meaning of individual data within themes.

Some interviewees, such as John, Gordon and Simon particularly were more expressive of emotion. It may be that it was therefore easier to identify with some individuals who were more expressive in their emotional language. In order to ensure that an all voices were represented throughout the analysis, I found it helpful to stop and slow down to consider participants data, rather than only those which may be easier to recall due to the emotive content.

### Discussion

#### 4.1 Overview of Discussion

This chapter reviews the findings of the current study by considering how they relate to existing literature with a specific focus on identity after traumatic brain injury and men's health behaviour. The clinical implications for rehabilitation are discussed. An evaluation of the strengths and limitations of the current research is presented followed by consideration of directions for future research.

## 4.2 Review of Findings and Existing Literature

The current research aimed to explore men's experiences of TBI in relation to their identity as a man. The findings illustrate this group of men's experiences of adjustment and their identity as a man within their individual contexts.

Participants identified differences between the ideals of masculine identity and their own experiences. This included ideals about ways of being in the world such as being selfreliant, autonomous, decisive and in control, as well as the roles and positions which they felt they should occupy within relationships, family, work and social contexts. The findings also illustrate how these men made sense of their experiences and the impact that this had on their perceptions of themselves. Participants identified challenges in adjustment to TBI when they experienced conflict between their lived experience and identity as a man. However, in contrast to this, ways in which masculine identity may have been helpful in adjustment to TBI and may have enabled participants to overcome some of the challenges they faced were also considered. The findings will now be discussed in-depth.

103

### 4.2.1 A discrepancy between ideals and lived experience.

The current study suggests that participants identified a difference between masculine ideals, or what they considered to be normal for a man, and their own experience. Discrepancies between past, present and future self is a widely evidenced experience within TBI literature (Gracey, Evans & Malley, 2009; Howes et al., 2005). The findings of the current study highlights how the effects of TBI including physical changes, communication difficulties, headaches, and memory difficulties lead to a feeling of a discrepancy in masculine identity. Participants talked about this discrepancy in relation to aspects of self as a man including physical appearance, roles as father, husband, activities, work roles, social or peer group expectations.

The findings support that when participants felt they did not meet pre injury standards that they experienced a conflict between masculine identity and disability (Barrett, 2014). The findings are consonant with the theory of gender role strain (Pleck, 1995; O'Neil, 2008) which suggests that when an individual does not meet the social expectations associated with gender, this can result in different stresses which may be harmful to an individual's wellbeing (Berger et al., 2008; Levant, 2011).

The degree to which participants identified explicitly and spontaneously with the idea that their identity as a man might be affected by TBI varied from participant to participant. For some, such as John and Jake they used phrases such "less of man" or "emasculating" throughout the interview. The variability of the explicitness may reflect the individual meaning or importance that men may place on their identity as a man. However, even when men did not so explicitly refer to masculine identity and may have placed less of an importance on their identity as a man or on adhering to masculine ideals, they did express common experiences. This therefore appears to support existing research which suggests that

104

even although men may not ascribe to dominant ideals, they continue to be influenced by them (O'Brien et al., 2005; Stergiou-Kita et al., 2015).

Activities which participants talked about differed, for example both Luke and Peter, the youngest participants identified that they were not engaging in activities such as 'going out' at the weekend with peers, whereas older participants focussed more on relationships and parenting. Where participants felt that they were able to engage in age related gender expectations, this appeared to be protective for them. This may be understood in relation to the framework outlined by Thomas et al. (2014) as facilitating a continuation of aspects of sociocentric identity or that their experience of personhood in interactions (Yeates, Gracey, & McGrath, 2008) has been maintained and therefore identity may br protected. The findings in this study therefore demonstrate how the expectations relating to masculine identity are influenced by an individual's context.

### 4.2.2 Loss of ability and fulfilling masculine ideals.

Participants' experiences of loss of independence, autonomy, and ability to carry out activities in relation to roles conflicted with their identity as a man. Participants talked about how their experiences of being restricted by the cognitive or physical impact of the injury and not feeling in control of body and mind conflicted with their views of how a man should be able to take control, make decisions and manage responsibilities. The experiences of loss of individual agency and not being able to maintain the pre-injury activity is well evidenced in existing literature (Levack et al., 2010). The current study extends these findings through consideration of how these experiences relate to masculine identity and suggest that these experiences can be linked to a sense of adequacy as a man.

Many of the men talked about how their physical appearance or fitness had changed and that this was an important aspect of their masculine identity. Participants discussed how their physical ability had changed due to TBI, for example some talked about how they had long periods being inactive during hospital admissions. Physical recovery and looking more like they had done pre-injury, or building up stamina was identified as positive within transcripts. This appeared to be important to participants as it enabled them to fulfil work and social roles, such as being able to work longer hours, to lift a respectable weight in the gym, or do physical activities which required body strength. Self-confidence and sense of masculinity has previously been associated with strength and muscularity (Kilmartin, 2007; Walker & Jaubert, 2011). Existing literature has proposed a relationship between traumatic experiences and shame which can influence men's perception of themselves as being weak and vulnerable (Joubert, 2014). Joubert's (2014) research suggested that striving to be physically stronger was related to feeling emotionally stronger and developing selfconfidence in men. From a phenomenological perspective, the current study suggests that some men related physical strength or ability and feeling adequate as man. From a more interpretative perspective, developing and demonstrating physical strength, for example through participating in pre-injury activity or engaging in competitive physical challenges, appeared to be a way of proving resilience and value as a man to others as well as themselves.

The cognitive or physical effects of their injuries for many men in this study resulted in becoming reliant on others in aspects of their daily lives. The need for someone to supervise and remind about daily activities such as cooking or finding it difficult to take large-scale responsibility for things such as managing household budget or legal settlements conflicted with masculine ideals around independence, personal control and self-reliance. Participants described the meaning of this as not being trusted to be responsible, or as role

106

reversal. A prominent example is the loss of independent financial responsibility which may conflict with self-reliance ideals of masculinity and the idea of the man as a provider as well as having implications for men's roles within relationships.

### 4.2.3 Participation in roles as a man.

TBI had a salient impact on how men participated in their life, changing the ways in which they carried out roles and relationships. Discussion of different roles by participants in the current study highlights how different social systems in which an individual is situated can influence their masculine ideals (Connell, 2012).

### 4.2.2.1 Being a father

When asked about the impact of TBI on roles and relationships as a man, all participants who were currently in relationships or had young children talked about ways in which the injury had changed the ways in which they carried out these roles. Fathers in the current study identified that they felt they were not fulfilling their role as a father as result of their injury. This included not being able to be responsible to care for children, not fulfilling the role of a provider and also not being able to cope with a busy family environment. In addition, difficulties in managing emotional responses and not being able to participate in shared leisure activity resulted in participants having a concern about their relationships with children and a recognition of a need to maintain a good relationship with their children. This supports existing literature which suggests that being a father who has a brain injury has additional challenges (Morriss, Wright, Smith, Roser, & Kendall, 2013) and also supports suggestions that brain injury has been found to be associated with higher levels of stress sand family dysfunction (Kieffer-Kristensen & Teasdale, 2011). However, for all of the participants who were fathers, this role appeared to be one which provided them with a purpose and motivation to adapt in order to strive to feel more able to fulfil their role as a

#### Masculine Identity After Traumatic Brain Injury

father. Although wider literature research identifies a tension between masculine identities and fatherhood (Dolan, 2014) which often relates to the expectation of being the breadwinner (Doucet, 2004), research also suggests that men do reconstruct or reject previous meanings of this role. For example, Rochlen, Suizzo, McKelley, and Scaringi (2008) identified that men who were stay at home fathers, although aware of ideals and stereotypes, either changed their perception of the norms or distanced themselves from ideals as they considered that they were providing for their family beyond financial means and the providing was "manly" (p. 202).

There is little existing literature on parenting with a traumatic brain injury (Morriss et al., 2013). However, through conducting individual interviews with fathers, partners and clinicians Morriss et al. (2013) provide a framework for considering how brain injury impairments may have an impact on different aspects of participating in a father role, including family functioning and perceptions of parenting. The study highlighted how fathers often had negative perceptions of their own ability to be a father in comparison to the perceptions of others. It was suggested that due to the complex interaction between brain injury and the differing impact on fathers' participation in this role, that an individualised approach to supporting parenting is required. The current study also suggests that the ability to enact their roles as a father was important to participants, and this role was identified as a protective factor by some participants. Therefore, this role could be an expression of identity which can promote a positive sense of self. Being able to enact their roles as fathers appeared to be quite critical to participants and appeared to be both a source of positive self-esteem and masculine identity but also be a source of reduced self-esteem and diminished masculine identity. Given the significance of this role, and the ongoing and evolving nature of it, when negative perceptions of ability to fulfil this role exist this may be particularly detrimental to masculine identity. Within rehabilitation this role is therefore an important one to consider

for an individual and it may be that aspects of this need to be re-considered as families change over time.

### 4.2.2.2 Occupational and Relational Roles

Day-to-day occupations of all of the participants in the current study had changed with the exception of one participant who had returned to his previous employment role. How men spent their time on a day-to-day basis was considered in relation to their identity as a man.

A prominent finding was that the loss of the role of being the breadwinner was salient for participants. This was particularly significant for participants who were in a relationship. It appeared that men considered this change as preventing them from fulfilling a role of providing a certain lifestyle or standard of living for their partner or family and appeared to threaten the participants' identity as a man within the relationship. In addition, a role reversal was identified in relation to household responsibilities and occupation. Participants also considered how other men may be better able to fulfil this role than they were. These social comparisons appeared to result in experiences of shame.

Some participants found that other activities enabled them to fulfil aspects of being a man which they valued, such as growing vegetables as a way of providing for the family. This may be understood as men reformulating masculine identity (Barrett, 2014; Gerschick, 2000) as masculine ideals, such as providing, were reconsidered in order to be in line with their own resources in their context. A change in roles and responsibilities may therefore be experienced by couples and the change can be unequal resulting in caregiver burden and couples face challenges in renegotiating their relationship together (Douglas & Bracy, 2013; Godwin, Chappel, & Kreutzer, 2014). Giving consideration to men's relational context and

the couple's relationship context within rehabilitation may therefore be a particularly valuable way of considering masculine identity after TBI.

Jones and Curtin (2011) consider how changes from breadwinner to a more domestic role is experienced by men who have had a TBI. They suggest that men placed emphasis on masculine components such as leadership and self-reliance in domestic activities in order to maintain a narrative of themselves which was aligned to hegemonic masculinity. They consider that this was easier for men to do when they had more flexible perceptions of masculinity, but when hegemonic ideals were strongly adhered to, men felt that their changed activity did not fulfil ideals. The impact of the changes in these roles has been related to a cause of psychological distress (Hoy, 2012) and it is therefore important to consider how men make sense of these day-to-day changes in activity in relation to their identity as a man.

The current study highlights how men's experiences of changes in occupation challenged their identity as a man, not only as a breadwinner, but also due to a more general sense of loss of purpose and value. Men talked about their pre-injury self in relation to activity and the meaning of this activity to their identity as a man. Engagement in social occupations can contribute to a person's knowledge of self and this may be illustrated where participants appeared to strive for activity which fulfils pre-injury occupation (Douglas, 2013). The role of occupation in self-identity after TBI is evident within the literature (Bryson-Campbell, Shaw, O'Brien, Holmes, & Magalhaes, 2013; Klinger, 2005; Thomas et al., 2014) and the current findings support that occupation is one way in which individuals strive to reconstruct their place in the world following TBI (Levack, 2010). The significance of these experiences for men in the current study support findings that making sense of the self is done through the process of engaging in social and practical activity (Gracey et al., 2008; Klinger, 2005; Ylvisaker et al., 2008). This is consistent with social identity theory and also supports Thomas et al.'s (2014) model where occupation assumes a central role both

as a threat to self-identity, through its loss or modification, and in the reconstruction selfidentity, through engaging in occupational activities.

The findings in the current project suggest that for men the desire to live life as they had done and the consideration of adapting occupations were particularly influenced by the meaning of occupation as being able to make a contribution, maintaining a connection with social roles such as provider, demonstrating self-reliance as well as strength and risk taking. However, for some men, the desire to return to life as it was, may restrict opportunities for new roles. Gutman and Napier-Klemic (1996) identified that men appeared to depend on traditionally masculine activities and activities they had previously engaged in. They suggested that rehabilitation after TBI should therefore support men to explore new ways in which they can express these values or roles as a man through meaningful occupation.

One way in which adapting the expression of these values through meaningful occupation has been considered in relation to masculine identity is engaging in community volunteering (Jones and Curtin, 2011). Interviews with men who were no longer in employed work due to TBI suggested that community roles enabled men to engage in aspects of masculine identity such as taking the lead on community projects. Contributing in this way enabled men to find value in their changed roles and to express and maintain masculine identity. Three of the participants in the current study had developed new roles through activities within their community. In line with previous research, contribution to the community appears to promote a sense of value as well as provide a source of acknowledgment of skill and improve self- esteem (Ylvisaker & Feeney, 2000). For the men in the current study, this appeared to relate to making a contribution and their skills being of value to others and in this way their expression of masculine identity was reformulated.

### 4.2.4 The shame of loss of identity as a man

The experience of shame for the men in the current study related to their perceived devaluation of their identity as a man. The interpretative phenomenological approach applied in the current research offers a more in-depth understanding of the internal experiences of these men, including the emotional experiences of shame previously identified in literature around the stigma of brain injury (Freeman, et al.,2014; Nochi, 1998).

In the current study an explicit reference to embarrassment or shame was present in half of the interviews and included experiences where participants talked about feeling embarrassed, degraded or humiliated. The presence of this theme suggests that men were able to explicitly recognise shame. This contrasts to the results of Freeman et al. (2014) who highlight that shame was only explicitly cited by two men out of nine in their study. Similarly, Gutman and Napier-Klemic (1996) identified that men talked about their activities with little expression of feeling but instead referred to states of activity such as working or not working. Although there was variation in emotional expression throughout the interviews for this study, the prominence of shame in the findings of the current study may reflect the more direct questioning about the meaning of experiences, therefore enabling a more in-depth understanding of the experience of shame in relation to identity as a man. The participants experienced shame associated within aspects of day-to-day life which had previously been a source of pride as a man. This finding suggests that the experience of shame may be particularly related to changes to identity as a man following TBI as ideals about masculinity appeared to influence the ways in which participants compared themselves to others and perceived themselves.

The way in which participants perceived themselves after TBI appeared to depend on the extent to which they fulfilled gender norms and on how they considered that others may view them in relation to this. Discrepancies between ideals and reality resulted in guilt,

#### Masculine Identity After Traumatic Brain Injury

Ruth MacQueen 2016

shame and loss of confidence. Participants expressed concerns about being viewed negatively by others which is consonant with previous research findings where during interviews about self after TBI, participants expressed concern of abnormality and as being viewed as crazy or stupid (Nochi, 1998). The current study provides a more in-depth understanding of this phenomenology by highlighting that these concerns relate to feeling *"less of a man"* (Gutman and Napier-Klemic, 1996, p538) as a result of not meeting the standards or expectations of self and others. For some participants in this study, the threat that a difference between the self and social expectations of being a man might be noticed or highlighted resulted in social withdrawal.

In addition to the shame associated with comparing poorly with masculine ideals, shame was also prominent in relation to the impact of the injury on their loved ones and also in relation to others who they had perceived as having experienced a more severe TBI. The latter was primarily in relation to use of rehabilitation services and feeling that they were not as deserving as others of resources. This is consistent with the findings of Nochi (2000) where participants talked about how others "are worse off" (p1798). The implication of this for the participants in the current study appeared to be that if other people were more deserving then it would mean their need for support may be viewed as lacking resilience. This appeared to relate to broader experiences of shame and to perceptions of being negatively judged by others, particularly linked with how others may view them as being weak or not being able to fulfil social roles as a man, such as providing a lifestyle. This may be understood in relation to social identity theories as social comparisons can enable others to identify with a social group. It may be that these men did not want to identify with a group they associated with more severe disability and negative evaluations of masculine identity, however found themselves as part of this group (Haslam et al., 2008; Haslam, Jetten, Postmes, & Haslam, 2009).

Part of the experience of shame therefore appears to be similar to those reported by Nochi (1998), particularly the theme of "loss of self in the eyes of others." For men, this could be considered as a loss of social status which conflicts with competitive and status driven aspects of dominant masculine ideals. The interviews in the current study suggest that self-comparison and placing others as higher in social rank results in vulnerability to shame when men viewed themselves as inferior. Due to pressure to endorse gender stereotypes and developmental learning associations (Courtenay, 2000b), men may be reacting to the threat of rejection and the threat to self as inferior which may be a particular causes of distress influencing experiences of shame (Kingerlee, 2012).

Participants in the current study referenced their experiences in relation to others who had experienced TBI and considered both positive and negative aspects of their experiences with others. Drawing on positive aspects of social learning, the role of mentors has been considered in both brain injury literature and male psychology (Gutman, 1999; Wilson & Cordier, 2013). Gutman (1999), with the aim of elevating gender role strain in men, encouraged men to develop relationships with others who have experienced TBI and as male mentors. Gutman highlighted how this approach enabled men to see that others shared their experiences and concerns who were in similar situations and that this promoted a feeling of being understood and accepted. Mentoring has also been recommended in men's mental health (Robertson, Bagnall & Walker, 2015). Although men in the current study did not talk about any direct experiences of being mentored, they did express how social media groups as well as community groups promoted a positive sense of masculine identity. Social media groups may also provide a sense of shared experiences and therefore may be a source of community which is protective of shame.

