BEYOND THE TIP OF THE ICEBERG: EXPLORING INVISIBLE, UNMETABOLISED LOSS

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TABLE OF CONTENTS

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THE FOLLOWING PARTS OF THIS THESIS HAVE BEEN REDACTED FOR DATA PROTECTION REASONS:

Section D: Client Study……………………………….................................pp.231-249

LIST OF TABLES

LIST OF BOXES

LIST OF FIGURES

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Completing a research study for a doctorate is, of necessity a lonely path to tread, and in this case it has also been a very protracted one. However, I have not been without company on the journey and without the love and support of many people it is a journey I would not have been able to complete.

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[1] Surnames omitted to protect the identity of participants

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This portfolio is dedicated to Gladys Früs-Smith and Michael Vincent Früs-Smith.

Mam and Dad.

I'm sorry you were not able to see me finish it.

DECLARATION

I, Alison Mary Clark, the author of this portfolio, hereby grant powers of discretion to the librarian at City, University of London, to allow this thesis to be copied in whole or in part without further reference to me. This permission covers only single copies made for study purposes, subject to normal conditions of acknowledgement.

KEY TO ABBREVIATIONS AND SIGNS USED IN INTERVIEW TRANSCRIPTIONS

All extracts from the interviews appear in italics.

Par: …………………….. Participant's words

Int: ……………………… Interviewer's words

(8) ……………………….. a pause of 8 seconds

(words/sounds in brackets) …………………….. someone speaking during another person's discourse

= …………………………………..speaking at the same time

[ ] ……………….tells of something that happens in the interview e.g. [interviewer blows her nose]

X ………………………place or person name anonymised to maintain confidentiality

xx ……………………….. a word that is undiscernible on the recording

{} a word that is difficult to comprehend but I think this is what is being said

[OV]………………. Indicates that the participant used his own voice

[AUG]……………… Indicates participant used his augmentative communication system

SECTION A - PREFACE

The principal theme of this portfolio is recognising and working with invisible, and thus unmetabolised, loss. While there are auxiliary themes, including significant work relating to power, culture and identity, this theme has been chosen because of its ability to link the three individual pieces of work herein. The portfolio is organised into four distinct but interrelated sections: the preface; the critical literature review; the research study and the client study. In this preface I will review the main theme, and the way in which each piece is linked to it, and give a brief overview of the personal context within which it was written.

Loss is one of the earliest themes identified in psychological work and perhaps also one of the most significant. Freud's (1917) paper outlines the difference between healthy mourning, where a recognised object has been lost and the process of mourning can move to completion, and pathological melancholia where 'one cannot see clearly what it is that has been lost, and it is all the more reasonable to suppose that the patient cannot consciously perceive what he has lost either.' (p. 245. Freud, 1917). In the latter case the patient may get stuck in the place of mourning and experiences a diminution of self-regard and a loss of ego which is not experienced in healthy mourning.

Each of the studies that comprise this portfolio identifies losses which may be not immediately apparent to either the therapist or the client. The losses are often related to identity and losing something important in relation to who we see ourselves to be.

In the literature review the losses relate to those which occur when culture is ignored and forced to conform to a powerful, dominant alternative culture. The review examines the interplay between a particular diagnostic label, that of PTSD, and understandings of the self in different cultural contexts with a particular emphasis on the importance of these factors in relation to counselling psychology practice. These are important issues to hold in mind when working with clients because of the power of Western, medical models of mental distress and potential power differentials between client and practitioner which may lead to important aspects of the client's presentation being missed or overlooked.

The research set out to explore sexuality and intimacy in the rehabilitation of young men who had sustained a TBI. Eight young men who had sustained a TBI between the ages of 16-25 were interviewed using a semi-structured interview. Transcripts of the interviews formed the core of the data which were analysed using the constructivist version of grounded theory (Charmaz, 2014).

This was the final piece of work to be completed for the portfolio and it helped me to recognise that my participants had sustained many unclear personal losses. They are in a situation where they are frequently told how lucky they are to be alive and yet they have lost so much, but many of those losses are abstract, unrecognised and unmetabolised: - the loss of potential; the loss of opportunity; the loss of "who I was".

From the analysis a core category of "*From alpha male to omega male"; an unwanted, uninvited individuation* was developed with central categories including: "*I felt like I was sinking at times"- "Wanting my old life back"; The aloneness of TBI; A shift in the narrative of time:* and "*A wasteland of intimacy"* being identified.

Sexuality and intimacy seem to be a taboo and neglected area within healthcare and the losses experienced in relation to them in TBI seem to be frequently left untouched with the understandable focus being on regaining function.

Theoretical developments arising from the research include a suggestion for developing Akhtar's (1995) concept of individuation relating to migrants, into a new category of individuation related to TBI and possibly other acquired disabilities. I also suggest developing Boss' (1999; 2010) theory of ambiguous loss in a way which specifically identifies intrapersonal ambiguous loss.

The study is highly clinically relevant, in particular to counselling psychologists and implications for practice are explored.

The client study describes a piece of work which was an important part of my formation as a counselling psychologist. John[2] was a long term mental health patient under the care of the community rehab and recovery team. Now in his mid-50s, he had experienced his first psychotic breakdown at the age of 18 and had been repeatedly sectioned over the years. For John, held for most of his life in the powerful narrative of the medical model, the losses related to his spirituality which was a vital link to his growing up and to his mother. John's own story of abuse, and much of his family history had disappeared along with narratives of his strength, friendships and survival which had lain neglected for many years submerged beneath a powerful narrative of diagnosis, treatment and helplessness. In our work together we explored many aspects of his history and personality that he said he had not been able to talk about before including his history of abuse and his deep spirituality.

The individual pieces of work that make up this portfolio were indeed just that, individual, separate pieces of work, written for separate assignments at very different stages of my training. The theme was not chosen at the beginning but rather was constructed in response to all I had seen and heard and experienced as part of completing this work and more importantly of interacting with my clients, participants, supervisors and teachers over the course of my training.

This portfolio represents the culmination of a 12 year journey towards becoming a psychologist. It was 2004/5 while I was completing my PGCE in post-compulsory education that I realised that although I was a very good teacher "this is not what rocks my boat" and that I wanted to return to psychology in some way, the interruption in my relationship with the field having been precipitated by the development of significant health problems after my first degree, and the birth of my beautiful daughter, Kit.

Due to personal circumstances, primarily my role as carer, the loss of both my parents, and developing further chronic health problems myself, as well as difficulties with the research which are discussed elsewhere, it has taken over 6 years to complete the course to qualify as a counselling psychologist. Over this period there has been a huge amount of change and development for me both personally and academically and I feel that this is evident in the work included in this portfolio. My critical literature review was completed during my first year in 2010/11, the client study was written early in my third year in 2012/13 and the writing of my thesis has been finished in the last few weeks. As a result there is, I feel, an evident difference and development in the style of the pieces. When I first began editing the earlier pieces for the portfolio it was very tempting to use a heavy hand and in places almost rewrite what had in fact been very successful pieces when they were originally submitted. This was particularly true for the client study which, when I read it two years later seemed to contain a degree of chaos that I had not noticed when I was writing it (and neither had the marker!) and so I began the process of editing. However, while occupied with this work I inevitably began reflecting on what I was doing and the meaning of it, and somehow it seemed that I was being

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[2] All names have been changed to protect the identity of participants and clients.

disloyal to my earlier self and to the process which is and has been at work in my formation as a psychologist.

It seemed that what I was viewing as the chaos of the client study was in fact very clearly a parallel process to what had been going in in my work with John and my own development as a psychologist. His story wasn't a neat, easily presentable package and neither was our work together nor my own story. I was very much finding my way and struggling with what it means to be integrative in my approach and with the place of power in the field of mental health and in my own work as a psychologist. I still struggle with this and suspect (and hope) I always will as I continue to choose to work in this way.

The beginnings of this struggle are seen in the literature review; somehow it felt (and still feels) too easy to pick an approach off the shelf and expect that it will fit all people in all contexts. The theory and practice of psychology is dominated by an American/Eurocentric focus and it seems to me that it is far too easy to become trapped in a position where this perspective represents an unquestionable 'truth' and holds the dominant position in any discourse, hence my choice of examining the way in which this position is juxtaposed on other contexts in relation to the construct we have come to know as PTSD.

This struggle with the place and power of dominant discourse is also seen in relation to the most recent piece of work, the research. Here my struggle was with the epistemological difficulties relating to the powerful positivist position which results in the debate over the place and value of qualitative research versus quantitative. Once again the theme of integration is seen, this time in relation to a holistic approach to clients with brain injury.

These threads relating to epistemology and the privileging of modern Western rational perspectives bring us back once more to the theme of invisible, unmetabolised loss and provoke many questions. Is it ever possible or helpful to apply the logical, rationalist concept of an independent, knowable truth to the profound mystery of human spirit, emotion and experience? How much is lost in applying this rational approach to the work of feeling? What is lost by imposing Western ways of knowledge, Western understandings of trauma on cultures that have a different understanding? What did John lose because no-one really listened to his distress? No-one heard what he was saying? No-one attended to his spirit? What do the young men who have sustained a traumatic brain injury lose by health care professionals focussing on functional goals and being unable or unwilling to address issues of sexuality and intimacy that lie at the very heart of their identity?