### 4.2.5 Protecting Masculine Identity.

Within the current research, it was clear that there were aspects of experiences which appeared to cause a threat to identity as a man. However, there were also aspects of experience which appeared to provide some protection of masculine identity. The drive to demonstrate ability to self and to others appeared to come from feeling a threat to masculine identity, but appeared also to provide motivation for participants to explore new ways of expressing masculine identities and perhaps influence post traumatic growth.

#### 4.2.5.1 Invisibility as a threat and protection to masculine identity.

The invisible nature of brain injury appeared to both threaten aspects of masculine identity as well as provide protection. The threat of the difficulties not being visible to others meant that men felt vulnerable to being viewed negatively by others as not being capable or as less of a man, causing them to strive to control their self-presentation in front of others. However, talking about their injury in order to promote others understanding also created a risk of not being viewed as normal and being judged negatively because of the stigma of TBI. Participants in the current study expressed that they felt they had to prove or demonstrate to others their ability to do pre-injury activity and demonstrate their value because of the stigma of TBI.

In contrast, the invisible nature of the injury also appeared to be protective of certain aspects of masculine identity, as participants talked about how they preferred to keep things private rather than share emotion and in this way they could maintain a "protective shell" (Nigel). This resonates with the findings of Nochi (1998) and Freeman et al. (2014) where participants identified that they were selective about the parts of themselves which they showed to others in order to appear 'normal.' The current study suggests that men were concerned that exposing their difficulties may exacerbate others negative judgments of them as a man. For men, particularly those who identify with culturally dominant ideals of

masculinity, this may be a particularly important as a way of "saving face" or status seeking (Kingerlee, 2012, p. 7) rather than expressing emotion, difficulties or weaknesses to others. This may facilitate adjustment, as men may feel more able to maintain existing expressions of identity, particularly when men are able to maintain pre-injury activity.

However, a negative consequence of putting on a front is that this may maintain the sense that the self is not acceptable and may result in avoidance of social participation leading to difficulties in wellbeing and adjustment (Kingerlee, 2012; Good et al., 2006). In addition, putting on a front may be a barrier to seeking appropriate support (Courtenay, 2000b). The current findings therefore support the trans-diagnostic model of male distress (Kingerlee, 2012). The approach used in the current study furthers the understanding of the experience of help-seeking in this population as men talked about how their reluctance to seek support or adopt compensatory strategies was influenced by their desire not to accept difficulties in their day-to-day life or to show weakness.

The current study also suggests that the invisible nature of the injury can be an empowering aspect of their experience when the value of being an expert in themselves is recognised. As the lived experience can only be understood by the individual, there is potential for recognition of this as a key component in their rehabilitation. Farrimond's (2012) research highlighted how preventative approaches in healthcare which emphasise the expert role of clients can result in a more equal relationship with the health care professional and that this can enable men to negotiate tensions between help-seeking and masculine identity. Being considered by professionals to be an expert of their own experience therefore appeared to enable men to feel more able to contribute to the relationship with professionals and be more involved in decisions. The findings of the current study suggests this may be particularly relevant within the context of brain injury because of the uniqueness of the experience of the impact of the injury.

#### 4.2.5.2 Reformulating acceptability of changes.

For many participants in the current study, making sense of their experiences of change had required a process of reformulation of the consequences and changes in order to develop an acceptance of the changes. Muenchberger et al. (2008) consider that the process of adjustment involves developing acceptance of brain injury, including acceptance of support from others and of not being able to do things. The current study extends the understanding of this process, as for men, this process required reformulating their identity or behaviour as a man. An example of this is evidenced in how John talked about changing the way he thought about resting during the day. By reviewing how a man thinks about himself in relation to his behaviour, this may facilitate a change becoming acceptable within the individual's identity as a man.

What is considered to be acceptable within a person's identity is suggested to be reconstructed through the revision of personal narrative (Levack, 2010). Levack describes that this includes "improving ones capacity (through effortful activity) and changing the way one thought about oneself" (p995). The current study highlighted how men reconstructed the way they thought about activities they did in order to integrate changes to be an accepted part of their own identity. For example, reformulating the ways in which they provide for the family, or changing the meaning of requiring to rest or pace in order to maintain other meaningful activity and roles. In addition, the use of coping strategies such as memory aids appeared to be more acceptable to use as a man when they were considered as a tool which promoted independence and self-reliance, rather than as a sign of being reliant or dependent.

## 4.2.5.3 Overcoming challenges and masculine identity.

The current study highlights how aspects of masculine identity can have a positive influence on adjustment to the effects of TBI. In considering the challenges which

#### Masculine Identity After Traumatic Brain Injury

Ruth MacQueen 2016

individuals faced and their ability to negotiate the impact of the injury on their lives, participants evaluated this experience as an indication of personal strength or resilience. This may be comparable with Muenchberger et al.'s (2008) findings where participants adopted the perspective on their injury as needing to "get over the hurdles in life" (p. 984) which promoted the integration of injury into their sense of self. For the men in the current study, it appears that the drive to keep going and overcome challenges was influenced by the ideals of resilience and strength. This study therefore extends existing research as masculine identity appears to encourage the desire to "get over the hurdles." In addition the current research highlights that this motivation is in part driven by a desire to prove ability and value to others and self.

Existing research suggests that adherence to dominant masculine ideals such as higher success, power and competition are associated with the perception of fewer barriers to community functioning (Good et al., 2006). Similarly, Hutchinson and Kleiber (2000) suggest that views of masculinity can enable men to overcome difficulties and conceptualises this as "heroic masculinity." The idea of "that which doesn't kill us makes us stronger, and more satisfied with life" is discussed in Jones et al.'s (2011) study of participants with various brain injuries including TBI. They found a positive correlational relationship between severity and life satisfaction. The current study provides a more in-depth understanding of the meaning of these statistical relationships. Participants in the current study talked about how the experience of TBI had lead them to consider their values and some also expressed a desire to live life to the full, rather than to be limited or feel cautious due to their brain injury. In particular this was often explicitly related to ideals of resilience and strength associated with masculine identity.

The current research also demonstrates how some men had reformulated help-seeking in a way which enabled them to be accepting of support and maintain their identity as a man.

#### Masculine Identity After Traumatic Brain Injury

This was evidenced in men who expressed that they viewed help-seeking as a demonstration of their resilience or strength in accepting difficulties. Literature which considers helpseeking behaviour in men acknowledges men as being more emotionally inhibited or emotionally controlled (Addis & Mahalik, 2003; Mahalik, Good & Englar-Carlson, 2003). In addition, it has been suggested that men are more likely to conceal feelings which are perceived as negative, and that this is influenced by the belief that negative mood states and emotions are shameful (Good, Thomson, & Brathwaite, 2005; Hoy, 2012).

The findings of the current study support Kingerlee's (2012) model of transdiagnostic distress which proposes that meta-cognitive beliefs about distress such as "I must not be weak or vulnerable" mean that help-seeking is more likely to be viewed negatively as a sign of weakness which can then lead to avoidance. Kingerlee (2012) argues that these processes combine to exacerbate symptom development. Participants in the current study appeared to have overcome this as help-seeking became acceptable through changing the meaning of it to being a demonstration of strength and resilience and facing up to challenges. This may have been partly influenced by their having survived a traumatic and potentially fatal injury which may suggest strength to survive in itself, therefore promoting these concepts as being associated with their recovery. In addition it may be that help-seeking was more acceptable because the need for support could be attributed to the serious nature of brain injury and also the biological nature of it. It appears that the drive to overcome difficulties and demonstrate strength and resilience, whether in relation to professional help seeking or adoption of compensatory strategies, was associated with masculine ideals of increasing self-reliance and taking control.

#### 4.3 Clinical and Rehabilitation Implications

The findings of the current study highlight the individual nature and complexity of the experience of masculine identity following TBI. Given that a key aspect of rehabilitation concerns helping individuals with their sense of self, this study suggests that there is a need to consider masculine identity as a significant aspect of neuropsychological rehabilitation.

Research illustrates that there are barriers to engaging in health services and support which relate to masculine identity (Mahalik, Burns, & Syzdek, 2007; O'Brien et al., 2005). However, there is increasing recognition that services need to adapt ways of working and create a system which supports men to engage in health and wellbeing services (Addis & Cohane, 2005; Kingerlee, 2012; Sullivan, 2011). This section outlines clinical considerations for rehabilitation arising from the findings.

#### **4.3.1** Engagement with the therapy team.

Providing a gender-sensitive service can begin during initial discussions when men are referred to a service. When providing information about a service, emphasising an active and expert role rather than being a passive recipient in rehabilitation may particularly promote a service which is in line with masculine ideals.

The current study highlighted how for a man, viewing the self as being reliant on others can lead to experiences of shame and the perception of the self as weak. This can mean that developing therapeutic relationships may also conflict with ideals of independence (Good et al., 2005; Sullivan, 2011). It has been suggested that in order to defend against shame in receiving support, intervention should facilitate men playing an active or leading role in order to promote pride (Kingerlee, 2012). The current study suggests that within rehabilitation, this could be facilitated by emphasising the value of the individual's lived

experience and the role of being an expert through experience. In addition, encouraging feedback from the individual within therapeutic relationships may provide a sense of having control as well as a sense of making a valued contribution within the therapeutic relationship. These aspects can contribute to a positive sense of masculine identity and may therefore promote engagement, empowering men to take active roles in rehabilitation, and increase involvement in decision making.

The findings of this study suggest that seeking support may be perceived as conflicting with masculine ideals and that this impacted on the participant's reluctance to engage with health professionals. However, avoidance of difficulties and seeking support are recognised to contribute to psychological distress in men (Kingerlee, 2012). In addition, there is a higher prevalence of mental health problems in the TBI population (Seel et al., 2003) and therefore it may be particularly important to work with individuals in reducing the stigma of mental health problems after brain injury. Previous research has suggested that normalising and validating the reasons for seeking support from health professionals can be a way of protecting masculine identity (Rohlen, 2005). The current study suggests that experiencing a brain injury may be one way in which men legitimise a reason for seeking support. Normalising the negative impact of TBI on mental health may therefore help reduce stigma and promote engagement.

## **4.3.2** Considering narratives in psychological therapy.

The meaning of masculine identity is specific to the individual, and the men in the current study therefore had to reconstruct their narrative of this aspect of their identity within their own individual contexts. An individual's narrative about what is important or meaningful to them as a man should therefore be considered within assessment, in addition to their narrative around help-seeking and receiving support. Exploring masculine identity and

associated narratives should be done in a sensitive manner given the shame that may be associated with this aspect of identity.

Participants highlighted shame in relation to their perceptions of themselves, as well as perceptions of others. Men also identified personal growth and strength as they made sense of their experiences in also in relation to engaging with support from services. Both shame and aspects of growth complement the compassionate mind approach (Gilbert, 2007) which has been applied in brain injury populations (Ashworth, 2014). It may be that supporting men to engage with support from services through drawing on concepts such as strength, wisdom, resilience and responsibility may be an adaptation in the therapeutic approach which promotes flexibility of an individual's narrative of masculine identity and enables a positive experience of services.

Participants in the current study talked about how they had reformulated their views on receiving professional support within their narrative of identity as a man. Specifically, this often involved an emphasis on the strength and responsibility that taking these steps to engage in support had demonstrated. Research which has considered engaging men in mental health services has emphasised the importance of language in constructing a service which is gender sensitive (Robertson et al., 2014). Robertson et al. (2014) give examples of language use such as 'regaining control rather than 'help-seeking' and promoting this as 'rational' and as a strength (p. 26) in order to provide male positive approaches in services.

Assessment and formulation should explore how narratives of masculine identity may provide positive functions such as being able to maintain social relationships and roles and promote new occupational expressions of identity. This is important given the findings of the current study which demonstrate how masculine ideals facilitated adjustment. It is also important to identify unhelpful aspects of narratives or meaning of masculine identity which may be barriers to adjustment. Future interventions with the individual can then consider

how these narratives may impact on men's values or roles. Examples which this study highlighted included a reluctance to rest when experiencing fatigue as this did not fit within the individual's narrative of masculine identity. However, by considering the negative impact on other values and roles, for example as a father, a more flexible narrative can be developed. Linking behaviour and values in this way may therefore facilitate men to consider new narratives of their identity as a man.

Developing new or flexible narratives and ways of expressing masculine identity in line with values may therefore support reformulation of masculine identity after TBI. These concepts appear aligned with recovery-focussed approaches such as Acceptance and Commitment Therapy which may encourage flexibility in narratives and behaviour though consideration of values. Similarly, approaches which focus on meaning, values and identity may be particularly relevant in supporting the development of new narratives. For example, Narrative Enhanced Cognitive Therapy (NECT) is an approach which targets self-stigma and has been developed in relation to serious mental illness (Roe et al. 2014). The therapy focusses on how self-stigma can negatively affect identity as well as self-esteem and social relationships (Yanos, Roe & Lysaker, 2012) and emphasises redevelopment of themes of agency and strength in individual's narratives. Given the findings of the current study, particularly in relation to loss of agency, shame and inadequacy as a man, NECT appears to be a highly relevant approach which specifically focus on issues highlighted by the men in this study.

Similarly, aspects of positive psychotherapy (Rashid & Seligman, 2013) are supported in the current study. Aspects such as growth and character strengths such as resilience, and positive mood were highlighted by the men. The application of positive psychology constructs in acquired brain injury rehabilitation has been explored in inpatient settings (Andrewes, Walker, & O'Neill, 2014) as well as outpatient settings (Cullen et al.,

2016). These initial studies indicate that the application of positive psychotherapy may promote wellbeing through ABI rehabilitation.

#### 4.3.3 Participation in meaningful occupation and roles.

This research highlights how socio-cultural ideals about the meaning of being a man can impact on aspects of day-to-day living for men following TBI. Therefore the life stage and the expectations a man may hold about himself in relation to peers, work roles, within relationships, and family roles should be considered by clinicians and explored with men. In particular, exploring the value, importance and meaning which a man may place on their position and roles within their own social context should be considered in assessment. This can enable clinicians and clients to explore new ways of expressing these meaningful roles.

Participants in the current study who had recognised and created roles within their social community talked about how they felt able to contribute to others and that this provided a sense of purpose and role as a man. The value in these roles identified by participants in the current study highlights the importance of having male-gendered activities and opportunities for exploring new activities in rehabilitation. Encouraging activity which may be considered to be masculine, such as sport, can provide not only benefits to cognitive health after TBI (Grealy, Johnson & Rushton, 1999), but also may provide a new expression of identity. In addition, this may protect against unhelpful externalising behaviours which may also be associated with an expression of masculine identity such as alcohol consumption (Good et al., 2008; Rochlen et al., 2008). In considering ways of engaging young men in rehabilitation after TBI, Sullivan, Gray, Williams, Green, and Hession (2014) explore the use of real life activities such as shopping, cooking, woodwork, sports and fishing within assessment and interventions. The findings gathered from interviews from the young men in

Within the UK, there is increasing recognition for gender-specific support and opportunity to develop wellbeing. For example, the UK Men's Sheds Association aim to connect men with others in the community and also provide opportunity to develop new skills and explore new activities (Wilson & Cordier, 2013). Groups which are specifically for individuals who have experienced a brain injury as well as engagement in social media may also be ways in which men can share experiences and develop meaningful occupation in ways which promote a positive sense of masculine identity.

## 4.4 Evaluation of Strengths and Limitations

This section provides a critical overview of the current study. Through consideration of recruitment, interviews and methodology in the current study, strengths and limitations are identified.

## 4.4.1 Recruitment.

This study aimed to explore the experiences of masculine identity following TBI. The broad inclusion criteria resulted in a range of cognitive, emotional and physical effects of TBI which therefore enables this research to consider how these different effects can interact with masculine identity. In addition, participants were recruited from open caseloads in a community rehabilitation team which supports the findings to be clinically relevant and for the participants to be situated in their individual social contexts. The range of ages, life stages and time since injury contributed to being able to recognise divergence as well as convergence in themes. The participants within the current research have relatively lower educational levels compared to other similar research (Freeman et al., 2014) therefore broadening representation of a range of backgrounds within the literature.

All participants had engaged in rehabilitation support and identified that they had had positive experiences. The findings represent these individual men who had expressed an interest in taking part in the research. Although there was variability in an individual's expression of their experiences, it may be that participants are men who were more willing and able to communicate the sense-making of their experiences and therefore not be representative of all men who have experienced a TBI.

This research considers the intersection between injury and gender. There are a range of ages which has also been considered in relation to this intersection. However, due to the population recruited, this study did not consider other factors such as diversity in ethnicity, race or sexuality which also impact on this intersection (Shakespeare, 1999).

The participants in this study had a range of cognitive, emotional, psychological and physical difficulties and therefore reflects a clinically relevant population. In addition, two participants had longer term physical consequences due to leg or spinal injuries. Again, this reflects the clinical population. IPA enables these contextual factors to be considered in the interpretation of the data. However, the interpretations which can be made about the different aspects of injury are therefore limited by the researcher's knowledge of the nature and extent of these aspects.

## 4.4.2 Interviews.

In line with the methodology and aims of the research, this study used a semistructured interview schedule to facilitate participants in sharing their individual lived experiences. A strength of this research is that it is the first to explicitly ask participants about their experiences in relation to identity as a man. The interviews aimed to be flexible so that the expert value of the participants experience was promoted (Smith et al., 2009). Gaining the balance between the schedule and following the course of the participant is a skill which was challenging within interviews, especially the earlier interviews. The interviews were of a sensitive and personal nature and for some participants who explicitly stated that they did not identify with an impact of TBI on different aspects of their life as a man, the richness of the data became limited at times. This reflects the difficulties in the researcher not wishing to make assumptions about the participant's experiences, or to make them uncomfortable with the research questions. In addition, the researcher can be faced with striving to capture what is meaningful for the participant, whilst looking for phenomenology relevant to the research question. Building confidence in directing interview questions to relate to the research question and facilitating conversation on a more specific rather than general level was a part of developing interviewing skills.

## 4.4.3 Methodology.

Using IPA has enabled this study to explore the experience of masculine identity after traumatic brain injury and meanings of these experiences. This has provided rich data and an in-depth understanding of individual's experiences which adds to the understanding of nomothetic research. This study therefore adds insight into men's health experiences. In particular this research considers men's experiences of adjusting to a sudden injury occurs which has a significant impact on day-to-day life.

The detailed analysis means that individual's experiences are considered within their context. This idiographic approach therefore allows for convergence and divergence within the data. For example the impact of the injury on social roles highlights how participants shared this theme relating to changes in social roles as a man, but highlights how this was experienced differently by participants. For example men who were married highlighted social roles as a husband, whereas the two younger participants talked more about roles in peer groups.

Given the emphasis of importance in IPA of privileging the individual's perspective of their own lived experience it was decided that additional demographic data which may be

#### Masculine Identity After Traumatic Brain Injury

commonly presented in brain injury literature, such as Glasgow Coma Scale Score, details of post traumatic amnesia, medical notes from the injury or neurocognitive assessment screen scores would not be collected. Obtaining this information would have required additional sources of information other than the participant themselves and would not have been in line with the approach. Furthermore, it would not have been available for all participants. However, the lack of medically accurate demographics in the current study means that the study is limited in considering the relationship between experience and the type or severity of injury.

Each of the three superordinate themes were present in all of the participant interviews. This is the most stringent criteria to establish these. In line with guidance for rigour in the analysis appropriate to the sample size, illustrations from at least three to four participants per theme are evidenced in the analysis of the current study. (Smith, 2011).

The analysis has provided interpretations which have been drawn from consideration of cognitive, affective and linguistic aspects of the data in order to better understand how individuals make sense of their experiences. This has enabled the current research to consider how individuals' may relate to masculine identity and how this can have an impact on the process of adjustment and making sense of themselves.

#### 4.5 Implications for Future Research

An important finding of this study is that ideals about masculine identity appeared to both promote adjustment and can also be a barrier to regaining a sense of self. There is a growing literature around gender-specific difficulties in adjustment and barriers to engaging in support. However, there is less research which considers how masculine identity may be have a positive impact on adjustment and recovery, particularly in relation to brain injury. For example, in the current study the ideas that as a man you've got to carry on, be strong, and be resilient appeared to be helpful for some participants in integrating the impact of their

#### Masculine Identity After Traumatic Brain Injury

injury and finding positive activity. Further research around post- traumatic growth could consider narratives of masculine identity which may promote wellbeing and adjustment after TBI. In addition, the application of recovery-focussed approaches such as Narrative Enhanced Cognitive Therapy (Roe et al. 2013) and Acceptance and Commitment Therapy in brain injury (Kangas & McDonald, 2011) could be further researched.

Men who were fathers in the current study all talked about this role in relation to their sense of self. However, there is a lack of existing research on the experience of parenting with a brain injury. Future research which considers this role could consider existing models suggested for intervention (Morriss et al., 2013) and how perceptions of the self as a father may relate to identity as a man.

The experiences of shame highlighted in this study, particularly around feelings of inadequacy as a man, indicate that future research may be beneficial in developing an understanding of this experience for men. Similarly, future research could further explore the concept of "luck" after brain injury as this prominent theme appeared to present a conflict of emotions for participants. Future qualitative research could consider different experiences of "luck" and how people make sense of this conflicting concept. Qualitative methods or case studies may best provide the depth of understanding of these complex emotional experiences. The use of existing data sources such as published narratives, blogs and biographies could also be considered as these could provide an additional insight into the lived experience.

Existing evidence highlights the value of exercise in rehabilitation and currently, the literature tends to focus on outcomes such as cognitive improvement. However, research also suggests that exercise can have a positive impact on psychological wellbeing following TBI (Wise, Hoffman, Powell, Bombardier, Bell, 2012). The current research highlighted how exercise and physical ability contributed to masculine identity. Further research could explore the use of interventions which encourage exercise as an activity to promote emotional

adjustment and positive self-identity, particularly in relation to masculine identity. Case study evidence could be explored initially to then further expand the development of interventions and build on the existing evidence base.

Given the social and cultural context of this research, this research could be carried out in other cultures. Cultural factors construct masculine identity and dominant ideals about what it means to be a man are culturally variable. Globally there is a higher male:female ratio of TBI. South Africa, has one of the highest ratios at 4:1 (Bruns& Houser, 2003) and this ratio is therefore a global concern (Hyder, Puvanachandra, Gururaj, & Kobusingye, 2007).

#### 4.6 Conclusions

This research offers an in-depth exploration and understanding of men's experiences of TBI in relation to their identity as a man. The findings suggest that men experienced a difference between what is "normal" for a man and their day-to-day lives across different aspects of day-to life including occupation, relationships and roles, including that of being a father. In particular, masculine identity faced challenges when ideals about independence, agency, and roles in relationships were challenged. When participants perceived that they were not meeting the expectations of being a man within their lives, or they felt inadequate as a man, this was experienced as shameful. Men also experienced a sense of vulnerability through their changed roles and ability which appeared to relate both to their physical abilities and also to the potential consequences of harm to themselves. It is important to consider that the significance and meaning of masculine identity is specific to an individual. These findings add a deeper understanding of changes to self-identity after TBI which can be added to existing research.

Ruth MacQueen 2016

Participants talked about how they felt others judged them negatively due to the stigma of TBI and in relation to their ability to fulfil roles as a man, and this resulted in shame and loss of confidence. In addition, their own self-comparisons to either "normal" men or to others who had experienced a TBI resulted in shame as they either perceived themselves to be inadequate or undeserving of support. Exploring opportunities to develop pride in new or changed roles may therefore be particularly important in rehabilitation. Encouraging active roles with professionals and in the community may enable a sense of meaningful and valued contribution which can promote a positive sense of masculine identity.

The findings of the current study suggest that masculine ideals such as resilience and strength may be helpful in adjusting to the impact of TBI. Participants appeared to reformulate their behaviour, such as help-seeking or adopting compensatory strategies, and reformulate changes in their roles as a demonstration of strength, taking control or "regaining manliness." Working with men to explore the values which are meaningful to them as individuals, particularly in relation to masculine identity, may therefore enable the exploration of new ways of expressing their identity as a man. Given the experiences of reformulation and growth identified by participants, the findings indicate that further research into recovery-based approaches which focus on narratives and values would therefore be useful in order to explore the clinical value of these for men who have had a TBI.

# **Reflection 4: Reflection on ending position**

Throughout the process I have felt I have moved around in the hermeneutic cycle as I reconsider the data and existing research as I encounter new information. This has helped me to realise and tolerate that there is not an end point where I will feel that my knowledge and understanding has reached saturation. Rather than it will continue to develop as I continue to use and engage with the data in my research and in clinical practice in the future.

I have continued to be fascinated by the reality of this experience for the participants in the study. I have been surprised by how open some of the participants have been in talking to me about their own personal experiences, and the interviews have been meaningful. I have also been interested in aspects of the experience which I had not considered, such as how the invisible nature of the injury could both cause shame and protect against shame. Although I began this research having reviewed the literature to consider that it was important to understand more about masculine identity and TBI, the reality of this experience was difficult to fully appreciate prior to speaking to individuals and engaging in this research process.

#### References

- Addis, M. E., & Cohane, G. H. (2005). Social scientific paradigms of masculinity and their implications for research and practice in men's mental health. *Journal of Clinical Psychology*, 61(6), 633–647. doi:10.1002/jclp.20099
- Addis, M. E., & Mahalik, J. R. (2003). Men, masculinity, and the contexts of help seeking. *The American Psychologist*, 58(1), 5–14. doi:10.1037/0003-066X.58.1.5
- Addis, M. E., Mansfield, A. K., & Syzdek, M. R. (2010). Is "masculinity" a problem?: Framing the effects of gendered social learning in men. *Psychology of Men & Masculinity*, *11*(2), 77–90. doi:10.1037/a0018602
- Allmark, P., Boote, J., Chambers, E., Clarke, A., McDonnell, A., Thompson, A., & Tod, A. M.
  (2009). Ethical issues in the use of in-depth interviews: Literature review and discussion. *Research Ethics Review*, 5(2), 48-54. doi:10.1177/174701610900500203
- Anderson, E. (2009). *Inclusive masculinity: The changing nature of masculinities*. New York: Routledge.
- Andrewes, H. E., Walker, V., & O'Neill, B. (2014). Exploring the use of positive psychology interventions in brain injury survivors with challenging behaviour. *Brain injury*, 28(7), 965-971.
- Ashworth, F. (2014). Soothing the injured brain with a compassionate mind: Building the case for compassion focused therapy following acquired brain injury. *Neuro-Disability and Psychotherapy*, 2(1-2), 41-79.
- Ashworth, P. (2003). An approach to phenomenological psychology: The contingencies of the lifeworld. *Journal of Phenomenological Psychology*, *34*, 145–156.
  doi:10.1163/156916203322847119

Ajzen, I. (1991). The theory of planned behavior. Organizational Behavior and Human Decision

Processes. 50(2), 179-211.

- Baron-Cohen, S. (2003). The Essential Difference: Men, Women and the Extreme Male Brain. London: Penguin.
- Barrett, T. (2014). Disabled Masculinities : A review and suggestions for further research. *Masculinities and Social Change*, *3*(1), 36–61. doi:10.4471/MCS.40
- Berger, M., Levant, R., McMillan, K., Kelleher, W., & Sellers, A. (2005). Impact of gender role conflict, traditional masculinity ideology, alexithymia, and age on men's attitudes toward psychological help seeking. *Psychology of Men & Masculinity*, 6(1), 73–78.
- Biggerstaff, D., & Thompson, A. R. (2008). Interpretative phenomenological analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative Research in Psychology*, 5(3), 214–224. doi:10.1080/14780880802314304
- Blakemore, J. E. O., Berenbaum, S. A., & Liben, L. S. (2008). *Gender Development*. Psychology Press.
- Brenner, L. A., Ignacio, R. V., & Blow, F. C. (2011). Suicide and traumatic brain injury among individuals seeking veterans health administration services. *The Journal of Head Trauma Rehabilitation*, 26(4), 257-264.

Brinkmann, B., & Kvale, S., (2014) InterViews. Los Angeles, California: SAGE Publications.

- British Psychological Society (2010) Code of human research ethics. Leicester: BPS. Retrieved from http://www.bps.org.uk/sites/default/files/documents/code\_of\_human\_rese arch\_ethics.pdf
- Brocki, J., & Wearden, AJ. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health*, 21(1), 7– 108. doi:10.1080/14768320500230185

- Bruns, J., & Hauser, W. A. (2003). The epidemiology of traumatic brain injury: A review. *Epilepsia*, 44(s10), 2-10.
- Bryson-Campbell, M., Shaw, L., O'Brien, J., Holmes, J., & Magalhaes, L. (2013). A scoping review on occupational and self identity after a brain injury. *Work*, 44(1), 57–67. doi:10.3233/WOR-2012-01561
- Bullen, K., Edwards, S., Marke, V., & Matthews, S. (2010). Looking past the obvious:Experiences of altered masculinity in penile cancer. *Psycho-Oncology*, *19*(9), 933–940.
- Buss, D. M. (1995). Psychological sex differences: Origins through sexual selection. *American Psychologist*, *50*(*3*)164-168. <u>http://dx.doi.org/10.1037/0003-066X.50.3.164</u>
- Bussey, K., & Bandura, A. (1999). Social cognitive theory of gender development and differentiation. *Psychological Review*, *106*(4), 676–713. doi:10.1037/0033-295x.106.4.676
- Campaign Against Living Miserably (2016). *Suicide* Retrieved from https://www.thecalmzone.net/help/get-help/suicide/
- Campaign against Living Miserably (2015) #Mandictionary campaign. Retrieved from <a href="https://www.thecalmzone.net/mandictionary/">https://www.thecalmzone.net/mandictionary/</a>
- Carroll, E., & Coetzer, R. (2011). Identity, grief and self-awareness after traumatic brain injury. *Neuropsychological Rehabilitation*, 21(3), 289-305. doi: 10.1080/09602011.2011.555972
- Cassidy, J. D., Carroll, L., Peloso, P., Borg, J., Von Holst, H., Holm, L., ... & Coro-nado, V.
  (2004). Incidence, risk factors and prevention of mild traumatic brain injury: results of the WHO Collaborating Centre Task Force on Mild Traumatic Brain Injury. *Journal of Rehabilitation Medicine*, *36*, 28-60. doi:10.1080/16501960410023732

- Cloute, K., Mitchell, A., & Yates, P. (2008). Traumatic brain injury and the construction of identity: a discursive approach. *Neuropsychological Rehabilitation*, *18*(5-6), 651–670. doi:10.1080/09602010701306989
- Cohen, J. W. (2009) "What's Sex Gotta Do With It?: The Study Of Gender In Criminology and The Social Sciences" (Doctoral dissertation, Indiana University of Pennsylvania)
- Colantonio, A., Harris, E., Ratcliff, G., Chase, S., & Ellis, K. (2010). Gender differences in self reported long term outcomes following moderate to severe traumatic brain injury. *BMC Neurology*, 10. doi: 10.1186/1471-2377-10-102

Connell, R.W. (1995) Masculinities. Sidney, Australia: Allen & Unwin.

- Connell, R. W. (2005). Hegemonic Masculinity: Rethinking the Concept. *Gender & Society*, *19*(6), 829–859. doi:10.1177/0891243205278639
- Connell, R. W., & Messerschmidt, J. W. (2005). Hegemonic masculinity rethinking the concept. *Gender & society*, *19*(6), 829-859. doi:10.1177/0891243205278639
- Connell, R. (2012). Gender, health and theory: Conceptualizing the issue, in local and world perspective. *Social Science and Medicine*, *74*(11), 1675–1683.
  doi:10.1016/j.socscimed.2011.06.006
- Courtenay, W. H. (2000a). Behavioral factors associated with disease, injury, and death among men: Evidence and implications for prevention. *The Journal of Men's Studies*, *9*(1), 81-142.
- Courtenay, W.H., (2000b) Constructions of masculinity and their influence on men's well-being: A theory of gender and health. *Social Science and Medicine*, *50* (10), 1385–1401. doi:10.1016/S0277-9536(99)00390-1

Cullen, B., Pownall, J., Cummings, J., Baylan, S., Broomfield, N., Haig, C., ... & Evans, J. J. (2016). Positive PsychoTherapy in ABI Rehab (PoPsTAR): A pilot randomised controlled trial. *Neuropsychological Rehabilitation*, 1-17. doi:10.1080/09602011.2015.1131722

- De Visser, R., & Smith, J. A. (2006). Mister in-between :A case study of masculine identity and health-related behaviour. *Journal of Health Psychology*, *11*(5), 685-695.
- Doering, B. K., Conrad, N., Rief, W., & Exner, C. (2011). Living with acquired brain injury: self-concept as mediating variable in the adjustment process. *Neuropsychological Rehabilitation*, 21(1), 42–63. doi:10.1080/09602011.2010.525947
- Dolan, A. (2014). "I've learnt what a dad should do': The interaction of masculine and fathering identities among men who attended a "dads only" parenting programme. *Sociology*, 48(4), 812–828. doi:10.1177/0038038513511872
- Doucet, A. (2004). "It's almost like I have a job, but I don't get paid": Fathers at home reconfiguring work, care, and masculinity. *Fathering: A Journal of Theory, Research, and Practice about Men as Fathers*, 2(3), 277–303. doi:10.3149/fth.0203.277
- Douglas, J. (2013). Conceptualizing self and maintaining social connection following severe traumatic brain injury. *Brain Injury*, 27(1), 60-74
- Douglas, J. M., & Bracy, C. A. (2013). Coping efforts used by couples living with severe traumatic brain injury: A comparison with orthopaedic control couples. *Brain Impairment*, 14(1). 108-150
- Elliott R., Fischer C. and Rennie D. (1999). Evolving guidelines for publication of qualitative research studies in psychology and related fields. *British Journal of Clinical Psychology*, 38, 215-229.