Perhaps as counselling psychologists we are 'called', in the sense of the word derived from the Latin 'vocare'? Perhaps it is our vocation to distinguish knowledge from wisdom, and to apply the former judiciously and the latter liberally as we accompany those who seek our help on their journeys and whom it is our privilege to accompany?

As I look back over the last 7 years and the slow, messy progress I have made towards becoming a psychologist and towards developing my own integrative stance in relation to my work, I am reminded of the wisdom of Dr Mayuri Senapati, a clinical psychologist who was my supervisor and head of acute and inpatient psychology services when I worked on the ward:

"Alison, being a purist isn't viable; all we have is the tangled ball of wool".

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SECTION B - CRITICAL LITERATURE REVIEW

WITH REFERENCE TO POST-TRAUMATIC STRESS DISORDER, WHAT ARE THE IMPLICATIONS FOR COUNSELLING PSYCHOLOGY OF AN UNDERSTANDING OF CULTURE AND THE SELF?

Introduction

This paper grew out of my placement with an HIV team in East London. During the placement I worked with 2 African women who met the DSM-IV-r criteria for PTSD. With the first I was eager to learn how to deliver the 'evidence-based' treatment recommended by NICE i.e. trauma focussed CBT (NICE, 2005). When the second woman disclosed that she had witnessed her family being murdered, something held me back. She seemed so fragile that I was concerned that if I embarked on this form of treatment she would take flight. This experience, along with my growing awareness of some of the controversy surrounding the diagnosis of PTSD, my knowledge of the diversity of the population I serve and my own scepticism about the utility of diagnostic labels in mental health, led me to look at the literature relating to culture, understanding of the self and PTSD.

In this review of the literature the significance of the question posed will be highlighted in the context of counselling psychology, then having outlined the search methodology, it will explore the notions of culture, the self and PTSD, looking at some of the interplay between them and the implications for therapy within the framework of a counselling psychology setting.

The question posed here is relevant to psychologists engaged in clinical work in general and, more specifically, to counselling psychologists, both with reference to the importance of recognising the impact of culture in the formulation of meaning underlying a client's symptoms and experience; and in relation to the socio-political meanings bound up with applying a diagnostic label to a person.

Pilgrim (2000) highlights that discussion of the utility of psychiatric diagnosis for psychologists is not new, and that almost 40 years ago attempts were being made to demedicalise psychology and to maintain a separation between psychology and psychiatry. The debate has continued often polarising the so-called medical model, which "regards mental malfunctions as a consequence of physical and chemical changes" (Tyrer & Steinberg 1993), and critical/social constructionist approaches which view "madness as a meaningful individual response to the world" and the socially approved function of psychiatry being to "deal with abnormal and bizarre behaviour" in a way that prevents social and economic disorder (Moncrieff, 2007 & 1997).

These ideas are of particular importance for counselling psychologists. The standards of proficiency for practitioner psychologists from the Health and Care Professions Council (HCPC) outline the minimum standards to be met by practitioners in order to practice safely and effectively. These include generic standards to be met by all professional psychologists and standards specific to counselling psychologists e.g. to “understand social and cultural contexts and the nature of relationships throughout the lifespan.” Furthermore the Division of Counselling Psychology states that at the heart of the counselling psychologist’s professional identity is the need to maintain an open reflective stance. This is articulated by Frankland & Walsh who express it thus: “what Counselling Psychologists tend to see is the uniqueness and complexity of each individual, which is not captured by typology or biology or by measuring, atomizing or comparing but only by knowing” (Frankland & Walsh, n.d.). Meanwhile, James (2010), in a paper on the current position of counselling psychology, highlights some of the core values of the discipline including the centrality of the self and the importance of a person-centred, non-diagnostic approach that respects a person’s own account of their difficulties without assuming that any particular type of knowledge or way of experiencing, valuing or knowing is automatically superior to any other way.

These factors all contribute to the need for counselling psychologists to develop a broad understanding of the meaning of culture and the impact of cultural issues on assessment, formulation and treatment, which in turn demands the need to be reflexive and questioning about both their own cultural and epistemological assumptions and those of the profession.

Methodology

Literature searches were conducted using a range of databases including Psych Info, SciVerse, EmBase and Scopus. The Google Scholar search engine was also used. Search terms included “counselling psychology” both individually and combined with “culture” and “cultural”. In Psych Info “culture” was searched as a keyword and “culture (anthropological)” was exploded. Post-traumatic stress disorder and PTSD were also searched, along with “cultural differences”. “The self” and “self-concept” were also used in combination with some of these other terms. Further literature was found using the bibliographies and citations of articles identified through the searches. The Division of Counselling Psychology and the WHO websites were also used.

Searches were confined to papers written in English which resulted in the majority of the papers included being written from a Western perspective, however, papers which highlighted Western and non-Western cultural differences were privileged. Much of the extant literature on culture originates from the discipline of sociology and while certain classic papers were included e.g. Geertz (1973), papers drawn from the discipline of psychology were favoured as these have most relevance to the current field of study. Papers were drawn from a 40 year timeframe beginning in 1970/71 and ending at the time of writing (2011).

Culture

Many people might claim to understand what culture is, but find themselves struggling if asked to define it. People may refer to language, beliefs, traditions of dress, food or music. Anthropologists have debated the definition of culture for many years and the difficulties over this are set into context by the work of Kroeber and Kluckhorn who identified 160 different definitions of culture (Jervis, 2006).

Anthropologists have identified a number of dimensions through which culture may be understood. These include Macionis’ value systems and Brown & Lundrum-Brown’s eight dimensions of culture (Bonacci, 2005). Perhaps one of the most comprehensive definitions is offered by Bodley (1994) who argues that culture is comprised of 3 components: what people think, what they do and what they produce, and 6 properties: it is shared and symbolic; learned and passed between generations; adaptive and integrated. Culture guides behaviour and influences the way people think and what they believe; the values and priorities of a people are also in part determined by their culture. Geertz (1973) talked about culture in terms of signs, symbols and their prescribed meanings. He viewed people as creating their own meanings within the groups to which they belong.

Markus & Hamedani (2007) and Whealin (2008) suggest that culture is not just a matter of which part of the world a person comes from, many aspects of their lives can be regarded as having cultural significance e.g. religions and professional or work groups. From this perspective the view arises that individuals may belong to multiple cultures relating to many areas of their lives including nationality, religion, occupation, sexual orientation, and physical ability.

Within the field of mental health the most frequently encountered, and arguably most powerful, culture is that of the medical model. This is the corner-stone of general medicine and proposes that disease has a specific cause such as a malfunction within or damage to the systems of the body, or an invasion of the body by something harmful e.g. a toxin or micro-organism. The model is rooted within a positivist epistemology which posits that the causes and treatment of disease are open to scientific inquiry and that diseases with similar causes and courses will respond to similar treatment.

In the mid 1800's Kraeplin applied this model to psychiatric disorders, asserting that emotional difficulties and unusual behaviours had a biological basis. This assertion is now fully integrated into psychiatry (Moncrieff, 2007). The categorisation of mental distress has been enshrined in the Diagnostic and Statistical Manual of Mental Disorders (DSM), of which a 5th edition is in preparation, and within the International Classification of Diseases (ICD). Powerful forces underpin the supremacy of the medical model, not least economics. Leaving aside the issue of the profits of pharmaceutical companies, Blumenfield (2010) predicted profits from DSM 5 would be approximately $1,000,000 per year over the first 8-10 years.

For those counselling psychologists working within contexts such as the NHS, which is dominated by the medical model, it is important to be aware of the power of this model in standardising the experience of individuals by fitting them into diagnostic, and consequently treatment, categories. Counselling psychologists may assert that they stand outside this medical culture, however, the discipline is subject to professional cultural influences of its own.

Counselling psychologists adhere to the concept of the scientist-practitioner as central to their way of working and those entering the profession are expected to accept this. The history of the scientist-practitioner model is beyond the scope of this article, however, it is worth remembering that the concept is one that is in itself culture bound and its genesis both in the United States and in the UK place counselling psychology firmly within the positivist/empirical paradigm (Myers, 2007, Corrie & Callahan, 2000).

Robbins (2008) highlights the difficulties in working with a client when there is a clash of cultures; in this case, although both the therapist and the client were from Traditional American Indian Tribes, it was the counsellor's professional culture that risked getting in the way of a useful experience of counselling for the client. He reflects on the importance of understanding the epistemological and cultural foundations upon which clients lives are based but, perhaps more importantly, on the need for therapists to identify and fully explore the foundations of their own cultural and epistemological assumptions, particularly the powerful ones relating to their profession.

The history of the study of culture in psychology is a mixed one. At times there has been considerable interest in the idea that context is an important influence on the way an individual behaves; at others the emphasis has been more firmly on the importance of the internal workings of the individual, particularly in the dominant North American perspective on psychology (Markus & Hamedani, 2007). Over the last 20 years however, there has been a resurgence in interest in the interplay between the individual and their contexts, and increasingly there is acknowledgement that the two are inseparable (Kitayama & Uskal 2011). Inevitably this focus on the interplay between the individual and their context has fuelled an interest in cultural differences in understanding of the self.