- Etherington, K. (2007). Ethical research in reflexive relationships. *Qualitative Inquiry*, *13*(5), 599-616.
- Ervik, B., & Asplund, K. (2012). Dealing with a troublesome body: a qualitative interview study of men's experiences living with prostate cancer treated with endocrine therapy. *European Journal of Oncology Nursing : The Official Journal of European Oncology Nursing Society*, 16(2), 103–8. doi:10.1016/j.ejon.2011.04.005
- Farace, E., & Alves, W. M. (2000). Do women fare worse: a metaanalysis of gender differences in traumatic brain injury outcome. *Journal of Neurosurgery*, *93*(4), 539-545.
- Farrimond, H. (2012). Beyond the caveman: Rethinking masculinity in relation to men's helpseeking. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 16(2), 208–225. doi:10.1177/1363459311403943
- Finlay, L. (2005). "Reflexive Embodied Empathy": A phenomenology of participant-researcher intersubjectivity. *The Humanistic Psychologist*, 33(4), 271–292. doi:10.1207/s15473333thp3304\_4
- Finlay, L. (2008). A dance between the reduction and reflexivity: Explicating the "phenomenological psychological attitude." *Journal of Phenomenological Psychology*, 39(1), 1–32. doi:10.1163/156916208X311601
- Finlay, L. (2009) Debating phenomenological research methods. *Phenomenology & Practice. 3*, 6-25
- Finlay, L. (2013). Unfolding the Phenomenological Research Process: Iterative Stages of "Seeing Afresh." *Journal of Humanistic Psychology*, 53(2), 172–201. doi:10.1177/0022167812453877

Freeman, A., Adams, M., & Ashworth, F. (2014). An exploration of the experience of self in the social world for men following traumatic brain injury. *Neuropsychological Rehabilitation*, 1–27. doi:10.1080/09602011.2014.917686

Freud, S. (1905). On psychotherapy. Standard edition, 7(267), 64-145.

Fulton, R., & Anderson, S. W. (1992). The Amerindian" Man-Woman": Gender, liminality, and cultural continuity. *Current Anthropology*, 33(5), 603-610.

Gadamer (1990/1960). Truth and Method (2nd rev edn). New York: Crossroad

- Galdas, P. M., Cheater, F., & Marshall, P. (2005). Men and health help-seeking behaviour: Literature review. *Journal of Advanced Nursing*, 49(6), 616–623.
- Geary, D. C. (1998). *Male, female: The evolution of human sex differences*. Washington, DC: American Psychological Association.
- Gelech, J. M., & Desjardins, M. (2011). I am many: the reconstruction of self following acquired brain injury. *Qualitative Health Research*, *21*(1), 62–74. doi:10.1177/1049732310377454
- Gerschick, T. and Miller, A., 1994. Gender identities at the crossroads of masculinity and physical disability. *Masculinities*, *2*, 34–5
- Gerschick, T. J. (2000). Toward a Theory of Disability and Gender. *Signs*, 25(4), 25(4), 1263–1268.
- Gibbs, L. (2005). Gibbs applications of masculinity in chronic illness.pdf. *International Journal of Men's Health*, 4(3), 287–298.
- Gilbert, P. (2007). Evolved minds and compassion in the therapeutic relationship. In Gilbert, P.
  & Leary, R. (Eds) *The therapeutic relationship in the cognitive behavioural psychotherapies* (pp.106-142). London: Routledge

- Godwin, E., Chappell, B., & Kreutzer, J. (2014). Relationships after TBI: A grounded research study. *Brain injury*, 28(4), 398-413.doi:10.3109/02699052.2014.880514
- Good, G. E., Schopp, L. H., Thomson, D., Hathaway, S., Sanford-Martens, T., Mazurek, M. O.,
  & Mintz, L. B. (2006). Masculine roles and rehabilitation outcomes among men
  recovering from serious injuries. *Psychology of Men & Masculinity*, 7(3), 165.
- Good, G. E., Schopp, L. H., Thomson, D., Hathaway, S. L., Mazurek, M. O., & Sanford-Martens,
  T. C. (2008). Men with serious injuries: relations among masculinity, age, and alcohol
  use. *Rehabilitation Psychology*, 53(1), 39–46.
- Good, G. E., Thomson, D. A., & Brathwaite, A. D. (2005). Men and therapy: Critical concepts, theoretical frameworks, and research recommendations. *Journal of Clinical Psychology*, 61(6), 699–711. doi:10.1002/jclp.20104
- Gough, B. (2006). Try to be healthy, but don't forgo your masculinity: Deconstructing men's health discourse in the media. Social science & medicine, 63(9), 2476-2488. <u>doi:10.1016/j.socscimed.2006.06.004</u>
- 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), 627–50. doi:10.1080/09602010802041238
- Gracey, F., Evans, J. J., & Malley, D. (2009). Capturing process and outcome in complex rehabilitation interventions: A "Y-shaped" model. *Neuropsychological Rehabilitation*, 19(6), 867-890.
- Grealy, M. A., Johnson, D. A., & Rushton, S. K. (1999). Improving cognitive function after brain injury: the use of exercise and virtual reality. *Archives of Physical Medicine and Rehabilitation*, 80(6), 661-667.

- Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and "ethically important moments" in research. *Qualitative inquiry*, *10*(2), 261-280.
- Gutman, S. A. (1999). Alleviating gender role strain in adult men with traumatic brain injury: An evaluation of a set of guidelines for occupational therapy. *The American Journal of Occupational Therapy*, *53(1)*, 101–110.
- Gutman, S. A., & Napier-Klemic, J. (1996). The experience of head injury on the impairment of gender identity and gender role. *American Journal of Occupational Therapy*, 50(7), 535– 544. doi:10.5014/ajot.50.7.535
- Haslam, S. A., Home, C., Iyer, A., Jetten, J., & Williams, W. H. (2008). Maintaining group memberships: Social identity continuity predicts well-being after stroke. *Neuropsychological Rehabilitation*, 18(5-6), 671-691.
- Haslam, S. A., Jetten, J., Postmes, T., & Haslam, C. (2009). Social identity, health and wellbeing: an emerging agenda for applied psychology. *Applied Psychology*, 58(1), 1-23.
- Headway (2014), *Key Facts and Statistics* Retrieved from <u>https://www.headway.org.uk/key-facts-and-statistics.aspx</u> accessed 28.08.2015
- Headway (2016) *Statistics resources*. Retrieved from https://www.headway.org.uk/about-braininjury/further-information/statistics/statistics-resources/
- Hefferon, K., Grealy, M., & Mutrie, N. (2009). Post-traumatic growth and life threatening physical illness: A systematic review of the qualitative literature. *British Journal of Health Psychology*, 14(2), 343-378.
- Heffron, K. & Gil-Rodriguez, L., (2014) *The Hermeneutic Cycle*. London IPA training Resource Pack.

Heidegger, M. (1962/1927). Being and Time. Oxford: Blackwell.

- Heller, W., Levin, R. L., Mukherjee, D., & Reis, J. P. (2006). Characters in contexts: identity and personality processes that influence individual and family adjustment to brain injury. *Journal of Rehabilitation*, 72(2), 44-49.
- Hollis, S. J., Stevenson, M. R., McIntosh, A. S., Shores, E. A., Collins, M. W., & Taylor, C. B.
  (2009). Incidence, risk, and protective factors of mild traumatic brain injury in a cohort of Australian nonprofessional male rugby players. *The American Journal of Sports Medicine*, *37*(12), 2328-2333.
- Houghton, C. E., Casey, D., Shaw, D., & Murphy, K. (2010). Ethical challenges in qualitative research: examples from practice. *Nurse Researcher*, *18*(1), 15-25.
- Howes, H., Benton, D., & Edwards, S. (2005). Women's experience of brain injury: An interpretative phenomenological analysis. *Psychology & Health*, 20(1), 129–142. doi:10.1080/0887044042000272903
- Hoy, S. (2012). Beyond men behaving badly: A meta-ethnography of men's perspectives on psychological distress and help seeking. *International Journal of Men's Health*, 11(3), 202–226. doi:10.3149/jmh.1103.202
- Husserl, E. (1982) Ideas Pertaining to a Pure Phenomenology and to a Phenomenological Philosophy. (F. Kersten, Trans.) Dordrecht: Kluwer.
- Hutchinson, S. L., & Kleiber, D. A. (2000). Heroic masculinity following spinal cord injury: Implications for therapeutic recreation practice and research. *Therapeutic Recreation Journal*, 34(1), 42.
- Hyder, A. A., Wunderlich, C. A., Puvanachandra, P., Gururaj, G., & Kobusingye, O. C. (2007).
  The impact of traumatic brain injuries: a global perspective. *NeuroRehabilitation-An Interdisciplinary Journal*, 22(5), 341-354.

- Javouhey, E., Guerin, A. C., & Chiron, M. (2006). Incidence and risk factors of severe traumatic brain injury resulting from road accidents: a population-based study. Accident Analysis & Prevention, 38(2), 225–233. doi:10.1016/j.aap.2005.08.001
- Jetten, Haslam & Haslam, 2012 The case for a social identity analysis of health and wellbeing. In J.Jetten, C Haslam & S.A. Haslam (Eds) The social cure: *Identity, health and wellbeing* (pp3-21) Hove, United Kingdom, Psychology Press
- Jones, J. A., & Curtin, M. (2011). Reformulating masculinity: traumatic brain injury and the gendered nature of care and domestic roles. *Disability and Rehabilitation*, 33(17-18), 1568–1578.
- Jones, J. M., Haslam, S. A., Jetten, J., Williams, W. H., Morris, R., & Saroyan, 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 & Health*, 26(3), 353–369. doi:10.1080/08870440903440699
- Joseph, L., & Lindegger, G. (2007). The construction of adolescent masculinity by visually impaired adolescents. *Psychology in Society*, *35*, 73-90.
- Joubert, H. E. (2014). *What is the role of shame for male anabolic androgenic steroid users?* (Doctoral dissertation, School of Psychology, University of Leicester).
- Kangas, M., & McDonald, S. (2011). Is it time to act? The potential of acceptance and commitment therapy for psychological problems following acquired brain injury. *Neuropsychological Rehabilitation*, 21(2), 250-276.
- Kieffer-Kristensen, R., & Teasdale, T. W. (2011). Parental stress and marital relationships among patients with brain injury and their spouses. *NeuroRehabilitation*, 28(4), 321–330. doi:10.3233/NRE-2011-0660

Kilmartin, C.T. (2007) The Masculine Self. Cornwall on Hudson: Sloan publishing

- Kingerlee, R., Precious, D., Sullivan L., & Barry, J., (2014) Engaging with the emotional lives of men. *The Psychologist*, 27 (6), 418-421
- Kingerlee, R. (2012). Conceptualizing men: A transdiagnostic model of male distress. *Psychology and Psychotherapy: Theory, Research and Practice*, 85(1), 83–99.
  doi:10.1111/j.2044-8341.2011.02017.x
- Kirkevold, M., 2010. Translating chronic illness research across the lifespan. In: D. Kralik, B.
   Paterson and V. Coates, eds. *Translating chronic illness research into practice*. Oxford: Blackwell Publishing Ltd, 37–57
- Klinger, L. (2005). Occupational adaptation: Perspectives of people with traumatic brain injury. *Journal of Occupational Science*, *12*(1), 9–16. doi:10.1080/14427591.2005.9686543
- Kohlberg, L. (1966). A cognitive-developmental analysis of children's sex- role concepts and attitudes. In E. E. Maccody (Ed.)*The Development of Sex Differences*. Stanford, CA: Stanford University Press.
- Kvigne, K., Kirkevold, M., Martinsen, R., & Bronken, B. A. (2013). Masculinity and strokes: the challenges presented to younger men by chronic illness. *Journal of Gender Studies*, 23(2), 197–210. doi:10.1080/09589236.2013.790797
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, *3*, 102–120. doi:10.1191/1478088706qp062oa
- Levant, R. F. (2011). Research in the psychology of men and masculinity using the gender role strain paradigm as a framework. *American Psychologist*, *66*(8), 765.
- Laverty, S. (2008). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Journal of Qualitative Methods.* 2(3) 21-35

Lennon, A., Bramham, J., Carroll, I., Mcelligott, J., Carton, S., Waldron, B., ... Benson, C. (2014). A qualitative exploration of how individuals reconstruct their sense of self following acquired brain injury in comparison with spinal cord injury. *Brain Injury*, 28(1), 1362–301. doi:10.3109/02699052.2013.848378

- Levack, W. M., Kayes, N. M., & Fadyl, J. K. (2010). Experience of recovery and outcome following traumatic brain injury: a metasynthesis of qualitative research. *Disability and Rehabilitation 32*(12), 986–999. doi:10.3109/09638281003775394
- Lloyd, V., Gatherer, A., & Kalsy, S. (2006). Conducting qualitative interview research with people with expressive language difficulties. *Qualitative Health Research*, 16(10), 1386– 1404. doi:10.1177/1049732306293846
- MacQueen, R., Fisher, P., & Williams, D. (2015, March) Masculine Identity After Traumatic
  Brain Injury: Using IPA to manage the complexity. Poster presented at the National
  Brain Injury Symposium, Royal Hospital for Neuro-disability, London
- Mahalik, J. R., Burns, S. M., & Syzdek, M. (2007). Masculinity and perceived normative health behaviors as predictors of men's health behaviors. *Social Science and Medicine*, 64(11), 2201–2209. doi:10.1016/j.socscimed.2007.02.035
- Mahalik, J. R., Good, G. E., & Englar-Carlson, M. (2003). Masculinity scripts, presenting concerns, and help seeking: Implications for practice and training. *Professional Psychology: Research and Practice*, 34(2), 123-131. <u>http://dx.doi.org/10.1037/0735-7028.34.2.123</u>
- Mahalik, J. R., Locke, B. D., Ludlow, L. H., Diemer, M. A., Scott, R. P., Gottfried, M., & Freitas, G. (2003). Development of the Conformity to Masculine Norms Inventory. *Psychology of Men & Masculinity*, 4(1), 3-25. <u>http://dx.doi.org/10.1037/1524-9220.4.1.3</u>

Mauthner, N. S., Mauthner, N. S., Doucet, A., & Doucet, A. (2003). Reflexive Accounts and

Accounts of Reflexivity in Qualitative Data Analysis. *Sociology*, *37*(3), 413–431. doi:10.1177/00380385030373002

- McDowell L (2003) *Redundant Masculinities? Employment Change and White Working Class Youth.* London: Blackwell.
- McGrath, J. (2004). Beyond restoration to transformation: positive outcomes in the rehabilitation of acquired brain injury. *Clinical Rehabilitation*, *18*(7), 767-775.

McGrath, J., & Linley, P. A. (2006). Post-traumatic growth in acquired brain injury: a preliminary small scale study. *Brain Injury*, 20(7), 767–73. doi:10.1080/02699050600664566

Merleau-Ponty (1962) Phenomenology of Perception. London: Routledge.

- Morriss, E., Wright, S., Smith, S., Roser, J., & Kendall, M. (2013). Parenting challenges and needs for fathers following acquired brain injury (ABI) in Queensland, Australia: A preliminary model. *Special Issue: Family Support and Adjustment Following Acquired Brain Injury: An International Perspective.*, 19(2), 119–134. doi:10.1017/jrc.2013.15
- Muenchberger, H., Kendall, E., & Neal, R. (2008). Identity transition following traumatic brain injury: a dynamic process of contraction, expansion and tentative balance. *Brain Injury :* [BI], 22(12), 979–992. doi:10.1080/02699050802530532
- Murray CJL, Lopez AD, eds. The global burden of disease: a comprehensive assessment of mortality and disability from diseases, injuries and risk factors in 1990 and projected to 2020. Cambridge, MA, Harvard School of Public Health on behalf of the World Health Organization and the World Bank, 1996 (Global Burden of Disease and Injury Series, Vol. I).

- Meyers, N. M. (2012). The effect of traditional masculine gender role adherence on community reintegration following traumatic brain injury in military veterans. (Doctoral Thesis)
   American University, Washington, D.C
- National Institute for Clinical Excellence (2014). *Head Injury: assessment and early management guideline*. Retrieved from <u>http://www.nice.org.uk/guidance/cg176/</u>
- Nochi, M. (1998). "Loss of self" in the narratives of people with traumatic brain injuries: A qualitative analysis. *Social Science and Medicine*, *46*(7), 869–878.
- Nochi, M. (2000). Reconstructing self-narratives in coping with traumatic brain injury. *Social Science and Medicine*, *51*, 1795–1804. doi:10.1016/S0277-9536(00)00111-8
- Nolan, M. (2013). Masculinity lost: a systematic review of qualitative research on men with spinal cord injury. *Spinal Cord*, *51*(8), 588-595.
- O'Brien, R., Hunt, K., & Hart, G. (2005). "It's caveman stuff, but that is to a certain extent how guys still operate': men's accounts of masculinity and help seeking. *Social Science & Medicine*. *61(3)* 503-516
- Office for National Statistics (2016) Statistical Bulletin Suicides in the UK, 2014 Registrations released 04 February 2016 retrieved from <u>http://www.ons.gov.uk/ons/rel/subnational-health4/suicides-in-the-united-kingdom/2014-registrations/stb-suicides-2014.html</u> on 07.02.2016
- O'Leary, V. E., & Ickovics, J. R. (1994). Resilience and thriving in response to challenge: an opportunity for a paradigm shift in women's health. *Women's Health*, *1*(2), 121-142.
- Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), 93-96.

- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, *13*(4), 695–705.
- O'Neil, J. M. (2008). Summarizing 25 years of research on men's gender role conflict using the gender role conflict scale new research paradigms and clinical implications. *The Counselling Psychologist*, *36*(3), 358-445.

Onsworth, T (2014) Self-Identity after Brain Injury. Hove: Psychology Press

- Ownsworth, T., & McKenna, K. (2004). Investigation of factors related to employment outcome following traumatic brain injury: a critical review and conceptual model. *Disability and Rehabilitation*, *26*(13), 765-783.
- 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
- Pattman, R., Frosh, S., & Phoenix, A. (2005). Constructing and experiencing boyhoods in research in London. *Gender and Education*, *17*(5), 555-561.
- Peters, K., Ryan, M. K., & Haslam, S. A. (2015). Marines, medics, and machismo: Lack of fit with masculine occupational stereotypes discourages men's participation. *British Journal* of Psychology, 106(4), 635-655.
- Pleck, J.H. (1995). The gender role strain paradigm: An update. In R.F. Levant & W.S. Pollack (Eds). A New Psychology of Men (pp11-31). New York: Basic Books.
- Poole, G. (2014). Towards an integrated meta-theory of gender : thoughts on the potential use of Ken Wilber 's AQAL model to develop an Integral Gender Theory. *New Male Studies: An International Journal*, 3(1), 42–66.

Postic, R., & Prough, E. (2014). That's Gay! Gay as a Slur Among College Students. SAGE

Open, 4(4), 2158244014556996.

- Pringle, R. (2010). Inclusive masculinity: The changing nature of masculinities (A Review). *Sociology of Sport*, 27, 319–322. doi:10.1177/0094306110367909a
- Rashid, T., & Seligman, M. (2013). Positive Psychotherapy. In Wedding & Corsini (Eds.)*Current Psychotherapies*, (pp 461- 494). Belmont: Cengage Learning.
- Ratcliff, J. J., Greenspan, A. I., Goldstein, F. C., Stringer, A. Y., Bushnik, T., Hammond, F. M.,
  ... & Wright, D. W. (2007). Gender and traumatic brain injury: Do the sexes fare
  differently?. *Brain Injury*, 21(10), 1023-1030.
- Renner, C., Hummelsheim, H., Kopczak, A., Steube, D., Schneider, H. J., Schneider, M., ...
  Stalla, G. K. (2012). The influence of gender on the injury severity, course and outcome of traumatic brain injury. *Brain Injury*, 26(11), 1360–1371.
  doi:10.3109/02699052.2012.667592
- Richards, H. M., & Schwartz, L. J. (2002). Ethics of qualitative research: are there special issues for health services research? *Family Practice*, 19(2), 135-139. doi: 10.1093/fampra/19.2.135
- Roberts, S. (2013). Boys Will Be Boys ... Won't They? Change and Continuities in Contemporary Young Working-class Masculinities. *Sociology*, 47(4), 671–686. doi:10.1177/0038038512453791
- Robertson, S., Bagnall, A., & Walker, M. (2015). Evidence for a gender-based approach to mental health programmes: Identifying the key considerations associated with "being male". Project Report. The Movember Foundation. Retrieved from <u>http://eprints.leedsbeckett.ac.uk/1773/</u>

- Robertson, S., Sheikh, K., & Moore, a. (2010). Embodied masculinities in the context of cardiac rehabilitation. *Sociology of Health and Illness*, 32(5), 695–710. doi:10.1111/j.1467-9566.2010.01249.x
- Rochlen, A. B. (2005). Men in (and out of) therapy: Central concepts, emerging directions, and remaining challenges. *Journal of Clinical Psychology*, *61*(6), 627-631.
- Rochlen, A. B., Suizzo, M.-A., McKelley, R. A., & Scaringi, V. (2008). "I'm just providing for my family": A qualitative study of stay-at-home fathers. *Psychology of Men & Masculinity*, 9(4), 193–206. doi:10.1037/a0012510
- Rodham, K., Fox, F., & Doran, N. (2015). Exploring analytical trustworthiness and the process
  of reaching consensus in interpretative phenomenological analysis: lost in transcription. *International Journal of Social Research Methodology*, *18*(1), 59-71.
  doi:10.1080/13645579.2013.852368
- Roe, D., Hasson-Ohayon, I., Mashiach-Eizenberg, M., Derhy, O., Lysaker, P. H., & Yanos, P. T. (2014). Narrative enhancement and cognitive therapy (NECT) effectiveness: A quasiexperimental study. *Journal of Clinical Psychology*, 70(4), 303-312.
- Russ S, Ellam-Dyson V, Seager M, & Barry JA. (2014) "I don't want to generalise, but...". The views of coaching psychologists and life coaches on differences in treatment style for male and female clients. Paper presented at The Male Psychology Conference, London. Abstract retrieved from

http://www.newmalestudies.com/OJS/index.php/nms/article/download/141/138

Samaritans, (2010). *Men on the ropes campaign*. Retrieved from: http://www.samaritans.org/media-centre/our-campaigns/men-ropes (accessed 28.01.2016)

- Sánchez, F. J., Westefeld, J. S., Liu, W. M., & Vilain, E. (2010). Masculine gender role conflict and negative feelings about being gay. *Professional Psychology: Research and Practice*, 41(2), 104.
- Sartre, J-P. (1956/1943). Being and Nothingness. New York: Washington Square Press.
- Schopp, H., Good, E., Barker, B., Mazurek, O., & Hathaway, L. (2006). Masculine role adherence and outcomes among men with traumatic brain injury. *Brain Injury*, 20(11), 1155.
- Schopp, L. H., Shigaki, C. L., Johnstone, B., & Kirkpatrick, H. a. (2001). Gender Differences in Cognitive and Emotional Adjustment to Traumatic Brain Injury. *Journal of Clinical Psychology in Medical Settings*, 8(3), 181–188. doi:10.1023/a:1011369620254
- Scott. R; Morison, L, John, M., & Killian, K (2014) The influence of conformity to masculine norms and emotional intelligence on men's intentions to seek help for psychological distress. Paper presented at The Male Psychology Conference, London. Abstract retrieved from

http://www.newmalestudies.com/OJS/index.php/nms/article/download/141/138

- Seager, M., & Wilkins, D. (2014). Being a man putting life before death. *The Psychologist*, 27(6), 404–405.
- Segal, D. (2010). Exploring the importance of identity following acquired brain injury: A review of the literature. *International Journal of Child, Youth and Family Studies*, 1(3/4), 293-314
- Seel, R. T., Kreutzer, J. S., Rosenthal, M., Hammond, F. M., Corrigan, J. D., & Black, K. (2003).
   Depression after traumatic brain injury: a National Institute on Disability and
   Rehabilitation Research Model Systems multicenter investigation. *Archives of Physical Medicine and Rehabilitation*, 84(2), 177-184.

- Shakespeare, T. (1999). The sexual politics of disabled masculinity. *Sexuality and disability*, *17*(1), 53-64.
- Shinebourne, P. (2011a). The theoretical underpinnings of interpretative phenomenological analysis (IPA ). *Existential Analysis*, 22(1), 16–31.
- Shuttleworth, R., Wedgwood, N., & Wilson, N. J. (2012). The Dilemma of Disabled Masculinity. *Men and Masculinities*, *15*(2), 174–194. doi:10.1177/1097184X12439879
- Silver, J. M., Kramer, R., Greenwald, S., & Weissman, M. (2001). The association between head injuries and psychiatric disorders: findings from the New Haven NIMH Epidemiologic Catchment Area Study. *Brain Injury*, 15(11), 935-945.
- Smith, A., Braunack-Mayer, A., Wittert, G., & Warin, M. (2007). "I've been independent for so damn long!": Independence, masculinity and aging in a help seeking context. *Journal of Aging Studies*, 21(4), 325–335.
- Smith, J. A. (1996). Beyond the divide between cognition and discourse: Using interpretative phenomenological analysis in health psychology. *Psychology and Health*, *11*(2), 261-271.
- Smith, J. A. (2007). Hermeneutics, human sciences and health: Linking theory and practice. *International Journal of Qualitative Studies on Health and Well-Being*, 2(1), 3–11. doi:10.1080/17482620601016120
- Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review*, 5(1), 9–27. doi:10.1080/17437199.2010.510659
- Smith, J. A., Flowers, P., & Larkin, M. (2009). Interpretative phenomenological analysis: Theory, method and research. London, England: Sage.

- Smith, J. P., Tran, G. Q., & Thompson, R. D. (2008). Can the theory of planned behavior help explain men's psychological help-seeking? Evidence for a mediation effect and clinical implications. *Psychology of Men & Masculinity*, 9(3), 179–192. doi:10.1037/a0012158
- Stergiou-Kita, M., Mansfield, E., Sokoloff, S., & Colantonio, A. (2015). Gender Influences on Return to Work Following Mild Traumatic Brain Injury. *Archives of Physical Medicine* and Rehabilitation. doi:10.1016/j.apmr.2015.04.008
- Sullivan, L. (2011) Men, Masculinity and Male Gender Role Socialisation: Implications for Men's Mental Health and Psychological Help Seeking Behaviour (Doctoral Thesis, Salomons, Canterbury Christ Church University)
- Sullivan, C., Gray, M., Williams, G., Green, D., & Hession, C. (2014). The use of real life activities in rehabilitation: The experience of young men with traumatic brain injuries from regional, rural and remote areas in Australia. *Journal of Rehabilitation Medicine*, 46(5), 424–429. doi:10.2340/16501977-1788
- Tajfel, H., & Turner, J. C. (1979). An integrative theory of intergroup conflict. *The Social Psychology of Intergroup Relations*, 33(47), 74.
- Teasdale, G., & Jennett, B. (1974). Assessment of coma and impaired consciousness: a practical scale. *The Lancet*, *304*(7872), 81-84.
- Thomas, E. J., Levack, W. M. M., & Taylor, W. J. (2014). Self-reflective meaning making in troubled times: Change in self-identity after traumatic brain injury. *Qualitative Health Research*, 24(8), 1033–1047. doi:10.1177/1049732314542809
- Thompson, H. J., McCormick, W. C., & Kagan, S. H. (2006). Traumatic brain injury in older adults: epidemiology, outcomes, and future implications. *Journal of the American Geriatrics Society*, 54(10), 1590-1595.

- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. doi: 10.1093/intqhc/mzm042
- Tracy, S. J. (2010). Qualitative quality: Eight "big-tent" criteria for excellent qualitative research. *Qualitative Inquiry*, *16*(10), 837-851.
- Turner, C., & McClure, R. (2003). Age and gender differences in risk-taking behaviour as an explanation for high incidence of motor vehicle crashes as a driver in young males. *Injury Control and Safety Promotion*, 10(3), 123-130. doi:10.1076/icsp.10.3.123.14560
- Tyerman, A., & Humphrey, M. (1984). Changes in self-concept following severe head injury. International Journal of Rehabilitation Research, 7(1), 11-24.
- Tyerman, A. (2009) Facilitating Psychological Adjustment. In Psychological approaches to rehabilitation after traumatic brain injury (eds A. Tyerman and N. S. King), Oxford, UK: BPS Blackwell.
- United Kingdom Acquired Brain Injury Forum, (2016). *About brain injury*. Retrieved from http://ukabif.org.uk/data/
- Vickery, C. D., Gontkovsky, S. T., & Caroselli, J. S. (2005). Self-concept and quality of life following aquired brain injury: A pilot investigation. *Brain Injury*, *19*(9), 657-665.
- Wagner, A. K., Fabio, A., Puccio, A. M., Hirschberg, R., Li, W., Zafonte, R. D., & Marion, D.
  W. (2005). Gender associations with cerebrospinal fluid glutamate and lactate/pyruvate levels after severe traumatic brain injury. *Critical Care Medicine*, *33*(2), 407-413.
- Walker, D. M., & Eli Joubert, H. (2011). Attitudes of injecting male anabolic androgenic steroid users to media influence, health messages and gender constructs. *Drugs and Alcohol Today*, 11(2), 56-70.

- Wilber, K. (2000). A theory of everything: An integral vision for business, politics, science, and *spirituality*. Boston: Shambhala Publications.
- Wilkins, D. (2013). "Getting It Sorted": identifying and implementing practical solutions to men's health. *Journal of Men's Health and Gender*, 2(1), 13-16. doi:10.1016/j.jmhg.2004.12.005.
- Wilkins D. & Kemple M. (2011). Delivering Male: Effective practice in male mental health. Retrieved from https://www.mind.org.uk/media/273473/delivering-male.pdf
- Wilson, N. J., & Cordier, R. (2013). A narrative review of Men's Sheds literature: Reducing social isolation and promoting men's health and well-being. *Health and Social Care in the Community*, 21(5), 451–463. doi:10.1111/hsc.12019
- Wilson, N. J., Shuttleworth, R., Stancliffe, R., & Parmenter, T. (2012). Masculinity theory in applied research with men and boys with intellectual disability. *Intellectual and Developmental Disabilities*, 50(3), 261–272. doi:10.1352/1934-9556-50.3.261
- Wise, E. K., Hoffman, J. M., Powell, J. M., Bombardier, C. H., & Bell, K. R. (2012). Benefits of exercise maintenance after traumatic brain injury. *Archives of Physical Medicine and Rehabilitation*, 93(8), 1319-1323. doi:10.1016/j.apmr.2012.05.009
- Wood, E., Desmarais, S., & Gugula, S. (2002). The impact of parenting experience on gender stereotyped toy play of children. *Sex Roles*, *47*(1-2), 39-49.
- Wood, W., & Eagly, A. H. (2002). A cross-cultural analysis of the behavior of women and men: implications for the origins of sex differences. *Psychological Bulletin*, 128(5), 699.
- World Health Organisation (2006). Neurological disrders: Public health challenges. Retrieved from <u>http://www.who.int/mental\_health/neurology/neurodiso/en/</u>

- Yanos, P. T., Roe, D., West, M. L., Smith, S. M., & Lysaker, P. H. (2012). Group-based treatment for internalized stigma among persons with severe mental illness: Findings from a randomized controlled trial. *Psychological Services*, 9(3), 248-258. http://dx.doi.org/10.1037/a0028048
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, *15*(2), 215-228.
- Yardley, L. (2008). Demonstrating validity in qualitative psychology. *Qualitative Psychology: A Practical Guide to Research Methods*, 2, 235-251.
- Yeates, G. N., Gracey, F., & McGrath, J. C. (2008). A biopsychosocial deconstruction of
  "personality change" following acquired brain injury. *Neuropsychological Rehabilitation*, 18(5-6), 566–89. doi:10.1080/09602010802151532
- Ylvisaker, M., & Feeney, T. (2000). Reconstruction of identity after brain injury. *Brain Impairment*, *1*(01), 12-28.
- Ylvisaker, M., Mcpherson, K., Kayes, N., & Pellett, E. (2008). Metaphoric identity mapping:
  Facilitating goal setting and engagement in rehabilitation after traumatic brain injury. *Neuropsychological Rehabilitation*, 18(5-6), 713–741. doi:10.1080/09602010802201832

## Appendices

# **Appendix A Clinician Information Sheet**

Clinician Information Sheet Version 3: 8th December 2014



Norwich Medical School Postgraduate Research Office Elizabeth Fry Building University of East Anglia Norwich NR4 7TJ Email:r.macqueen@uea.ac.uk Tel: STUDY MOBILE

### Masculine Identity after Traumatic Brain Injury

#### Guide for clinicians discussing the research with potential participants

Dear Clinician,

Thank you for taking the time to consider whether my research is appropriate for your client/ patient. This research aims to explore how men experience masculine identity after a traumatic brain injury. The Participant Information Sheet provides detailed information about the study. This document aims to highlight the key points which may help you to explain the research to your client/ patient so they can decide if they want to know more.

#### Items which you may wish to discuss with patient:

- The research aims to explore what it is like to be a man after a traumatic brain injury.
- The research is not connected to treatment and the patient does not have to take part if they do not wish to.
- It is hoped that by understanding this better, the research can help inform future rehabilitation programmes to provide support for men who have had a traumatic brain injury.
- There is a participant information sheet which details the research for the participant. All
  participants will need to read this before taking part. It will let them know everything they
  need to know.
- It is being run by Ruth MacQueen, a Trainee Clinical Psychologist at the University of East Anglia. Taking part would mean meeting with Ruth for around one hour either here or at home, wherever is easiest for the individual. At the meeting, Ruth would ask questions about what it is like for the individual to live with a traumatic brain injury as a man.
- This research project has received NHS ethical approval and R&D approval by the trust.

#### The next steps are:

- If the individual is interested in taking part in the research, please complete the consent to share contact details form. Completing this form does not mean the patient is agreeing to take part, and they can change their mind at any time.
- The patient should be given the participant information sheet if you see them face-to-face. Ruth will send this out if you are contacting individuals via telephone.
- If they agree to share contact details, I will then contact them to discuss the research further.

Thank you for supporting this project! If you have any questions then please contact (NAME of, designated clinician within this service) or myself.

#### Ruth MacQueen

Trainee Clinical Psychologist, University of East Anglia

## **Appendix B Participant Information Sheet**

Participant Information Sheet Version 6: 17th April 2015



Norwich Medical School Postgraduate Research Office Elizabeth Fry Building University of East Anglia Norwich NR4 7TJ

Email:r.macuqeen@uea.ac.uk Tel: 07538613093

### Information about the Research "Exploring the impact of brain injury on masculine identity"

My name is Ruth MacQueen. Lam a Trainee Clinical Psychologist at the University of East Anglia who is undertaking a Doctorate in Clinical Psychology. As part of this Lam required to conduct a research study and Lwould like to invite you to take part. Before you decide whether or not you would like to participate, please take time to read this information sheet. It will tell you why the study is being done and what you can expect if you take part. Please talk to others about it if you wish and contact me to ask any questions.

This sheet is divided into 2 sections.

Part 1 tells you about why this study is happening and what would be asked from you. Part 2 gives you more information about the conduct of the study.

### Part 1

### What is the purpose of this study?

The study aims to find out about what life is like for men who have had a traumatic brain injury. The focus of this research is on how this experience might relate to your identity as a man. By understanding this more, it is hoped that this study will contribute to future rehabilitation programs in being able to provide support for men.

### Why have I been invited to participate?

You have been invited to participate in this study because you are a male who has experienced a traumatic brain injury. This study is for men between the age of 18 and 64 years who have experienced a traumatic brain injury.

### Do I have to participate?

It is entirely up to you to decide whether or not to take part. You may wish to discuss taking part with others you know. You do not have to give a reason if you do not wish to take part. If you agree to take part, you will be asked to sign a consent form. This would not affect the standard of care you receive.

### What happens to me if I take part?

If you decide you would like to participate you will be asked to consent for your clinical team to share your contact details with me. I will then contact you and you can to ask me any questions you have about the study. If you would like to participate we will arrange a convenient time and place to meet, which may be where you meet with your rehabilitation team or may be at your home where a quiet and private room will be needed.

We would meet once and this is likely to last around one hour. In the meeting, I will ask you some questions to find out a bit about you, for example your age and how you came to have an injury. The focus of our meeting will be for you to talk about what it is like for you as a man to live with a Participant Information Sheet Version 6: 17th April 2015

traumatic brain injury. I will ask you some questions about how your day-to-day experiences might relate to your identity as a man.

I will encourage you to do most of the talking so that what we talk about is meaningful to your life experiences. You should only share with me the things that you feel comfortable sharing. You do not have to talk about anything which you do not want and can tell me that you would prefer not to discuss something.

If there is anything we talk about which you feel has caused you some distress or you feel you would like to follow up on some of the things we've discussed, we can talk about how this is best done within the clinical team working with you or with your GP. If I am concerned about a risk of harm to yourself or others then I will discuss this with others involved in your care. I will always try to discuss this with you first.

Our meeting will be audio-recorded so that I can listen back to our discussion and consider carefully what we talked about. After our session, the recording will be transferred onto a password protected memory stick. A written transcription of our discussion will be typed but your real name will not be used.

Direct quotes from what you have said during our interview will be used in the write up of this project. This means that others who read the research will read some of the things which you discussed with me. Your real name will not be used in any of the write up of this project.

#### Will my taking part be kept confidential?

All the personal information about you will be kept confidential. Ethical and legal practice will be followed and all information about you will be handled in confidence. Any data entered onto a computer will be done so under a pseudonym (a made up name). The direct quotes used in the final project will be carefully considered to ensure that they do not contain identifying information and are anonymised.

Your consent forms will be stored separately from the interview data (written transcripts and audio recordings) securely at the University of East Anglia. In accordance with guidelines, the data needs to be kept securely for 10 years. Only I (the primary researcher) will have access to your personal details and audio recordings. The transcripts of our interview which use a pseudonym may be accessed by the research supervisors at the University of East Anglia.

If there is cause for concern of harm to yourself or others during our meeting I may need to inform other professionals. I will always try to let you know if I am going to do this.

#### What are the possible benefits of taking part?

This study aims to contribute to understanding about what it is like to be a man who has experienced a traumatic brain injury. The information we get from this study will help improve the understanding clinicians have about the impact of traumatic brain injury. By gaining understanding about this, clinicians can be more able to support rehabilitation. Your participation will contribute to developing the understanding in this area. As we will only meet once, the meeting will not provide therapy or counselling. However, you may find that talking about your experiences in relation to your identity as a man is helpful for you.

#### What are the possible disadvantages or risks of taking part?

The topic of the interview is one which is very personal for you and it is important that you only share what you feel comfortable sharing. It may be that talking about your experiences may be difficult and upsetting. If you experience distress during our meeting, we can end the session. We Participant Information Sheet Version 6: 17th April 2015

will also discuss how other professionals such as the clinical team working with you can support you following our meeting.

### What happens when the research stops?

The interview data collected in this study will be analysed and a report detailing the findings will be written. The final report will contain direct quotes from what you have said in our meeting. The aim is for the research to be published in academic journals and also presented at conferences. If you would like a summary of the report I am happy to send you one after the work has been completed.

The information collected in relation to the study will be kept for 10 years at the University of East Anglia in line with the UEA Research Data Management Policy.

### Can I claim my travel expenses?

If you travel to the interview, your travel expenses will not be reimbursed.

### Part 2

### What will happen if I don't want to carry on the study?

You are free to withdraw from this study at any time up until 2 weeks after the interview. You can let me know and you do not have to give a reason. After 2 weeks, I will start to analyse our interview and the interview data cannot be removed.

### What if there is a problem?

If you have a concern about any aspect of this study, you can speak to me and I will do my best to answer your questions. Alternatively you can contact my supervisor, Dr Paul Fisher. Either of us can be contacted using the contact details given below. If you remain unhappy and wish to complain formally, you can do this this by contacting Professor Ken Laidlaw at the University of East Anglia, 01603 593076. You can also use the NHS formal complaints procedure, for more advice on this process you can contact Patient Advice and Liaison Service at Elliott House, 130 Ber Street, Norwich, Norfolk, NR1 3FR by telephone 0800 088 4449 or email <u>pals@nchc.nhs.uk</u>. Alternatively, you can contact <u>POhWER</u> on 0300 456 2370.

### Who is organising and funding the research?

This research is being conducted as part of a Doctorate of Clinical Psychology course at the University of East Anglia (UEA). There is no additional funding for this research.

### Who has reviewed the study?

This study has been reviewed by NHS ethics and relevant research governance for participating agencies.

### Further information and contact details

Ruth MacQueen (Trainee Clinical Psychologist) Email: <u>r.macqueen@uea.ac.uk</u> Tel: 07538613093 (9-5 Monday- Friday)

Supervised by Dr Paul Fisher (Clinical Psychologist and Clinical Tutor in Clinical Psychology at the University of East Anglia).

Email: p.fisher@uea.ac.uk

Tel: 01603 593084

Thank you very much for the time you have taken to read this information sheet it is much appreciated.

# Appendix C Consent to Share Information Form

| Consent to | Share | Information | Form | Version | 35 | 17 <sup>th</sup> . | April | 201 | 5 |
|------------|-------|-------------|------|---------|----|--------------------|-------|-----|---|
|            |       |             |      |         |    |                    |       |     |   |

| University of East Anglia  | Norwich Medical School<br>Postgraduate Research Office 2.30<br>Elizabeth Fry Building<br>University of East Anglia<br>Norwich<br>NR4 7TJ<br>Email:r.macqueen@uea.ac.uk<br>Tet: STUDY MOBILE |
|--|---|
| CONSENT TO SHARE INFORM  | MATION FORM   |
| Title of Project: Masouline identity After Traumatio Brain   | injury  |
| Name of Researcher: Ruth MaoQueen  | Please initial boxes. (If verbal<br>consent is being gained over<br>telephone then clinician taking<br>consent should initial.)   |
| <ol> <li>I confirm that my clinician has informed me that I an<br/>above study.</li> </ol>   | m eligible to participate in the  |
| <ol> <li>I confirm that I have received the information sheet</li> <li>6) for the above study.</li> <li>OR</li> </ol>                                      | dated 17 <sup>th</sup> April 2015 version   |
| I have not received the participant information shee<br>Information about the study to (e-mail or preferred add  | ress):  |
| <ol> <li>I give consent for my clinical team to share my con<br/>researcher.</li> <li>My preferred contact details are: (Insert preferred telep</li> </ol> | hone or e-mail):  |
| Name of Participant Date   | Signature (Eprecent)  |

Name of Person taking concert. Dare

Signature

Consent to share information form 17.04.2015 Version 3 Page 1 of 1

# **Appendix D Topic Guide**

### Interview Topic Guide

The participant will be orientated to the area of research through use of the participant information sheet. Before the interview begins the key aims of the study will again be explained. The following will be outlined although is not a rigid script:

"This research is about finding out what it is like to live with a traumatic brain injury as a man. I am interested in finding out about your individual life experiences in relation to your identity as a man and there are no right or wrong answers. I'd like to hear about the kinds of things that are important for you and at times I might ask you to expand on what you've said or give examples, as long as you feel comfortable to do so. Firstly, I have a few questions to find out a bit about you and then we'll move on to talking more about what is like for you as a man to have a traumatic brain injury."

### Background Information

- Current Age:
- · Who lives at home with you?
- Educational background: what age did you leave school? Do you have any years of further education?
- Employment: If you were employed before your injury what did you do? Are you currently employed? What do you do?
- What age were you when you had the injury?
- · Can you tell me about how you came to have a traumatic brain injury?
- Following your injury did you have an inpatient stay in an acute and/or specialist hospital? What was the duration of your stay?
- Are you currently receiving any support from professionals? (duration, type of therapy?)

So now I've asked a few questions to find out a bit more about you, I'd like to ask move on to talking more about what is like for you as a man to have a traumatic brain injury."

### Questions about masculine identity:

- For you, as a man, what is it like to live with your brain injury on a day-to-day basis? (prompts: day-to-day activities, how you fill your day, interactions with others)
- Can you tell me about any times when you particularly felt TBI impacted your identity as a man?

Topic Guide Version 3: 8th December 2014

- Since having a TBI, are there any changes in what it is like for you to be a man? Prompts: are there any differences for you, as a man, between before and after your injury?
- Since having a TBI, can you tell me about what it is like doing things which you feel are part of your role, as a man?
- As a man, what is it like to come for appointments and meet with health professional's here/hospital/ rehabilitation clinicians?
   Prompts: clinicians involved e.g. physio/OT, attending appointments, meetings with professionals.
- I've been asking lots of questions so far, but is there anything else you wanted to say about what it's like for you as a man to experience a brain injury
- What has it been like talking to me today about your experiences? Prompts: to encourage reflection on interview process. Debrief procedure to be followed.

Further questioning using prompts will be used throughout. For example, "can you give me an example of that?" "Can you tell me more about that?" "Can you describe that in more detail to me" "How did that feel at that particular moment?"

Norwich NR4 7TJ

### **Appendix E Consent to Participate Form**

University of East Anglia





# CONSENT TO PARTICIAPTE FORM Title of Project: Masculine Identity After Traumatic Brain Injury Name of Researcher: Ruth MacQueen Please initial 1. I confirm that I have read and understand the information sheet dated boxes 17<sup>in</sup> April 2015 (version 6) for the above study. I have had the opportunity to consider the information, ask questions and these have been answered satisfactorily. 2. I understand that my participation is voluntary and that I am free to withdraw at any time up until 2 weeks after the interview has taken place, without giving any reason. I understand that my medical care or legal rights will not be affected. 3. I understand that an audio recorder will be used and that the things I say may be directly quoted in the final report and publication of this study. I understand that my real name and any other details which may identify me or anyone else will not be used. 4. I understand that should the researcher have any cause for concern of risk of harm to myself or others that other professionals will be made aware. The researcher will discuss this with me first if possible. 5. I agree to take part in the above study. I wish to receive a written summary of the findings of the research. Please send this to: ..... Name of Participant Date Signature

Name of Person taking consent

Signature

Date

Page 1 of 1

### **Appendix F Debrief Sheet**

Debrief Sheet Version 2: 8th December 2014



Norwich Medical School Postgraduate Research Office Elizabeth Fry Building University of East Anglia Norwich NR4 7TJ

Email:r.macqueen@uea.ac.uk Tel: Study mobile

### Masculine identity after Traumatic Brain Injury

#### Debrief Sheet

Thank you for taking part in this research project. The time you have taken to talk to me about your experiences has been greatly appreciated.

The study hopes to understand the impact of brain injury further. It aims to find out about men's experiences of traumatic brain injury in relation to male identity. Research shows that men are more likely to have a traumatic brain injury than women. Research also shows that changes which occur due to the impact of traumatic brain injury can mean that individuals have to adjust to a different view of themselves and make sense of their identity. It is hoped that by understanding more about this experience for men, the research can help inform future rehabilitation programmes to best provide support for men who have had a traumatic brain injury.

#### What will happen next?

What we have talked about will be written down and can be analysed. If you decide that you do not want what you have said to be used in this study, you can contact me and withdraw from the study up to 2 weeks after our meeting. You do not have to give a reason and your care will not be affected.

If you have told me that you wish for me to send you a summary of the finding s of the research, you will receive this after May 2016, once the final report has been written. For further information, please see the Participant Information Sheet.

### What if the interview has caused me distress?

During the interview, it is likely that you talked about very personal experiences. These experiences can be difficult to think about and to talk about. If you experience upset or distress following our interview today then you can consider how best you can be supported with this.

- You may wish to discuss your experience today with family or friends.
- You can contact the team here at The Colman Centre on (01603 697300) or you can contact your GP. You can then decide with them what the best next steps are for you.
- Outside of working ours you should contact your GPs out of bours service.
- You can also contact The Samaritans 08457 90 90 90 or the Campaign Against Living Miserably (CALM) Spm – midnight which is free to call on 0800 58 58 58

#### Thank you for sharing your experiences with me today. It has been greatly appreciated.

Ruth MacQueen

Trainee Clinical Psychologist, University of East Anglia

Supervised by Dr Paul Fisher, Clinical Tutor in Clinical Psychology, University of East Anglia

# Appendix G Example of reflective diary: Excerpt following interview

## **Interview 5 (Gordon)**

That felt like a less positive interview compared to others I've done so far.

I felt sat at the losses which he talked about. I thought about how unfair it seemed and how rubbish that he has had this happen to him.

I think the boundary between clinical and researcher was evident during this interview. I found myself consciously thinking about how I might respond clinically, and then trying to show empathy but ensure that the interview remained focussed on the research. I felt able to focus on drawing on specific experience he talked about and asking more questions about the impact on identity as a man. He talked so openly about very personal experiences. It was striking how open and honest he was whilst still appearing to manage the sensitive and distressing content.

Physical disability is also part of his experience. He talked about how this was easier to see and that initially he was unaware of his TBI. I wondered about how this had impacted his relationship with professionals, however he appeared to be positive about his experiences of professionals following this and I was surprised.