The Self

The concept of the self is complex, encompassing ideas about the physical, external body, the internal world and the way in which both relate to others. Hollan (1992) stated that most social and cultural anthropologists accept that there are different ways of understanding the self and that clarity about what is being discussed is important because the concept encompasses many aspects of subjective experience e.g. Triandis (1989) uses Cooley's 1902 definition of the self as being all statements using words such as I, me and mine etc.

Markus & Kitayama (1991) identify two aspects of the self which comprise a range of different components. The first aspect is the "universal aspects of the self" which relates to the external reality of the self, including the idea that all people develop a sense of themselves as existing physically separate from other people, anchored in time and with an understanding of their own continuity i.e. they are the same person today that they were yesterday; the second is "divergent aspects of the self" i.e. those aspects which relate to the inner self, may arise primarily out of belonging to a particular culture at a particular time, and give rise to the public self that relates to others.

Many of the components of the "divergent aspects of the self" have been researched including honor [sic], religiosity and hierarchy (Kitayama & Uskul, 2011) however, one of the components of the self most frequently referred to in the literature is the self in relation to others. This is rooted in Mead's observation that cultures vary in the extent to which they value competition, co-operation and individualism (Triandis, 1988). Triandis argues that this maps directly onto the psychological concept of allocentrism-idiocentricism within the personality and that Hofstede labelled the corresponding components of the self individualism vs collectivism.

Hofstede's construct of individualism vs collectivism, one of four original dimensions developed from a study of work related values, contrasts individualism - where individuals are viewed as responsible only for themselves and their immediate family, and the ties between individuals are loose - with collectivism, where people see themselves as belonging to a cohesive group, often the extended family, which looks after all its members in exchange for their loyalty (Hofstede & Bond, 1984; Hofstede, 1993).

Markus and Kitayama (1991) subsequently developed the construals of independence and interdependence which Matsumoto (1999) argues shows similarities to many earlier concepts of the self in relation to others including those proposed by Freud, Angyal and Balint. The hypothesis that variation between independence and interdependence, or individualism and collectivism, is a key factor underpinning differences in social orientation between cultures has generated considerable research with a move towards increasingly experimental methods (Kitayama & Uskul, 2011).

Markus and Kitayama (1991) reviewed some of the early research into these ideas, looking at the impact of cultural differences in understanding of the self on cognition, emotion and motivation which had previously been assumed to be biologically fixed. They refer to a number of studies that relate to cognition including one by Kitayama, Markus, Tummala, Kurokawa and Kato showing that perceived similarity between self and others is influenced by the independent/interdependence construal. A study by Shweder and Bourne (1984) showed that personal descriptions of close acquaintances differ between cultures, with respondents in India (interdependent) providing descriptions that were more situationally focussed, more relational and more focussed on behaviour e.g. “He behaves properly with guests but feels sorry if money is spent on them”(p172); while American’s descriptions (independent) were more context free and made more attributions about the person e.g. referring to the same type of person as ‘tight’. Finally a study by Miller (1984) called into question the assumption of a purely biological/cognitive basis for fundamental attribution error when Indian participants gave greater weight to a person’s social role than Americans trying to understand events.

In relation to emotions Matsumoto, Kudoh, Schrer and Wallbott (1988) found that although American (independent) and Japanese (interdependent) participants placed emotions in the same order based on which they experienced for longest, Americans reported qualitatively different experiences of each emotion experiencing them for longer periods of time, feeling them more intensely and having more associated physical symptoms. Markus & Kitayama (1991) suggest that this may relate to the fact that most of the emotions listed were “ego-focused” which independent participants would attend to more readily because inner feelings/emotions are an important constituent of the self in their culture.

Markus & Kitayama (1991) further highlight anger in cross-cultural studies. They note that the expression of anger in an interdependent context would not be adaptive as it threatens the basis upon which the interdependent self exists. They refer to groups where it is asserted that anger is not experienced e.g. Tahitians & Ukta Eskimos, and to the Chinese culture where formulaic ways of interacting make it easier to avoid the expression of anger. Describing a study by Miyake, Campos, Kagan & Bradshaw, they highlight evidence suggesting that children are acculturated to the expression of emotions prevalent in their culture from a very early age, suggesting that cultural differences in child-rearing practices impact on the child’s interaction with the environment.

Similar studies are reported suggesting cultural differences in motivation.

Another field where it has been assumed that a fixed biological basis underpins processing is information processing, however, this too is now being questioned. Nisbett & Miyamoto (2005) examined evidence relating to the impact of cultural differences on perception and assert that people from independent cultures tend to use more analytic, context independent processes in perception, while people from interdependent cultures tend to use more holistic forms of perception that focus on context and relational aspects of the target. Their assertion is supported with a wide range of evidence from a variety of experimental conditions.

Masuda & Nisbett (2001) conducted a series of well-designed experiments which had examined perceptual differences between American and Japanese participants. Initially they presented American (independent) and Japanese (interdependent) subjects with short videos of an underwater scene. Participants were first asked to recall what they had seen. Masuda & Nisbett conducted a detailed analysis of what was said, looking particularly at the first sentence uttered by participants. As expected independent participants were more likely to begin by talking about salient objects, while interdependent subjects focussed more on context. Examination of the sentences demonstrated that Japanese participants were more likely to talk about salient objects in relation to the field, and made more time and behaviour related comments than the Americans. Participants were later presented with an unexpected recognition task where some items presented had been in the original scene, some had not. All items were presented either against the original background, a novel background or no background. As expected interdependent subjects, who had been hypothesised to attend more to the whole scene were considerably hampered by the novel background in the recognition task.

As Japanese participants were arguably more familiar with the sea and varieties of fish than mid-western participants, a second study was conducted using American scenes and animals. Participants viewed pictures of animals against a background and had to make a judgement about how much they liked them. Again an unexpected recognition task was presented but, in addition to scores, reaction times were recorded to test the hypothesis that Japanese reaction times would be faster when judging animals they had seen before with their original backgrounds because they would have already automatically bound the scene and the object when first seeing them, whereas American participants would have to match them while making the judgement. This hypothesis was born out and in addition, there was no difference between American and Japanese participants with the novel animals regardless of background, further supporting the hypothesis that the previously seen animals and backgrounds were already bound together in Japanese participants' memories.

This was a complex series of well-designed experiments. In the first study where sentence structure was examined, all data was translated and analysed in both Japanese and English to ensure accuracy of data coding. Further, concerns in study 2 about the magnitude of difference between the reaction times of independent and interdependent participants led to a follow up study to examine this.

Other evidence reviewed by Nisbett and Miyamoto (2005) suggests that because elements of interdependent and independent culture can be found in all people, the results of a task can be influenced by priming culture prior to undertaking that task. Kühnen and Oyserman (2002) influenced the results of a perceptual task by first asking participants to circle pronouns either in the first person singular or first person plural. Where participants focused on the first person singular they performed an analytic perceptual task more quickly, where they focussed on the first person plural they performed a holistic task more quickly in spite of being from independent cultures.

Miyamoto, Nisbett & Masuda (2006), found that American urban environments were consistently less complex and contained fewer objects than Japanese urban environments suggesting that the environments may each encourage particular patterns of attention for their respective cultures, although it is important to note that it is not known whether the environments originally produced the modes of perception and social interaction or whether they were themselves a product of it (Nisbett & Miyamoto, 2005).

Like Kitayama & Markus (1991), Nisbett & Miyamoto (2005) present evidence from child development. They cite an early experiment by Chiu showing that children match objects according to shared analytic features if they are from independent cultures and according to relational or contextual information if they are from independent cultures. They also cite evidence from Bernstein, and Fernald and Morikawa showing that Japanese mothers (interdependent) play with their children by engaging them in social routines whereas American mothers (independent) tend to label toys and point out their attributes to their children. Analysis of the language mothers use shows that the Japanese mothers use verbs more frequently, emphasising relationships between objects and context, while American mothers use nouns more frequently emphasising the object. This bias is reflected in the speech production of the infants and it is suggested that these child-rearing practices help to direct the infants to the predominant social orientation within their culture.

Within the last 8 years, interest in the field of socio-cultural psychology has developed further with the genesis of cultural neuroscience. Kitayama & Park (2010) argue that until recently the idea that the mind could be significantly influenced by socio-cultural contexts has been stunted by the premise that the neural structures of the brain are both innate and common to all. They assert that cultural neuroscience is an interdisciplinary field that provides a framework that “seeks to establish an alternative view of the human mind as biologically prepared and, yet, supplemented, transformed and fully completed through active participation and engagement in the eco-symbolic environment called culture” (p111-112).

Introducing neuro-science to the concepts of culture and the self allows direct measurement of neural mechanisms that give rise to the psychological processes being studied; an example of this is the work of Zhu, Zhang, Fan and Han (2007). The Prefrontal cortex (PFC) is highly interconnected with other parts of the brain including the amygdala, pons, hypothalamus and mid-brain and is generally considered to be responsible for executive function - co-ordinating the function of different parts of the brain. Specifically the dorsolateral prefrontal cortex (DLPFC) is implicated in cognitive tasks such as maintenance of information in working memory; representations of future goals or predictions and past events; and changing behaviour as demands of a task change. The Medial Prefrontal Cortex (MPFC) is associated with pain perception; attention to demanding cognitive tasks; metacognitive processes, retrieving information from long-term memory stores and decision-making (Siddiqui, Chatterjee, Kumar, Siddiqui & Goyal, 2008). A number of studies had demonstrated that medial prefrontal cortex (MPFC) activation is stronger when judgements are being made about the self as opposed to others (Craik et al., & Zhang et al., cited in Zhu et al., 2007). Zhu et al hypothesised that, because of their interdependent culture, Chinese participants would show activation in the MPFC during fMRI scans, when thinking of intimate others but Western participants would not. Participants were asked to make judgements about whether visually presented trait words were relevant descriptions of themselves, their mothers or a famous person. To control for visual perceptual processing on the scans, a font identification task was also included. Following the scans participants were asked to complete an unexpected word recognition task based on the trait words used in the scanning procedure.