Age seemed to be predominant – i.e. expectations of what he should be doing a s a man his age, hopes and dreams of what life would be like at this point compared to feeling childlike. Teenager.

| - | 2 | 2 | • |
|---|---|---|---|
|   | h | - |   |
|   |   | = |   |
|   | Ċ | 5 |   |
|   | - | 5 |   |
| 7 | - | - | ۴ |
|   | Ł | J |   |
|   | È | ì |   |
| 1 | Ē |   |   |
|   | ĩ | 3 |   |
|   | ü | ñ |   |
|   | č | f |   |
|   | ñ | ā |   |
|   | Ľ | ï |   |

| Crisis point/ family reactions     | 198 | not monkey camel's (he laughs) back. And (wife) said look me and (child1) are   | Word findine? Impact on family created   |
|------------------------------------|-----|---|--|
| trigger help seeking               | 199 | scared to be in the house with you because of this, you need help and so she booked   | turning point. Does role in family as  |
| Help seeking in order to protect.  | 200 | an appointment with the GP and I actually admitted I had issues, accepted I had demossion and arviety on preservined relevant modiration and told the Dr what Pd                    | husband/father become dominant and so  |
| other, identities / roles          | 202 | been do with the tablets up until that point, think I had a mental health referral at   | steps taken to protect masculine identity<br>in these roles? wife is the one who takes |
|                                    | 203 | that point as well and then that was just the start of another cycle because it was   | actin – books appointment  |
|                                    | 204 | such a relief to accept there was something wrong, and it was such a relief to accept   | relief to start to accept difficulties and   |
| Cyclical processes                 | 205 | help gcm, it also made me quite emotional, I feel emotional talking about it now  | get help   |
| Accepting difficulties meant       | 206 | actually, erm but at the same time, it started another cycle of emasculation because  | emotional part of conversation   |
| becoming dependent.                | 207 | suddenly like live kind of got this name to stuff, live got a title for it, live got a reason<br>for what's wrong with me but it means that lim then denendent on rertain things so | Dilemma? relief at understanding but   |
|                                    | 209 | like the medication erm and over a period of time the realisation that actually (wife)  | emasculation at becoming dependent on<br>hole (wife 8, modimetical) second whete       |
|                                    | 210 | had had to quit her job at his point because I, left to my own devices all sorts  | is the reason? Denression / something  |
| Loss of ability to be trusted as a | 211 | happened, (laughs) I set the kitchen on fire twice because I put bacon on and forgot  | wrone – externalisine?   |
| father                             | 212 | it was there, little things like that, (child 1), I'd been looking after her on my own one  | Changes in family life due to impact   |
|                                    | 213 | afternoon and fell asleep on the sofa, (wife) came home, <u>I couldn't be trusted</u> with  | Gives examples of times he was not able  |
|                                    | 214 | my own daughter on my own, I couldn't be trusted to do anything to my own devices   | to be responsible feeling of not being   |
| Humiliatine experience of          | 215 | or be left with any responsibility and although (wife) had quit her job, (wife) said she  | trusted by others is not being trusted to  |
| changes in martial relationship    | 216 | quit her job to be at home with (child 1) but that was basically what she told me to  | be responsible also emasculating. It   |
|                                    | 217 | keep me happy, I mean like now she receives carers allowance erm and there was a  | sounds childlike. Wife trying to protect   |
| are to treening support of care    | 218 | long period after we got married, probably 2 years, where it didn't feel like I was, we   | him.   |
|                                    | 219 | were a married couple, it <u>didn't feel</u> like we were husband and wife, <u>it didn't feel</u> like  | Rpt – it didn't feel   |
|                                    | 220 | we were in love with one another, it felt like I was loved and was being cared for, erm   | Change in roles within the home – man  |
| Daily activities as demeaning      | 221 | and that's pretty humiliating. And as far as being emasculating, I was like the one at  | at home. Even on traditionally feminine  |
| Embarrassment and shame at         | 222 | home pottering about, doing little houseworkey chores, but (wife) was having to tell  | tasks he needed prompting.   |
|                                    | 223 | me what to do. I wasn't doing anything that I felt contributed to my family. I felt like  | Humiliation of not contributing  |
| peing a purden vs peing            | 224 | an embarrassment, I felt that my kids, or my kid at that time would grow up to be so  | Recalls child's question   |
| provider. & contributor            | 225 | ashamed like when people at school say oh what does your daddy do? I mean I   | Not feeling able to fulfil or be adequate  |
|                                    | 226 | remember (daughter) asking me for the first time "Daddy what do you do for a job? "   | in father role as provider?  |
|                                    | 227 | I was like erm I didn't know how to answer it. Erm, yeh I didn't really, I mean what  | contrast of burden vs provider   |
|                                    | 228 | was my purpose, my existence revolved around medical appointments, medical  |  |
|                                    | 229 | assessments and being a burden to everyone around me. It was horrible. I didn't   |  |
|                                    | 230 | provide anything for anyone, yeth there was a roof over our heads and all the rest of   |  |

Exploratory Coding

| Appendix H Example of initial analysis: coding and en |                |
|---|----------------|
| Appendix H Example of initial analysis' coding and en | mergent themes |
| appendia if indiple of minut analysis, cound and on   |                |

Masculine Identity After Traumatic Brain Injury

5

| callialli illadialli   | Transcript (John)   | Exploratory Coding  |
|--|---|---|
| Barriers to engaging in health care:<br>- Comparison to others<br>- emasculating to admit and<br>ask |   | Guilt linked to media and comparison<br>with others burden/ drain on <u>resourcses</u><br>Who is more deserving? Harder to admit<br>to others? Pride.<br>Emphasises the Describes experiences as  |
| Emasculating experience is very significant for him  | <ul> <li>138 P: Emasculating, emasculating is <i>the</i> word that has defined the last 6 1/2 years for</li> <li>139 me.</li> <li>140 I: it would be good to hear a bit more about that</li> <li>141 P: (He laughs) - <u>oooh</u> are you sure?</li> <li>142 P: wes hease (laughs)</li> </ul>   | emasculating<br>As if he has too much to say/<br>overhwhelming?<br>Before/ I was/ and then after  |
| Things in the past which made<br>him a man as compared to<br>others and his previous view            |   | overall his experiences have made him<br>feel less of a man?<br>Jokes – sense of opening a can of worms<br>he has a lot to say<br>I was – talks about achievements/success<br>in finance, career, property ownership,<br>music, football, women, compares self to |
| Loss of earnings and therefore<br>pride  | 149 career ladder with degrees didn't own their own house yet and I'd got 2, one in<br>150 (city) and one in (city of residence). And so and then like I kind of had this rock and<br>151 roll life style on the side of it as well. Kind of did this professional mature thing by<br>152 day and then the music stuff at weekends and playing football. So <u>erm</u> , prior to           | others these features seem to be what<br>he regards as making him the man he<br>was. has a different perspective now to<br>then exclamation implies this was his  |
| Receiving support is childlike<br>Degrading experiences  | 153 meeting (wife name) I kind of had one or two lady friends (he laughs) I was a bit of a<br>154 man about town! I was a bit of an arsehole to be honest, like looking back now, but<br>155 at the time, <u>erm</u> , I was a man! <u>Erm</u> and then after the accident, it's just like so many<br>156 thines. like I wasn't earning money so that sense of oride, vou earning money had | thought Changes after accident loss of<br>earning, pride, ability to do daily living<br>tasks and required support  |
| The level of care he required<br>meant that he could not be<br>viewed as a man by his wife           |   | snaving – activity associated with<br>masculinity expectation that at his age<br>he shouldn't need this help? Or that it<br>was degrading experience illustrating by  |
| Avoidance/ denial  | 161 sexy (he laughs) if she's got to basically wipe my arse for me, not literally wipe my<br>162 arse, but just a way of speaking. The first 2 years I drank quite a lot, I was constantly<br>163 going out, I was trying to be the old me, I wouldn't accept there was anything wrong,<br>164 it took me a long time to accept there was anything wrong and erm the Dr kept.               | objectively the experience. How he feels<br>care changes relationship Laughter – is it<br>unthinkable that she would? Coping by<br>avoidance, alcohol   |

# Appendix H Example of initial Analysis: coding and emergent Themes (continued)

| 1.0      |
|----------|
| ăi       |
| ~        |
| <u> </u> |
| 10       |
| <u> </u> |
| -        |
|          |
|          |
|          |
|          |
| - Bo     |
| - 200    |
|          |
| ~        |
| E .      |
|          |
| - And    |

| Emergent Themes   | Transcript (John)   | Exploratory Coding   |
|---|---|--|
| Defiance at help given  | 165 prescribing me antidepressants and I'd take them, as in take them home because I<br>166 thought right the Doctor's doing what he needs to do, I thought it was load of shit,<br>167 Excuse mv language. I'm sorry   |  |
| Reluctance to become reliant or<br>dependent on medication            |   | resistance/emotion/dismissing<br>Feeling nagged?<br>Speaks in defiant tone<br>Doesn't want to be reliant/dependant?      |
| Reliance/ dependency as weak or<br>meaning something bad about<br>him |   |  |
| Denial of difficulties  | 174 first born, she was born (date) 2010 and when she came along I was still sort of in<br>175 denial of there being much wrong first Christmas she was 6 months old and I ruined<br>176 Christmas for everyone. erm Christmas eve (wife's) parents came over to our house  | Key events- daughters birth & Christmas<br>memory of ruining Christmas   |
| Awareness of difficulties in hindsight                                | 177 and I didn't sleep the night before through anxiety and stress about people coming<br>178 round, I didn't know I had anxiety then, and was pretty suicidal, well actually no I was<br>179 more murderous, I wanted to kill the lad who'd run me over because he'd taken<br>180 answershift as far as I was concerned and it would's head better far events of far | Feeling low, angry seeking revenge<br>Looking back realising difficulties due to<br>anxiety but not aware then increased |
| Comparison of self to child   |   | now? Sense of not being<br>gs clearly at the time.<br>o child  |
| Not being the provider for family                                     |   | Rpt suffocating<br>Experience of anger resulting in conflict<br>with family  |
| Conflict in family relationships                                      | 186 cause I'd lost my wages through (workplace) and stuff and Christmas was a bit lavish.<br>187 Basically everyone in my family I'd <u>spend like £100-£150</u> on each person and so on<br>188 Christmas day everyone was opening presents and my nan, grandad, parents and<br>189 they wore all really appreciative and repared " don't fine thank we for these    | ensation as blood money. Provider<br>pride of earnings lost? - <u>mot</u><br>ig this role as he had imagined?            |
|   |   | Anger<br>Arguments/ difficult <u>relatinships</u> with<br>family.  |
|   | 193 spent a load of money on you lot. Don't thank me for it (driver of car) bought it for<br>194 you. And then my nan, bless her, said do you wanna come round ours for boxing day<br>195 and I told her to fuck off. I told her I didn't want to see anyone on boxing day. I   |  |
|   | wanted to<br>the only th  |  |

# Appendix H Example of initial Analysis: coding and emergent Themes (continued)

| Cluster                            | Subordinate emergent themes   |
|------------------------------------|---|
| Loss of Individual                 | Walting for external factors  |
| agency/ control                    | •   |
| agencjo control                    | <ul> <li>Feeling wound up waiting</li> <li>Waiting for external</li> </ul>  |
|                                    | -   |
|                                    | The impact on mood of waiting for external  |
| Loss of<br>Independence            | Relance on partner  |
| independence                       | Relance on others   |
|                                    | Relance on partner     Selse stuck  |
|                                    | <ul> <li>Being stuck</li> <li>Not driving is loss of independence</li> </ul>                                      |
|                                    | Loss of independence  |
| Feeling vulnerable/                | Feeling vulnerable/ high stakes   |
| cautious                           | Feeling older, vulnerable, anxious  |
|                                    | Cautious  |
|                                    | <ul> <li>Avoidance of vulnerability makes maintaining work role</li> </ul>  |
|                                    | difficuit   |
| impact/ load on                    | Relance is adding to partner's load   |
| partner                            | <ul> <li>The impact on partner as trigger for help-seeking</li> </ul>   |
|                                    | <ul> <li>Not helping as he should</li> </ul>  |
|                                    | <ul> <li>Load on partner</li> </ul>   |
| Loss of the father                 | <ul> <li>Not responding the same as the father he was</li> </ul>  |
| he was                             | <ul> <li>Doing wrong as parent</li> </ul>   |
|                                    | <ul> <li>Not being able to maintain pre injury parenting</li> </ul>   |
|                                    | <ul> <li>Not driving leads to anxiety/ uncertainty of how to financially</li> </ul>                               |
|                                    | support children  |
|                                    | <ul> <li>Not doing as a father should</li> </ul>  |
|                                    | <ul> <li>Loss of parental tolerance</li> </ul>  |
|                                    | <ul> <li>Guit about not controlling anger an impact on relationship</li> </ul>                                    |
|                                    | with children   |
|                                    | <ul> <li>Not driving means not doing father activities</li> </ul>   |
|                                    | <ul> <li>Father role has been compromised by injury</li> <li>Father role has been made clear by injury</li> </ul> |
| Dela dilata da caltura             |   |
| Prioritising family -<br>A changed | Father role,  |
| perspective on life                | changing Relationship     Reformulating values  |
| values                             | <ul> <li>Percentialario valoes</li> </ul>   |
| Others don't know                  | Avoidance of social   |
| his private Internal               | <ul> <li>Keeping things to himself</li> </ul>   |
| experience                         | <ul> <li>Others who don't know him don't see the invisible impact</li> </ul>                                      |
|                                    | <ul> <li>Being cared for vs wanting to keep things private</li> </ul>   |
| The value and loss                 | <ul> <li>Importance or maintaining pre injury work activity</li> </ul>  |
| of work                            | <ul> <li>Loss of pre injury activity</li> </ul>   |
|                                    | <ul> <li>Business/ work suffering</li> </ul>  |
| Luck                               | Luck  |
|                                    | Luck  |
|                                    | <ul> <li>Luck compared to others</li> </ul>   |
|                                    | <ul> <li>Luck compared to others</li> </ul>   |
| Loss of confidence                 | Loss of self confidence   |
| (Inked to                          | <ul> <li>Loss of independence and confidence linked</li> </ul>  |
| vulnerability,                     | <ul> <li>Loss of physical strength impacts confidence</li> </ul>  |
| physical, loss of                  | <ul> <li>Being reminded of injury impacts confidence</li> </ul>   |
| independence)                      |   |

# Appendix I Example of master themes for an individual (George)

# **Appendix J Summary of Themes**

# **Summary Table of Superordinate Themes and Master Themes**

| Doing life and<br>relationships<br>differently | Self-perceptions and the perceived view of others   | Managing the Impact   |
|--|---|---|
| • Loss of<br>individual<br>agency              | <ul> <li>The invisible nature of the injury</li> <li>Shame and loss of self-confidence</li> </ul>                     | <ul> <li>Coping with<br/>adjustments</li> <li>Re-evaluating<br/>life/ values</li> </ul> |
| • Roles and relationships                      | <ul> <li>Not feeling safe, feeling<br/>vulnerable</li> <li>Concern about being<br/>judged as less of a man</li> </ul> |   |

| Doing life and          | Self-Percer           | ptions and the    | Managing (          | he Imnact      |  |
|-------------------------|-----------------------|-------------------|---------------------|----------------|--|
| <u>relationships</u>    | Perceptions of Others |                   | Managing the Impact |                |  |
| differently             | <u>1 er ceptio</u>    |                   |                     |                |  |
| Loss of                 | Others can't          | Not feeling safe  | Coping with         | re-evaluating  |  |
| independence,           | see the               | - feeling         | Adjustments         | life / values  |  |
| agency                  | experience            | vulnerable        | still trying to     | Lucky and      |  |
| Being dependent on      | Importance            | Vulnerability     | be the old me -     | resilient to   |  |
| others & loss of        | of value of           | (John)            | defiance/           | survive (Jake) |  |
| agency.                 | lived                 | Safety and sense  | avoidance           | Luck           |  |
| Not understanding       | experience            | of self in BI     | Reformulating       | It could be    |  |
| self (John)             | (John)                | community vs      | his values and      | worse, you     |  |
| Loss of                 | Others don't          | vulnerability and | behaviour in        | just have to   |  |
| independence            | know his              | not fitting in    | order to protect    | get on with it |  |
| Loss of functional      | private               | with society      | his roles and       | (Nigel)        |  |
| ability but not         | internal              | (Gordon)          | maintain            | Getting        |  |
| motivation(Gordon)      | experience            | Specialist        | masculine           | better/ it     |  |
| Loss of                 | (George)              | services viewed   | identity (John)     | could be       |  |
| independence (Jake)     | The internal          | as supportive     | The                 | worse(Smith)   |  |
| Loss of                 | invisible             | safety net        | importance of       | Lucky to       |  |
| independence            | experience            | (Simon)           | changes             | survive/ be    |  |
| Not feeling in          | (Nigel)               | Feeling           | coming from         | OK (Peter)     |  |
| control of self         |                       | vulnerable/       | himself rather      | Prioritising   |  |
| (Chris)                 | The                   | cautious          | than others         | family - A     |  |
| External factors        | importance of         | (George)          | A desire to         | changed        |  |
| influence his life      | unique                | Being more        | progress&           | perspective    |  |
| (Smith)                 | individual            | cautious, less    | develop             | on life values |  |
| being restricted/ told  | experience            | confident         | Drive to make       | Luck           |  |
| what to do (Peter)      | (Gordon)              | (Smith)           | the most of his     | (George)       |  |
| loss of individual      | Individuality         | Shame and loss    | life (Luke)         | Post-          |  |
| agency/ control         | & expert in           | of self-          | Becoming            | traumatic      |  |
| (George)                | himself               | confidence        | aware of the        | growth (John)  |  |
| Roles                   |                       | Shame and         | impact (Chris)      | Self-          |  |
| Loss of roles as        | (Luke)                | guilt(john)       | Strategies to       | development    |  |
| provider,               | Other's               | Loss of self-     | cope with           | & positive     |  |
| contributor,            | perceptions           | confidence in     | difficulties        | outcomes       |  |
| protector in activities | of his                | physical          | Desire to get       | from injury.   |  |
| as father and           | invisible             | appearance        | back to normal      | (Chris)        |  |
| husband, man (John)     | injury                | (Luke)            | (Jake)              |                |  |
| Frustration about not   | (Chris)               | Shame and         | Finding ways        |                |  |
| being able to           |                       | embarrassment/    | around things       |                |  |
| maintain previous       | <u>Concern</u>        | feeling stupid    | to compensate       |                |  |
| activity (Luke)         | <u>about being</u>    | (Gordon)          | and be able to      |                |  |
| The impact on           | judged as             | Loss of           | participate in      |                |  |
| relationship            | less of a man         | confidence        | role as father      |                |  |
| (Gordon)                | Others                | (linked to        | (Simon)             |                |  |
|                         | perceiving            | vulnerability,    | Strength is         |                |  |
|                         | him                   | physical, loss of | needed to           |                |  |

# **Detailed Hierarchical Structure of Themes Across Data**

| The impression of the  |                | to device device |                  |  |
|------------------------|----------------|------------------|------------------|--|
| The impact on his      | negatively     | independence     | overcome the     |  |
| role in his            | due to TBI     | (George)         | changes the      |  |
| relationship (Jake)    | (Luke)         | Shame(Nigel)     | injury has on    |  |
| Loss of roles as a     | Concern        |                  | roles as a man   |  |
| man and The impact     | about others   |                  | Reluctance       |  |
| on husband and wife    | having         |                  | towards          |  |
| relationship (Simon)   | negative       |                  | considering      |  |
| The impact on          | perceptions    |                  | difficulties and |  |
| husband and wife       | (Peter)        |                  | making           |  |
| relationship           | Starting       |                  | adaptations      |  |
| The potential impact   | again, having  |                  | Expectations     |  |
| of the injury on roles | to prove self  |                  | about            |  |
| (Nigel)                | (Chris)        |                  | improvement      |  |
| Not fulfilling roles   | Being viewed   |                  | are not the      |  |
| as he should (Chris)   | as fragile /   |                  | reality of his   |  |
| Dependency on          | treated        |                  | experience       |  |
| wife/ impact on        | differently    |                  | (Gordon)         |  |
| relationship (Smith)   | by peer group  |                  |                  |  |
| Conflict between       | (Jake)         |                  |                  |  |
| expectations of what   | The difficulty |                  |                  |  |
| he should be doing     | of acceptance  |                  |                  |  |
| and reality (Peter)    | of BI relative |                  |                  |  |
| Impact/ load on        | to physical    |                  |                  |  |
| partner                | for self and   |                  |                  |  |
| Loss of the father he  | others         |                  |                  |  |
| Was                    | (Gordon)       |                  |                  |  |
| The value and loss     |                |                  |                  |  |
|                        |                |                  |                  |  |
| of work (George)       |                | 1                |                  |  |

## Appendix K Example excerpt from reflective diary in analysis

## Jake clustering

Scanning over the themes and quotes I notice that he makes explicit links between what he feels a man should be like and how he feels less of a man.

He seems to talk about how he wants things to be normal — in a way minimalising the injury as e doesn't want others to see him as vulnerable and he has to prove it to them.

In trying to cluster Jake's themes I notice that my theme labels are quite long which may make it more difficult. I wonder if this is to do with trying to capture everything – but it then loses some phenomenology.

I have a cluster around how others view him. I wonder if this can be better captured in 2 themes

- 1. loss of social identity particularly in relation to how his identity in the group has changed.
- 2. something about future identity/ overcoming difficulties.

# Appendix L Criteria for good IPA

### Table 10. What makes a good IPA paper?

The paper should have a clear focus. Papers providing detail of a particular aspect rather than a broad reconnaissance are more likely to be of high quality. This focus may be determined at the outset or emerge during analysis. This focus is apparent in many of the good IPA papers illustrated, for example, Chapman et al. (2007) examine the impact of one particular technology in heart disease. Turner et al. (2002) sample one specific group of ex-professional sports players.

The paper will have strong data. Most IPA is derived from interviews and this means that, for the most part, getting good data requires doing good interviewing. This is a particular skill that must not be underestimated. The quality of the interview data obtained sets a cap on how good a paper can subsequently be. Examples of good data are given in many of the summaries of good papers presented earlier. High-quality data is integral to the success of these papers.

The paper should be rigorous. One should aim to give some measure of prevalence for a theme and the corpus should be well represented in the analysis. Extracts should be selected to give some indication of convergence and divergence, representativeness and variability. This way the reader gets to see the breadth and depth of the theme. For papers with small sample sizes (1–3), each theme should be supported with extracts from each participant. For papers with sample sizes of 4–8, in general, extracts from half the participants should be provided as evidence. For larger sample sizes, researchers should give illustrations from at least three or four participants per theme and also provide some indication of how prevalence of a theme is determined. The two papers on chronic fatigue syndrome by Dickson et al. (2007, 2008) have, for IPA, a relatively large sample size. Their persuasiveness is enhanced by careful articulation of measures of prevalence. The overall corpus should also be proportionately sampled. In other words, the evidence base, when assessed in the round, should not be drawn from just a small proportion of participants.

Sufficient space must be given to the elaboration of each theme. In certain circumstances it may well be better to present a subset of the emergent themes so there is room to do justice to each, rather than presenting all themes but doing so superficially. The French et al. (2005) paper on patient explanations for heart attack is enhanced by having an extended and elaborate account of one of the emergent themes.

The analysis should be interpretative not just descriptive. An interpretative commentary should follow each of the extracts presented. The author is thereby showing the particular ways extracts are contributing to the unfurling theme. In order to do this the researcher is engaging in the double hermeneutic: trying to make sense of the participant and trying to making sense of their experience. For further discussion on pushing interpretation deeper, see Smith (2004).

The analysis should be pointing to both convergence and divergence. Where an IPA study reports data from more than one participant, there should be a skilful demonstration of both patterns of similarity among participants as well as the uniqueness of the individual experience. The unfolding narrative for a theme thus provides a careful interpretative analysis of how participants manifest the same theme in particular and different ways. This nuanced capturing of similarity and difference, convergence and divergence is the hallmark of good IPA work.

The paper needs to be carefully written. Good qualitative work always requires good writing. The reader will feel engaged by a well-wrought, sustained narrative. As a result, he/she will consider they have learned in detail about the participants' experience of the phenomenon under investigation. Have a look at some of the papers rated good in this review to see what good writing looks like.

# Appendix M COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

### COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Торіс                                       | Topic Item No. Guide Questions/Description |  | Reported on |
|---|--|--|-------------|
|   |  |  | Page No.    |
| Domain 1: Research team                     |  |  |             |
| and reflexivity<br>Personal characteristics |  |  |             |
|   |  | which and a formation of the interview of the second states in the secon | 40          |
| Interviewer/facilitator                     | 1  | Which author/s conducted the interview or focus group? 4   |             |
| Credentials                                 | 2  | What were the researcher's credentials? E.g. PhD, MD   | 0           |
| Occupation                                  | 3  | What was their occupation at the time of the study?  | 48          |
| Gender                                      | 4  | Was the researcher male or female?   | 35          |
| Experience and training                     | 5  | What experience or training did the researcher have?   | 55          |
| Relationship with                           |  |  |             |
| participants                                |  |  |             |
| Relationship established                    | 6  | Was a relationship established prior to study commencement?  | 44          |
| Participant knowledge of                    | 7  | What did the participants know about the researcher? e.g. personal   | 48          |
| the interviewer                             |  | goals, reasons for doing the research  |             |
| Interviewer characteristics                 | 8  | What characteristics were reported about the inter viewer/facilitator?   | 35          |
|   |  | e.g. Bias, assumptions, reasons and interests in the research topic  |             |
| Domain 2: Study design                      |  |  |             |
| Theoretical framework                       |  |  |             |
| Methodological orientation                  | 9  | What methodological orientation was stated to underpin the study? e.g.   |             |
| and Theory                                  |  | grounded theory, discourse analysis, ethnography, phenomenology,   | 37          |
|   |  | content analysis   |             |
| Participant selection                       |  |  |             |
| Sampling                                    | 10   | How were participants selected? e.g. purposive, convenience,   |             |
|   |  | consecutive, snowball  | 44          |
| Method of approach                          | · · · · · · · · · · · · · · · · · · ·      |  |             |
|   |  | email  | 44          |
| Sample size                                 | 12   | How many participants were in the study?   |             |
| Non-participation                           | 13   | How many people refused to participate or dropped out? Reasons?  | 45<br>45    |
| Setting                                     |  |  |             |
| Setting of data collection                  | 14   | Where was the data collected? e.g. home, clinic, workplace   |             |
| Presence of non-                            | 15   | Was anyone else present besides the participants and researchers?  |             |
| participants                                | -  |  | 48          |
| Description of sample                       | 16   | What are the important characteristics of the sample? e.g. demographic   |             |
|   |  | data, date   | 46          |
| Data collection                             |  |  |             |
| Interview guide                             | 17   | Were questions, prompts, guides provided by the authors? Was it pilot  |             |
| and being a                                 | -  | tested?  | 160         |
| Repeat interviews                           | 18   | Were repeat inter views carried out? If yes, how many? It's  |             |
| Audio/visual recording                      | 10   | mere repeat men news carnes out. In jes, now many.   |             |
| Field notes                                 |  |  |             |
|   | 20   | Were field notes made during and/or after the inter view or focus group? 50 What was the duration of the inter views or focus group? 49  |             |
| Duration                                    | 21   |  |             |
| Data saturation                             | 22   | Was data saturation discussed?   | 52          |
| Transcripts returned                        | 23   | Were transcripts returned to participants for comment and/or n/a   |             |

# Appendix M COREQ (COnsolidated criteria for REporting Qualitative research) Checklist continued

| Торіс                        | Item No. | Guide Questions/Description   | Reported on |
|------------------------------|----------|---|-------------|
|                              |          |   | Page No.    |
|                              |          | correction?   |             |
| Domain 3: analysis and       |          |   |             |
| findings                     |          |   |             |
| Data analysis                |          |   |             |
| Number of data coders        | 24       | How many data coders coded the data?  | 52          |
| Description of the coding    | 25       | Did authors provide a description of the coding tree?                         | 405         |
| tree                         |          |   | 165         |
| Derivation of themes         | 26       | Were themes identified in advance or derived from the data?                   | 51          |
| Software                     | 27       | What software, if applicable, was used to manage the data?                    | n/a         |
| Participant checking         | 28       | Did participants provide feedback on the findings? n/a                        |             |
| Reporting                    |          |   |             |
| Quotations presented         | 29       | Were participant quotations presented to illustrate the themes/findings?      | 62          |
|                              |          | Was each quotation identified? e.g. participant number                        |             |
| Data and findings consistent | 30       | Was there consistency between the data presented and the findings? 62-1       |             |
| Clarity of major themes      | 31       | Were major themes clearly presented in the findings? 62-10                    |             |
| Clarity of minor themes      | 32       | Is there a description of diverse cases or discussion of minor themes? 62-100 |             |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

### **Appendix N Ethical Approval Documents**



### NRES Committee South West - Central Bristol

Whitefriars Level 3, Block B Lewin's Mead Bristol BS1 2NT Email: nrescommittee.southwest-bristol@nhs.net

25 August 2015

Miss Ruth MacQueen Trainee Clinical Psychologist Cambridge and Peterborough NHS Foundation Trust Elizabeth Fry Building University of East Anglia Norwich NR4 7TJ

Dear Miss MacQueen

| Study title:      | Masculine Identity After Traumatic Brain Injury |
|-------------------|---|
| REC reference:    | 15/SW/0073                                      |
| Protocol number:  | N/a   |
| Amendment number: | 1   |
| Amendment date:   | 14 July 2015                                    |
| IRAS project ID:  | 169254  |

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

| Document                                    | Version | Date         |
|---|---------|--------------|
| Notice of Substantial Amendment (non-CTIMP) | 1       | 31 July 2015 |
| Participant information sheet (PIS)         | 7       | 10 July 2015 |
| Research protocol or project proposal       | 7       | 14 July 2015 |

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

A Research Ethics Committee established by the Health Research Authority

### **Appendix N Ethical Approval Documents continued**

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at <u>http://www.hra.nhs.uk/hra-training/</u>

| 15/SW/0073: | Please quote this number on all correspondence |  |
|-------------|--|--|
|-------------|--|--|

Yours sincerely

(é)

Pp Mr Brian Pixton Chair

Enclosures: List of names and professions of members who took part in the review
Copy to: Ms Clare Symms, Norfolk & Suffolk Primary & Community Care Research Office Mrs Sue Steel

# Appendix N Ethical Approval Documents continued

### NRES Committee South West - Central Bristol

# Attendance at Sub-Committee of the REC meeting in correspondence August 2015

### Committee Members:

| Name            | Profession   | Present | Notes |
|-----------------|--|---------|-------|
| Mr Brian Pixton | Retired solicitor  | Yes     |       |
|                 | Senior Lecturer/ Chair of<br>Faculty Ethics<br>Committee | Yes     |       |

### Also in attendance:

| Name         | Position (or reason for attending) |
|--------------|------------------------------------|
| Ms Fran Race | REC Assistant                      |

### **Appendix N Ethical Approval Documents continued**

Norfolk Community NHS Health and Care

Ref: 2015GC01

### Norfolk & Suffolk Primary & Community Care Research Office

Miss Ruth MacQueen Cambridge and Peterborough NHS Foundation Trust Norwich Medical School Postgraduate Research Office Elizabeth Fry Building, University of East Anglia Norwich Norfolk NR4 7TJ United Kingdom Hosted by: South Norfolk CCG Lakeside 400 Old Chapel Way Broadland Business Park Thorpe St Andrew Norwich NR7 0WG

Tel: 01603 257283

23 April 2015

Fax: 01603 257292 E-mail: snccg.randdoffice@nhs.net http://nspccro.nihr.ac.uk

Dear Ruth MacQueen

Re: 2015GC01 Masculine Identity After Traumatic Brain Injury REC Number: 15/fw/0073 Chief Investigator: Miss Ruth MacQueen Sponsor: University of East Anglia

Further to your submission of the above project to the Norfolk & Suffolk Primary & Community Care Research Office your project has now been reviewed and all the mandatory research governance checks have been satisfied. I am therefore pleased to inform you on behalf of **Norfolk Community Health & Care NHS Trust** that NHS permission (R&D approval) was granted on 23<sup>rd</sup> April 2015 for your study to take place at the following sites:

Norfolk Community Health & Care NHS Trust

You may now begin your study at the above sites. Please note also, if you wish to extend approval to any sites other than those listed above you must apply for this through the Norfolk & Suffolk Primary & Community Care Research Office.

This is on the understanding that:

- Clinicians will use their clinical judgement when inviting participants into the study and they will exclude those participants who could pose a risk to the researcher when working with them at home.
- Transfer of patient identifiable or confidential data must be in accordance with Trust policies

NHS Permission is granted on the basis of the information supplied in the application form, protocol and supporting documentation, if anything subsequently comes to light that would cast doubts upon, or alter in any material way, any information contained in the original application, or a later amendment application there may be implications for continued NHS Permission.

Chairman: Ken Applegate

Interim Chief Executive: Mark Easton

Norfolk Community Health and Care NH8 Trust Head Office: Elliot House, 130 Ber Street, Norwich, Norfolk NR1 3FR

The Norfolk & Suffolk Primary & Community Care Research Office, hosted by South Norfolk CCG, undertakes research management, design and delivery services for Primary and Community Care across Norfolk & Suffolk

### **Appendix N Ethical Approval Documents continued**

Permission is granted on the understanding that the study is conducted in accordance with the Research Governance Framework and the terms of REC favourable opinion.

If you have any queries regarding this or any other project please contact the research office at the above address. Please note, the reference number for this study is 2015GC01 and this should be quoted on all correspondence.

Yours sincerely

Clare Symms

Research Governance Manager, Norfolk & Suffolk Primary & Community Care Research Office Signed on behalf of Norfolk Community Health & Care NHS Trust

CC:

Sue Steel, Sponsor Representative University of East Anglia Dr Paul Fisher, Academic Supervisor, University of East Anglia

#### Conditions of NHS Permission

Please note the following conditions of NHS Permission - it is your responsibility to ensure that these conditions are disseminated to all parties involved in this project at the above sites.

You must notify the Norfolk & Suffolk Primary & Community Care Research Office of:

- · All proposed changes to this study, whether minor or substantial
- All Serious Adverse Events relevant to the above sites
- Any deviations from the protocol or protocol breaches including any urgent safety measures that are required to be taken in order to protect research participants against any immediate hazard to their health or safety
- All incidents<sup>1</sup> or complaints in relation to the research project at the above sites
- Any Sponsor or funder initiated audits, or any regulatory inspections to be conducted in relation to this study at the above sites
- The study conclusion and/or termination of the study; where smartcards have been issued, this
  notification must be made on a site by site basis to allow deactivation of smartcards at that site.
- All publications relating to the study

### Documentation:

You are required to maintain a site file for the study at your site. This should be maintained in accordance with ICH-GCP and will include as a minimum:

- (a) Final approved protocol
- (b) Copies of REC favourable opinion, NHS Permission letter relevant to your site, any other approvals necessary (e.g. MHRA)
- (c) Participant information sheets, consent forms, invitation letters, posters/adverts and any other documentation given to the participant

It is your responsibility to update the information held at each site with any amendments made to this documentation and all approval letters applicable to those amendments and to ensure that all essential documents held at site are maintained, stored and archived as appropriate.

### Scope of permission

 Please note that the above permission applies only to research activity on NHS staff or premises or involving NHS Patients and/or their tissues, data or samples. Separate agreements and permissions will be required for research involving private patients or those under the care of social services.

2015GC01

### **Appendix N Ethical Approval Documents continued**

<sup>&</sup>lt;sup>1</sup> An incident is defined as any event or circumstance that could have, or did, lead to harm, loss or damage and includes loss of data, confidentiality breaches, harm to researchers or staff or damage to property.



Research & Enterprise Services West Office (Science Building) University of East Anglia Norwich Research Park Norwich, NR4 7TJ

Telephone: +44 (0)1603 591486 Email: sue.steel@uea.ac.uk

Web: www.uea.ac.uk/researchandenterprise

TO WHOM IT MAY CONCERN

17 February 2015

Study: Masculine Identity after Traumatic Brain Injury

Chief Investigator: Ruth MacQueen

This is to confirm that the University of East Anglia and Subsidiary Companies have arranged insurance cover as detailed on the attached Company Public Liability and Professional Negligence Insurance certificates.

The cover is subject to the terms and conditions of the policy. If you require further details, please contact the undersigned.

Yours faithfully

Stel. 0

Sue Steel

Contracts Manager