Again the study was well designed with participants in both groups being matched on education level and time living independently. All participants were tested in their first language, were right-handed and had no neurological or psychiatric history. Trait words were matched for meaning in Chinese and English, with Chinese adjectives all being 2 characters long and English words being matched on length and number of syllables. The lists of trait words were equally divided between positive and negative words and these were presented in random order.

As predicted, all participants showed activation in similar areas of the MPFC when making self-judgements. When making other judgements there was no such activity, however, this inactivity in the MPFC was observed in Western participants both when thinking about the public figure and when thinking about their mother. In Chinese participants MPFC activity was seen in trials where they were thinking about their mother. In the memory test Western participants remembered personal traits related to their self-judgements better than those related to their mother judgements. This pattern was not observed in Chinese participants.

This type of study is important because it suggests that cultural differences in the orientation of the self, observed in behaviour, cognition and perception, may be mediated by differences at the neural level.

While much recent research has been based on the Markus & Kitayama (1991) hypothesis of two separate construals of the self, a Western independent understanding and an Eastern interdependent understanding, the authors do point out that even in Western cultures people are observed to conform and obey in a way that is not predicted by cultural models of the self, e.g. in the classic studies of Milgram, and Zimbardo, (cited in Atkinson & Atkinson, 1990). They also point out that there may be gender differences to which these construals of self are not sensitive, particularly in relation to Western women in whom the characteristics of awareness and sensitivity to others are valued.

Hollan (1992) points out that conceptual, cultural models of the self are often both simplified and idealised expressions of the real complexity that exists within a society. He asserts that it is difficult to know how far models can really equate to individual human experience of the self and questions whether differences in language used to describe experiences really points to a fundamental difference in the way humans experience cognition and emotion. This is an area that might lend itself to study through cultural neuroscience.

This raises the possibility that there is a continuum on which these dimensions of independence and interdependence exist, rather than the two being dichotomous positions. This idea is supported both by the reflections of Markus and Kitayama (1991) and by Bochner's (1994) experimental data testing Hofstede's individualism/collectivism distinction. In this work participants were classified on measures of being Idiocentric, Allocentric or Group self-referents reflecting the work of Baumeister and Greenwald & Pratkanis who posited that the self exists with reference to 3 dimensions – the private self which exists in relation to its own assessments (Idiocentric), the public self which exists in relation to assessments by generalised others (Allocentric) and the collective self which exists in relation to specific groups to which the individual belongs (Group) e.g. family, work etc. Triandis (1989) argued that people have a different probability of accessing these different aspects of the self depending on the culture in which they operate and that this impacts on their behaviour.

What is interesting about Bochner's (1994) data is not so much that the members of interdependent societies had a higher mean Group score than those from independent societies but that although the mean Idiocentric score was lower than that of the independent participants, it was still higher than their own Group score. This supports the idea that people are a complex mix of many factors, a hypothesis that is further supported in Nisbett & Miyamoto (2005) in their description of priming culture.

It should be remembered that people are not simply passive recipients of the culture that is passed on to them but they use it to shape and make meaning of their lives (Markus and Hamedani, 2007) e.g. Han et al (2009) found that when committed Chinese Christians & Buddhists think about themselves dorsal regions of the PFC activate rather than the MPFC.

PTSD

Post-Traumatic Stress Disorder (PTSD) was first accepted as a formal diagnostic category in 1980 when it appeared in DSM-III. Although the idea that exposure to extreme trauma could cause psychological distress was not a new one e.g. railway spine, shell-shock, the concept of

PTSD as a biomedical problem to be treated as a disease has proved controversial, and all the more so when linked with issues of culture and the self.

The diagnostic criteria for PTSD are that a person should have been exposed to a traumatic event where they experienced, witnessed or were confronted with an event that involved "actual or threatened death or serious injury, or a threat to the physical integrity to oneself or others" and that the person's response involved "intense fear, helplessness or horror". In addition, they must experience symptoms from each of 3 symptom clusters, intrusive recollections, avoidant or numbing symptoms, along with symptoms of hyper-arousal. These symptoms must have been present for more than one month and must cause clinically significant distress or have a significant impact on functioning (APA, 2000).

PTSD may be categorised as either simple or complex (NHS Choices, 2015). Complex PTSD is more likely to arise where a person has been exposed to repeated, severe traumatic experiences such as violence, neglect and abuse. While simple PTSD is very amenable to treatment using the CBT protocols and indeed, may resolve without the need for treatment, symptoms of complex PTSD may not appear until many years after the trauma and may take longer to treat requiring a period of stabilisation prior to beginning active treatment with CBT or EMDR for example. It is generally recommended that psychological treatments are tried before medication (RCPSYCH, 2013).

PTSD arose in the politically charged atmosphere of post-Vietnam war era in America and through its inclusion in DSM-III quickly became an accepted psychiatric condition (Tavakoli, 2010). Tavakoli, argues that there are 5 difficulties with the diagnosis of PTSD including that post-traumatic stress may simply be a natural reaction to extreme stress, rather than a pathological condition, and that it has not been possible to confirm it as a disease category.

Given the strength of the biomedical model in psychiatry, perhaps one of the most powerful arguments for PTSD as a psychiatric disorder would be evidence of a characteristic biological marker in those exhibiting symptoms. Tavakoli (2010), Gilbertson et al (2002) and Scott & Stradling (2006) all refer to studies which suggest that there is some evidence that adults experiencing symptoms of PTSD following a traumatic event show reduced hippocampal volume and Yehuda, McFarlane & Shalev (1998) identify that lower cortisol levels may play a role in the development of PTSD.

Scott and Stradling (2006) describe a model of PTSD where, following trauma, the amygdala becomes hypersensitive to danger signals coming in via the thalamus, while reduced hippocampal volume makes it difficult for the hippocampus to issue corrective information to the amygdala if the danger signals have been a false alarm. This model provides one of the fundamental theories of the way in which the symptoms of PTSD are generated and maintained through the abnormal formation of memories and persistent hyper-vigilance and flashbacks (Brewin & Holmes, 2003), however, the neurobiological evidence is not as clear cut as it might at first seem.

Gilbertson et al (2002) conducted a well-planned study using a case control design with monozygotic, male twins in which one of each pair of twins was a Vietnam combat veteran. The study grew out of animal studies which have suggested that increased levels of corticosteroids act as a neurotoxin causing atrophy and cell death in the hippocampus, and the human studies showing reduced hippocampal volume in adults with PTSD symptoms.

The study divided the twins into pairs where the combat exposed twin had gone on to develop chronic, unremitting symptoms of PTSD and those where no PTSD symptoms had developed; it then compared the hippocampal volumes of the pairs of twins in each experimental group to establish whether reduced hippocampal volume existed prior to the development of PTSD symptoms.

The study found that those with a diagnosis of PTSD did have hippocampal volumes of approximately 10% less than those without, crucially however, it also showed that their non-trauma exposed twins also had significantly reduced hippocampal volumes, suggesting that this may be a predisposing familial trait rather than a consequence of trauma which then goes on to produce PTSD symptoms. The study also claimed to be unique in that, in the selection of the twin pairs, it used twins where the non-exposed twins also had no history of major depression or alcohol abuse, conditions that are frequently co-morbid with PTSD and could account for reduced hippocampal volume.

The individual symptoms of PTSD are not unique to that disorder, (Breslau, 2004) and neither is some of the neurology (Gilbertson et al., 2002). The often repeated claim that it is unique in the DSM because of the association between a specific causal agent and a diagnosis, e.g. Tavakoli (2010) has also been called into question with Breslau (2004) pointing out the adjustment disorder makes the same link and that substance misuse also frequently has a close link between psychosocial antecedents and subsequent behaviour. He also highlights the fact that the psychological theories of faulty functioning of memory in PTSD “depend on modern Western conceptions of the self as constituted through continuities of memory” (Breslau, 2004), thus situating the disorder firmly within a Western individualist conceptualisation of the self. Summerfield (1999) lists seven assumptions that drive the provision of trauma interventions in war zones across the world. These include the principle that there is “a universal human response to highly stressful events, captured by Western psychological frameworks” (p1452); that “Western psychological approaches are relevant to violent conflict worldwide; and that “victims do better if they emotionally ventilate and ‘work through’ their feelings” (p1455). These assumptions coupled with the high regard within which western approaches to medicine are held across the world give rise to what Wessells called “a tyranny of Western expertise” (Marsella, 2010).

The global socio-political and economic impact of PTSD also needs to be taken into consideration. In America a soldier with a diagnosis of PTSD receives treatment and financial compensation. Tavakoli (2010) notes that research in America has shown that soldiers treated for PTSD do not always maintain their gains over time, and cites historical papers by Huddleson & Hunt, and Kardiner & Spiegal that express the view that compensation may be a significant factor in maintenance of symptoms.

What is perhaps of more concern is the way a diagnosis of PTSD appears to be being used in developing countries. One of the difficulties with PTSD is that it is a construction that has arisen from a particular social context but is now being applied indiscriminately to people across the world regardless of their priorities. Summerfield (1999) quotes the example of Cambodia which is seen by many to have a culture of silence in relation to the Pol Pot years. The people are unwilling to explore the supposed psychological consequences of the brutal regime; their concern, which seems to be taken less seriously by outsiders, is about the state of the economy.

Breslau (2004) pointed out that a narrative of PTSD can be used to reinforce positions of perpetrator and victim within societies, narratives that can be used to political advantage, when perhaps a more objective position would provide a more balanced account. He questions whether PTSD is always the most pressing mental health need, citing the work of Van Ommeren et al with displaced people in a camp on the Nepal/Bhutan border. They estimated the 12 month prevalence of psychiatric disorders to be 74.4% among tortured refugees and 48% among those who were not tortured. Among the camp population of

85,078, only 4% of the total with a psychiatric disorder were those with a history of torture (1,734 people) and yet this is where resources tend to be focussed leaving the greater proportion of people with psychiatric disorders, in this case 39,718, without help. Caple James (2004) also highlights the increasing role of a diagnosis of PTSD and building a trauma portfolio as being the gatekeeper to resources in areas where there has been political violence. She argues that it also has a role in converting unimaginable horror into a more acceptable narrative of stress and anxiety, and that the trauma of some populations is more ‘valuable’ than that of others.

Concern over the legitimacy of applying diagnostic labels from the Western medical paradigm to people from other cultures is not new. Kleinman (1987) observes that there may well be biases at work when Western researchers look for “cross-cultural ‘similarities’ and ‘universals’ in mental disorder” (p448), he expresses concern that cultural dimensions of an illness are down-played while biological aspects may be emphasised, and that there is a danger in cross-cultural research into mental distress of creating a category fallacy i.e. privileging of a disease category developed for one cultural group to the extent that it is then applied indiscriminately across other groups.

Assessment & Treatment

Assessment and treatment of PTSD presents another area fraught with difficulty not least because of language difficulties. Screening and assessment measures are likely to have a Eurocentric bias (Regel & Berliner, 2007). Kleinman (1987) and Mollica et al. (1992) explore some of the issues in translation and validation of measures for cross-cultural use.

The implications of the differences in orientation of the self discussed above are also profound for understanding of traumatic events. One example of this is the case of sexual trauma. Patel (2008) states that psychological conceptualisations of rape usually construct it as “individually embodied suffering”, however in many countries rape is used as a political tool through which entire communities can be controlled (see also Caple James 2004). To fail to recognise the context in which the trauma has taken place would be to perpetrate a further injustice on those who have experienced it.

Another legitimate question is to ask whether individually focussed Western therapies based on an independent understanding of the self will effectively translate to those with an interdependent understanding. The work of Ncube (2008) with traumatised orphans in Zimbabwe using The Tree of Life, suggests that perhaps there are more creative approaches to be explored.

Summary

This review examines the implications of an understanding of the concepts of culture and the self for counselling psychology practice in relation to PTSD. These are complex concepts and the review has drawn on literature from anthropology, psychiatry, cultural psychology and cultural neuroscience.

The purpose of the review is not to deny that people experience a range of distressing and sometimes disabling symptoms following a traumatic experience, however, it does call into question whether labelling these experiences as a psychiatric disorder is the most helpful way forward for all people across the globe.

There is increasing evidence that differences in behaviour across cultures map on to differences in cognition, emotion and perception, as well as to differences in the neural substrates underpinning these processes (Markus & Kitayama, 1991, Nisbett & Miyamoto, 2005 & Kitayama & Park, 2010). This calls into question many psychological models that are formulated on the supposition that there are theories of behaviour that apply across all people e.g. Ross' fundamental attribution error (Markus & Kitayama, 1991), as well as the basis upon which psychiatric diagnoses are made i.e. that there are biological processes and mechanisms that are common to all people that underpin mental distress.

The construct of PTSD grew out of a distinct socio-political situation. It is interesting that one group around whom the disorder evolved i.e. American combat troops, is now beginning to frame the disorder as "combat stress" rather than as a disorder (Tavakoli, 2010). PTSD has been enshrined in the DSM since 1980 and consequently is backed by the full authority of the Western, positivist epistemological paradigm. It is frequently used as a framework to explain the experience of people outside the original cultural group from whom the construct emerged and can be used as a means of controlling access to treatment. The increasing focus on PTSD in these contexts may also deny access to other more urgently needed forms of mental health care (Summerfield, 1999).

Counselling psychologists are uniquely placed to work with the complexity illustrated in this review. They are highly educated and therefore have the ability to draw on information and evidence from a range of disciplines. The values at the heart of the discipline are "to elucidate, interpret and negotiate between perceptions and world views but not to assume the automatic superiority of any one way of experiencing, feeling, valuing and knowing" and further "to work always in ways that empower rather than control" (Division of Counselling Psychology, 2005). Along with the emphasis on reflective practice, these values enable the therapist to move outside the most privileged paradigms to understand the experience of each individual they see and to work with them to understand the meaning behind the symptoms they are experiencing.

Conclusion

Developing an understanding of culture and the self has far reaching implications for counselling psychologists. Even where therapists ostensibly share the client's culture, there can be difficulties in the therapeutic relationship created when the complexity of cultural contexts in the room goes unrecognised or through inadvertently privileging one cultural narrative above others (Robbins, 2008).

In cross cultural work, if Western therapists do not take account of the clients' individuality and the cultural influences they have been exposed to, we risk colluding with and perpetuating the kind of damage inflicted during periods of colonisation and empire, through forcing people to conform to very narrow western views in the name of progress and civilisation. Not only do counselling psychologists have to remain true to the core principle of valuing the individual as someone composed of diverse parts, they must also constantly challenge and reflect on those aspects of their discipline that are very culture bound e.g. the idea of the scientist-practitioner, and ensure their discipline doesn't inadvertently become a tool of repression through adhering to inappropriate cultural norms.

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SECTION C: RESEARCH

"FROM ALPHA MALE TO OMEGA MALE": A GROUNDED THEORY STUDY OF SEXUALITY AND INTIMACY IN THE LIVES OF YOUNG MEN WHO HAVE SUSTAINED A TRAUMATIC BRAIN INJURY.

ABSTRACT

Original Aims:

- To explore the experiences, changes and difficulties in relation to their sexuality and intimate relationships, of young men who sustained a traumatic brain injury (TBI) between the ages of 16-25.
- To review practical and emotional support received during rehabilitation in relation to sexuality and explore how this might be improved.
- To address some of the gaps in the literature relating to this area.

Methods: Semi-structured interviews were conducted and analysed using the social constructionist approach to grounded theory.

Participants: Eight men who had sustained a TBI between the ages of 16-25, with no pre-existing disabilities or mental health difficulties, were recruited to participate in the research.

Main Findings: Four central categories and one core category were constructed from the analysis of the data. The central categories were *"I felt like I was sinking at times" – "Wanting my old life back"*; *The aloneness of TBI*; *"A wasteland of intimacy"* and *A shift in the narrative of time.* A core category of *"From alpha male to omega male": an unwanted, uninvited individuation* was developed and elevated to this central position within the analysis because of its ability to account for and contain all the other categories embedded within the data. Proposals are made for possible theoretical developments which may help healthcare professionals to understand and work with people post –TBI; these include the concept of an unwanted, uninvited individuation and a development of Boss' theory of ambiguous loss to specifically account for intrapersonal ambiguous loss in addition to interpersonal ambiguous loss.

Key words: traumatic brain injury; sexuality; intimacy; constructivist grounded theory; individuation; ambiguous loss

Introduction

Situating the Research

I was inspired to conduct this research by my work in neuro-rehabilitation in residential and community settings where most of the service users were men, many of them under 30. I observed that the only time issues around sexuality were discussed was in relation to ‘inappropriate’ sexual behaviour, usually highlighted by others rather than by the clients themselves. My suggestion that one of the married patients in the residential unit might be sexually frustrated and may benefit from being offered access to ‘girlie’ magazines was greeted with shock and the assertion that I must be very open minded. Similarly, in the community service, there was a reluctance on the part of staff to address the issue of sexuality and my suggestion of mentioning the issue during initial assessment was initially rejected out of hand.

Evidence suggests that young men are over-represented in the statistics for TBI. When I first proposed this research in 2011 there was a statistic from Headway which suggested that young men in this age group were 5x more likely to sustain a TBI than the general population. The general statistics currently available from Headway for 2013-4 still make difficult reading; in the UK there are 348,934 admissions to hospital each year with acquired brain injury of which 162,544 admissions are for a head injury, this translates to 445 per day or one every three minutes (Headway, 2015). There are no accurate figures for prevalence within the population although it is estimated that individual patients make up 90% of all head injury admissions[3] (Headway, 2015) thus, there is a not insignificant proportion of the UK population living with the consequences of brain injury, especially if you include the partners and families of those injured, which perhaps reinforces the idea that research in this field is necessary. While there are no current figures for young men, it would seem that they would still be more likely to sustain a TBI due to the kinds of risks they may take e.g. involvement in contact/dangerous sports and being generally more likely to take risks, for example, when driving.

An early review of the literature found that this is an area which is under-researched. While there is a considerable body of research relating to rehabilitation post brain injury, there is very little relating to sexuality and the emotions of intimate relationships, which Ponsford (2003) states is a much neglected area. Nothing was found that was specifically related to TBI and sexuality in young men; studies tended to be quantitative and examine the impact of brain injury on ‘performance’ or so called ‘inappropriate behaviour’. A few studies focus on those already in long term relationships and consequently tended to involve older couples, primarily in heterosexual relationships. No qualitative studies were identified (Moreno, Arango-Lasprilla, Gan & McKerral, 2012, and Elliott & Biever, 1996).

Another reason supporting carrying out this research is the documented difficulty health care professionals (HCPs) have in addressing issues around sex with their clients.

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[3] Admission numbers do not correspond exactly to individual patients because some patients have multiple admissions in one episode of care.

A small-scale service development project I conducted within the community neuro-rehab team, confirmed that while staff considered issues around sexuality to be of importance, they were reluctant to engage with clients about them. This echoes Couldrick's (2008) findings suggesting a theory-practice divide in community disability teams, with professionals saying that sexual expression should be addressed but not doing so in practice. Rubin (2005) and Dyer & das Nair (2014) found there were a range of reasons why professionals did not raise the issue of sexuality including fear of intrusiveness and lack of training.

Perhaps in part because my own sons were in their late teens at the time, and in part because of personal experience relating to disability and sexuality, I became interested in the field. This was a time when my sons were learning to negotiate relationships and learning how to be in close relationships with those from outside our family. Issues around sexuality, intimacy and relationships were of huge importance to them and yet they were rarely discussed with clients of a similar age that I worked with. I decided that if the opportunity arose I would undertake research in this area.

My Position as a Counselling Psychologist Researcher

The final question is why, as a counselling psychologist, am I undertaking this research and what do I think I can add with my particular professional perspective?

Elliot, Fischer & Rennie (1999) talk about the importance of "owning one's perspective" (p. 221) when undertaking research. As I have progressed through this project I have come to understand that perhaps the most important perspective is my developing role as a counselling psychologist.

Over the course of my training I have developed an understanding of counselling psychology as creating a space where the unspoken can be put into words. It is a place where the client can find a voice, perhaps for the first time, and in the company of a skilled practitioner, through the medium of a specific type of co-created relationship centred on curiosity and creativity, explore themes, difficulties and narratives, which may be silenced in other places. I understand the therapeutic space as a place where unheard, untold, unknown stories (Pearce Associates, 1999), and what might be regarded as untellable stories, may be explored.

Counselling psychology has been described as both science and art, having its roots in the science of psychology and, in the UK, in the humanistic movement (Orlans, 2013). Van Deurzen-Smith (1990), in her erudite overview of the philosophical foundations of counselling psychology, asserts that one of the things that should mark counselling psychology out as different is its ability to function as an art and that "most of psychology has lost" this ability (p. 10). Situated at the "interface between science and clinical practice" counselling psychology is intrinsically pluralistic requiring practitioners to be proficient in at least 2 therapeutic models, to draw upon a range of philosophical approaches and to "demonstrate a coherent integration of theory, practice and inquiry" (BPS, 2012). Counselling psychology also demands that practitioners "bring aspects of themselves", in combination with academic knowledge and understanding of psychological theories, to the shared endeavour of working with the client to understand and reduce their distress. Van Deurzen-Smith (1990) argues passionately that this includes drawing on our knowledge of literature, art, music, poetry and philosophy which all holds “a wisdom about life and people that has not been achieved in all the psychology research papers put together” (p. 8).

It is finding a balance in the overlap between science and art, and the bringing of self to the task that has become so important to me and that I want to embody as a counselling psychologist. Throughout the research process it has been important that my growing identity as a counselling psychologist is reflected in the way my research is conducted, however, this has necessarily meant engaging again with the tensions inherent within the pluralistic framework which informs that identity and with the epistemological assumptions therein. This process has been challenging, although a number of authors assert that grappling with this complexity is a mark of the process of research for counselling psychologists (Kaskett & Gil-Rodriguez, 2011 & Rafalin, 2010).

Although the field of neuro - rehabilitation is well established with a broad literature base across many professional fields including neuropsychology it is not an area in which counselling psychologists have traditionally played a role. I would assert that this may be for a number of reasons:- counselling psychology is a comparatively new discipline with the BPS division having only been established in 1984; the clear focus of counselling psychologists has, until comparatively recently, been adult mental health; and finally, there has perhaps been a view from outside the profession that the focus has been on less complex cases. This perception is gradually changing as more counselling psychologists qualify and are employed within complex services within the NHS and with the joint guidance issued by the BPS and Unison on advertising posts according to competencies rather than by adjectival title. Neuropsychology and work within areas associated with neuro-rehabilitation have remained an area that counselling psychologists have tended not to become involved in until comparatively recently (DoN & DCoP, 2015).

As in my therapeutic work, I also hold the awareness and tensions of being a white, English, middle-class, middle-aged, woman who is also a wife and mother, and a person for whom faith is the touchstone for the rest of her life. I bring to the research personal experience of disability and my belief that health care professionals should work with the whole person taking account of spirituality and sexuality as well physical and mental conditions. I think this is important as I believe that meaning in a person’s life is constructed, being influenced profoundly by language and context; if professionals can’t talk about sexuality openly this may impact on the client’s ability to form fulfilling relationships. I am passionate about the contribution I think counselling psychology can make to the field of neuropsychology and the lives of people with neuro-disabilities; with a counselling psychologist the client should be able to speak the unspeakable.

Initial Literature Review

The place of the literature review within grounded theory has been an issue of strong contention to be further discussed in the methodology. Within GTM, in contrast to many other methodologies, the literature review is not seen "as an essential foundation upon which to build a study" (Dunne, 2011), but is rather seen as having the potential to stifle original, creative thought arising out of the data collected, by the imposition of pre-existing theoretical frameworks. However, as Charmaz (2014) points out, in order to secure the necessary permissions to undertake a piece of research, the researcher usually has to undertake a significant piece of work which includes a detailed literature review situating their proposed research within the wider body of associated research. She suggests that once permission to carry out the research is obtained the literature review is set aside until after the analysis is completed.

In the case of this research an initial literature review was indeed carried out, however, it quickly became clear that there was no large extant body of literature relating to sexuality and intimacy in young men post-TBI so the literature review focussed on areas of psychology which might be linked to it and justifying why this might be a useful study. The literature was then set aside while data was gathered and analysed. As codes and categories started to emerge I began to read widely around relevant topics that emerged e.g. in the initial literature review I had not fully considered issues around masculinity and disability. As the analysis gained more substance my reading became more focussed.

The initial literature review is updated and recapitulated here in more detail in order to broadly contextualise the research; the literature which is more specifically related to the development of the theoretical framework for the study is explored in depth as part of the discussion.

The initial literature review falls into 3 broad categories giving an overview of each area: - brain, behaviour and TBI; sexuality and TBI; adolescent development.

Brain, Behaviour and Traumatic Brain Injury (TBI)

While a detailed account of brain structure is beyond the scope of this thesis an overview is provided in Appendix 1, however, one factor that does need to be highlighted is the change in understanding of the role of the glia in brain function. While previously they were thought of as simply the glue that holds everything together, hence the name, it is now recognised that they have an active role in maintaining the correct biochemical milieu; in the manufacture of the myelin sheath and in clearing detritus resulting from cell death (Purves, Augustine, Fitzpatrick et al, 2001). Crucially it has been recognised that this has a significant role in the cascade of processes set in train by brain injury.

Brain Injury

Brain injury has many causes and may be present from birth. An acquired brain injury (ABI) is one that occurs after birth, it may be traumatic or non-traumatic. Causes of non-traumatic brain injury include tumour, stroke, haemorrhage and hypoxia/anoxia (Royal Hospital for Neurodisability, n.d.). The focus of this research is TBI defined as "an injury to the brain caused by trauma to the head (head injury)" (Headway, 2016). In its simplest terms the initial external trauma to the head sets off a chain of events that can each contribute to the injury of the brain, either as a direct result of the trauma or indirectly as a result of the bio-chemical processes triggered following injury.

Traumatic Brain Injury

TBI results from an impact to the head. The injury may be categorised as either open, sometimes called penetrating, where something penetrates the brain either from outside e.g. a bullet, or from inside e.g. part of the skull (open is not necessarily indicative of an open wound to the outside); or closed, where there is an external impact but the brain is not penetrated e.g. where the head is hit with an object. Whilst an open head injury is more likely to lead to death, primarily because of the high frequency of gunshot wounds in this category, where the victim does survive the damage tends to be less diffuse and therefore the resulting impairments tend to be more circumscribed or neater; this is in part due to the ability of the energy of the impact to diffuse to the outside (Hannay, Howieson, Loring, Fischer & Lezak, 2004).

In closed brain injury damage to the brain is classified as two distinct types; the first is the focal damage caused by the direct impact and the second, more diffuse damage, is caused by the movement of the brain within the skull as a result of the external impact. Damage arising directly from the impact includes concussion, lacerations, haemorrhaging and bruising (Hannay, Howieson, Loring, Fischer & Lezak, 2004; Werner & Engelhard, 2007). The movement of the brain within the skull caused by the external impact is often a rapid acceleration/deceleration which may be in line with the centre of gravity of the brain, rotating around the centre of gravity or a combination of both due to movement of the head and neck. This rapid movement can cause bruising, swelling and diffuse axonal injury (DAI) – the shearing of axons due to the combination of mechanical forces exerted on the brain during the injury.

Brain injury is categorised according to severity. The Glasgow Coma Scale is a widely used, practical scale which uses levels of eye opening, verbal response and consciousness to measure and "communicate about the level of consciousness of patients with an acute brain injury" (Teasdale, 2014). A low score on any subscale indicates a poorer response e.g. spontaneous eye opening would be allocated a score of 4 while no eye opening would receive a score of 1. The lower the summed score across all three domains the more severe the brain injury is likely to be.

It is now widely recognised that TBI, particularly in relation to closed brain injuries, consists of two stages: the primary trauma, causing immediate mechanical damage as described above, and the secondary injury which results from what Park, Bell and Baker (2008) helpfully describe as a "multiple, parallel, interacting and interdependent" (p2) cascade of biochemical events set in train by the initial damage to the brain (Hannay, Howieson, Loring, Fischer & Lezak, 2004; Werner & Engelhard, 2007; Park, Bell & Baker, 2008). The mechanisms of this secondary damage are extremely complex. Werner & Engelhard (2007) give a good, clear overview of the processes describing in detail how terminal membranes become depolarized and excitatory neurotransmitters, such as glutamate, flood the brain. Cerebral blood flow (CBF) becomes disrupted, due to damage and/or vasospasm, leading to hypo-perfusion or hyper-perfusion and a potential “mismatch between CBF and cerebral metabolism” (Werner & Engelhard, 2007).

Another example of the complex processes relating to secondary brain injury is that of DAI. It was previously thought that this only occurred at the point of trauma, however, it is now recognised that a more complex cascade of events takes place causing this damage to the white matter to manifest progressively during the days following the initial insult (Park, Bell & Baker, 2008). This is intimately linked to the work of the glial cells in the disposal of accumulation of debris caused by damage to the myelin sheath (Wen et al, 2014). This may have been caused at the time of the initial trauma or subsequently, due for example to cell death initiated by the depolarization of membranes when mitochondria try to remove toxic levels of intracellular calcium and zinc produced in response to the excess concentrations of excitatory neurotransmitters such as glutamate. These secondary causes of damage are seen as an increasingly important influence on the outcome for the patient and a concise, scholarly overview of this area in relation to mild TBI following blast injuries is provided by Przekwas, Somayaji & Gupta (2016).

When working in brain injury rehabilitation it is often heard said that every brain injury is unique. It is an accepted truth that even if two people had identical injuries they would be unlikely to have identical consequences due to the presence of so many variables beyond the point of injury.

The ultimate consequences of brain injury are wide-ranging and may include physical problems e.g. difficulty with movement and balance, headaches, dizziness and sleep problems (Ashman, Gordan, Cantor & Hibbard, 2006); cognitive problems e.g. memory and concentration which may impact on the ability to live independently or return to work (Langlois, Rutland-Brown & Wald, 2006); behavioural problems such as disinhibition and difficulties with social interaction (Lezak, Howieson & Loring, 2004); and changes in personality including lack of motivation and difficulty in managing emotions (McAllister, 2011). In addition to the ‘biological’ consequences, TBI often has a profound psychological and social impact on the person who sustained the injury and their family and friends (Headway, 2016; Sander & Struchen, 2011).

In order to ameliorate the consequences of TBI patients often undergo a significant period of rehabilitation following their accident. Rehabilitation is a goal-directed process which reduces the impact of long-term conditions on daily life (BSRM, 2008). Following TBI rehabilitation may be undertaken in an inpatient setting or, usually later on, in the community. It is often delivered by multi-disciplinary teams which may include doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, and psychologists (Khan, Baguley & Cameron, 2003).

Sexuality and Intimacy

Sexuality is a complex area of human life which means many things to many people. While sexuality seems to hold ever increasing importance in modern Western society it is a difficult concept to define and may be viewed simply as a substitute for either the physical act of sex or a way of talking about orientation or preference (Rivers, 1998).

Sexuality is perhaps better thought of as a social construct embedded in and varying across cultural and historical contexts as suggested by Miller & Vance, 2004, and borne out by reflecting on the change in attitudes to homosexuality in Western countries over the course of the twentieth century. Weeks (2003) gives a comprehensive overview of the history of sexuality pointing out that understanding varies across academic disciplines and concluding that it does in fact have "many histories" (p19) and cannot be understood solely in terms of pressure and release, arguing that it results from "diverse social practices that give meaning to social activities". He concludes that "Sexuality is not a given, it is a product of negotiation, struggle and human agency" and cautions against "applying dominant Western definitions to other cultures".

Sexuality in the context of this research is taken in its broadest sense. The WHO (2006) international technical consultation on sexual health working definition states that "sexuality *is a central aspect of being human throughout life* and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction" (emphasis added). The definition recognises that sexuality does not exist in a vacuum but is influenced by many factors that interact including the biological, political, cultural, historical, religious and psychological (see Appendix 2). However, Thorn-Gray and Kern's definition is also useful - "the verbal, visual, tactual and olfactory communication which expresses love and intimacy between two people" (Ponsford, 2003) and somehow adds a very human dimension to the technical definition. Moreno , Lasprilla, Gan & McKerral (2013) note that sexuality across the lifespan is frequently linked to health and highlight the work of Murphy and Murphy & Elias who assert that the sexuality of individuals with disabilities may be impacted on by both functional limitations and societal barriers, which may be intentional or otherwise.

I felt that it was important to include the concept of intimacy in defining the research. Hatfield and Rapson (2007) point out that the word comes from the Latin, *intimus* meaning inner or inmost and that research has shown that people associate the term with "feelings of affection and warmth, with happiness and contentment, with talking about personal things and with sharing pleasurable activities" (p54). While the term intimacy can imply a sexual relationship, it also conveys a sense of an emotional or psychological closeness that sexuality alone may not encompass and so for this reason I wanted to bring it in to the research.

Sexuality, the brain & TBI

Within the neurological/neuropsychological literature sexuality and intimacy are viewed as complex bio-psycho-social behaviours demanding the integration of many aspects of brain functioning. The view tends to privileges the biological understanding of sexuality. Sexuality directly involves all parts of the nervous system (Horn & Zasler, 1990) and relies on a complex relationship between "neuroanatomic, neurochemical, neurophysiological and neuropsychological systems" (Moreno, Lasprilla, Gan & McKerral, 2013, p70) utilising variously the capacities to see, hear, move, negotiate, understand and communicate as well as the mechanisms of desire, arousal, orientation and fertility. Sustaining a brain injury can have a profound impact upon all aspects of functioning including the cognitive, behavioural, sensory, perceptual and relational realms, and this in turn can impact both directly and indirectly upon sexuality and intimacy (Simpson & Baguley, 2012).

Research has shown that TBI impacts on all types of existing relationships, both intimate and social, and on the ability to form new social relationships (Sander & Struchen, 2011). Sander and Struchen (2011) argue astutely that perhaps the most profound change following TBI is the depth of social isolation experienced by those who have sustained the injury and also note that "In spite of the obvious importance of social relationships for overall well-being and quality of life, there is a disproportionately low amount of rehabilitation research that focuses on predictors of social outcomes relative to productivity outcomes (such as work and school)" (p1). Having undertaken this research I would argue that the same is true, perhaps to an even greater extent, in relation to sexuality and intimate relationships.

Dombrowski, Petrick and Strauss (2000) and Ponsford (2003) affirm that an area often neglected in rehabilitation after TBI is that of sexuality and the emotions of intimate relationships which can be particularly affected. Elliot & Biever (1996), in a comprehensive review of the literature relating to head injury and sexual dysfunction, also found that this area has been neglected, in spite of evidence that brain injury impacts on sexuality and that it is important to people. Medlar's research (1998) underlined how important the issue was with his findings that 93% of the 42 clients he asked felt that people who have had a brain injury should be given educational information about the impact of their injury on sexuality, while 79% felt that the topic was of concern to people who had sustained a brain injury. Williams & Evans (2003) asserted that sexuality is crucial because it is such "a key aspect of human functioning and fulfilment". More recently there does seem to be a growing interest in issues around sexuality and intimacy following TBI (Simpson & Baguley, 2012), however, to date, the majority of literature seems to have focused on established couple relationships, or sexual disinhibition and hypersexuality. To date I have found no literature making a qualitative exploration of the issues from the perspective of the person who sustained the injury.

While Simpson & Baguley (2012) argue cogently that "the environment for addressing patient or client sexuality has never looked more promising" with more teaching and inclusion in textbooks than ever before, they also acknowledge that in spite of this, evidence suggests that the issue is still addressed in a very fragmentary way across a number of countries in relation to both general rehabilitation and specialist brain injury rehabilitation.

Dyer & Das Nair's (2012) literature review and subsequent research paper (2014) explored the attitudes of HCPs to sexuality and their work suggests that this is still an area that they find difficult to talk to clients about. This reflects my personal experience of working in neuro-rehabilitation in residential and community settings and a small-scale survey I undertook within the MDT, which suggested that while staff considered issues around sexuality to be of importance they were frequently reluctant to engage with clients about them (unpublished work). This echoes the findings of Gill regarding rehabilitation staff attitudes and practice in relation to sexuality (Ducharme & Gill, 1990) and Couldrick's findings which suggest a theory-practice divide in generic community disability teams, with professionals saying that sexual expression should be addressed but not doing so in practice (L. Couldrick, personal communication, December 2, 2008). And yet, sexuality is undoubtedly an area which can be profoundly affected as a result of TBI.

Both Zasler (1991) and Aloni & Katz (1999) highlight that sexual difficulties can be either a primary result of TBI e.g. when damage to the brain directly impairs genital function, or secondary to the emotional sequelae associated with TBI.

Ponsford (2003) reports that, following TBI, participants are more likely to report a decrease in frequency and quality of sexual encounters in comparison with controls, with influencing factors ranging from less opportunity to engage in sexual activity, less enjoyment and a decreased ability to stay aroused and to reach climax. Fatigue, pain, and loss of sensitivity were also perceived as contributory factors. There was a significant association between decreases in sexuality scores and in mood as measured by the HADs, however, those under 25 were less likely to report decreases on the dimensions of sexuality than others. The study does not suggest reasons for this, but it is possible to speculate that those who are older may be more likely to have been in long term relationships or be more familiar with their own sexuality and therefore more likely to notice differences.

Another factor that may contribute to difficulties with interpersonal skills and successful negotiation of sexual relationships is the impact of deficits in various aspects of social cognition on behaviour. Social cognition can be briefly described as a broad range of skills and processes that facilitate interaction and understanding between members of a species (Frith & Frith, 2007) although Adolphs (2001) gives a more nuanced definition which might be summarized as the metaprocess that enables the perception of socially relevant information, in order to recognize and manipulate to integrate it with the organism's own motivation, adaptive behaviour, emotional and cognitive systems to generate and/or modulate appropriate behavioural responses. Lezak first recognized that this area may be problematic post TBI in the late 1970s (MacDonald, 2013) but it is only recently that research into this area has begun (Stanley & Adolphs, 2013). In a comprehensive review of impairments in social cognition post severe TBI, MacDonald (2013) concluded that a number of aspects of social cognition can be affected in those who have sustained moderate to severe TBI including recognition of facial and vocal expression of emotion, theory of mind (ToM) and self-awareness, necessary for differentiating between the emotions and intentions of self and others. Milders, Ietswaart, Crawford, & Currie (2006) define ToM as "The ability to recognize and make inferences about other people's intentions and beliefs" found evidence of ToM deficits in adults with TBI regardless of the severity of their initial TBI. These ToM impairments were associated with executive function deficits and time did not ameliorate their severity. In an innovative study Milders Fuchs & Crawford (2003) began the work of trying to identify the neuropsychological deficits underlying the behavioural changes common following traumatic brain injury. The study compared injured participants with controls and asked a close relative (proxy) to rate changes in social and emotional behaviour since injury as well as the injured group. The results showed that the injured participants had significantly more problems in detecting verbal and facial expression of emotion and were more impaired at detecting social faux-pas. The proxies identified more changes in behaviour since injury than the injured participants themselves. In a development of this work, Spikman et al (2013) examined a larger cohort of participants with moderate to severe TBI using recent more tightly defined measures including the Dysexecutive Questionnaire. They assert that their study is the first to find a significant relationship between behavioural changes reported by carers and relations and performance on a measure of affect recognition in participants who have sustained a moderate to severe TBI. This is an important finding as it suggests that some behavioural difficulties post-TBI may be underpinned by deficits in social cognition.

This work on social cognition post TBI becomes particularly important in the context of research into the development of social cognition in adolescence.

Social Cognitive Development in Adolescence

The age range for this particular study was chosen because research suggests that young men between the ages of 16 and 25 are particularly vulnerable to TBI.

In 2009 Headway published data that suggested that young men between the ages of 16 - 25 were five times more likely to sustain a TBI than any other section of the population. The UK Acquired Brain Injury Forum (UKABIF) also state that those within the age range 15 - 24 are at higher risk of TBI than others, while figures from Headway for 2013/14 show that across all age groups men are 1.6 times more likely to sustain a brain injury than women. In the United States figures from the Center for Disease Control (CDC) for 2010 (CDC, 2016) show that men were more likely to be hospitalised in relation to a TBI and those aged 15-24 were second only to those over 65 in terms of risk.

Not only are young men more at risk of sustaining a head injury, they seem to have poorer outcomes subsequent to the injury. A recent, comprehensive study of longitudinal data from Sweden relating to outcomes of those sustaining a TBI before the age of 25, shows that outcomes across all measures are worse for those who sustain their first TBI after the age of 15 compared to those who sustain their first injury before this age, with risk rates for psychiatric hospitalisation and premature morbidity being almost twice as high for this group as for those who sustained their first TBI aged 0-4, even when degree of severity was controlled for (Sariaslan, Sharp, D'Onofrio, Larsson, & Fazel, 2016).

Adolescence, which may be defined as a period of social, psychological and physical development between childhood and adulthood (Blakemore, 2008), has long been viewed as a time of turbulence. While Hall famously coined the phrase “storm and stress” in 1904 to describe this period of development (Arnett, 1999), over 2,000 years earlier Aristotle described the young as “heated by Nature as drunken men by wine” and Shakespeare, in A Winter’s Tale, suggested that it would be better if “there were no age between sixteen and three-and-twenty” (Dobbs, 2011). Erikson viewed adolescence as a period of psychosocial stress when young people explore and develop their own identity, and endeavour to answer the questions “who am I?” and “what is my place in the world?” (Sokol, 2009). Coleman & Roker (1998) highlighted that adolescence may be viewed as a time of multiple transitions including changes in & development of, identity, relationships, gender and sexuality, a view supported by Spear (2000) who contrasts the ability to define puberty in precise neuro-endocrinological terms with the difficulties inherent in identifying the onset and ending of adolescence. Fryer identifies the development of sexuality and the formation of intimate relationships as major developmental tasks to be achieved in late adolescence (Ponsford, 2003).

Across the period of adolescence there are significant changes in social environment for a young person as they begin to move away from the support networks of childhood, often the family, to become progressively more independent, spending more time with their peers than their parents (Sebastian, 2012). The behavioural, social and psychological processes inherent in this stage are increasingly viewed as being underpinned by biological processes, and where these were once seen as being primarily related to the hormonal action triggered by the onset of puberty, there is now an increasing understanding of the role of the significant changes in neurobiology inherent in adolescence.

Until comparatively recently it was accepted that by late childhood the brain had fully matured and little further development took place, however, this view has been increasingly called into question over the last 15 years with the advent of MRI and fMRI which allows for the in vivo examination of the structure and function of the brain (Dumontheil, 2015; Blakemore, 2012).

In the bio-developmental literature Blakemore (2007), suggests that there is increasing evidence that the brain is not fully developed in childhood but that development continues into the early 20s, especially in areas relating to social cognitive skills. Further Blakemore & Choudhury (2006) & Blakemore, Choudhury & Charmin (2006) reported evidence from a number of studies indicating changes in density of white and grey matter throughout the period of adolescence, both building up and pruning neural connections. More recent studies have identified in fine detail changes in grey and white matter volume in areas of the brain closely associated with social cognition e.g. the medial prefrontal cortex, tempero-parietal junction, posterior superior temporal sulcus and anterior temporal cortex (Mills, Lalonde, Clasen, Giedd, & Blakemore, 2012). They have also identified the impact of the onset of puberty and the progression of the physiological process on the microstructure of white matter in the brains of adolescent boys (Menzies, Goddings, Whitaker, Blakemore, & Viner, 2015).

Social cognition is the set of skills and processes that enable members of a species to interact with and understand each other (Frith & Frith, 2007). In humans these processes are particularly complex and involve high level processing and interpretation of signals including language. The processes may be implicit and automatic, as in the generation of a fear response, or explicit, such as in Mentalizing, where a person is trying to understand the motivation or perspective of another (Frith & Frith, 2008). The changes which take place in adolescence with the move away from the family into the broader social context demand more complex social cognition; Happé & Frith (2014) suggest that better skills in social policing, conformity, emotion regulation and greater self-awareness are all necessary to facilitate this move.

The advances in social neuroscience may be particularly salient in relation to young men who have sustained a TBI with four areas being particularly useful: - risk-taking, metalizing, ostracism and falling in love.

The adolescent years often seem characterized by mismatch; nothing quite seems to ‘fit’. The growth of the physical body often outstrips the brain’s ability to perceive it. Proprioception, the brain/body’s facility to sense itself in space and in relation to other people and objects, apparently ‘disappears’ and once neat, contained children may become awkward, clumsy adolescents.

A number of models of development also suggest there is a mismatch in brain development (Sebastian, 2012), particularly between the system that processes emotions and reward signals, which includes the amygdala and ventral striatum, and the higher level cognitive capacities that subsequently develop and regulate it, often mediated by the prefrontal cortex. This neurodevelopmental mismatch presents as ‘classic’ adolescent behaviours such as emotional outbursts and increased risk-taking. In his comprehensive review of the neurobiology of adolescent risk-taking, Steinberg (2008) suggests that the “remodeling of the dopaminergic system” at puberty is at least in part responsible for the increase in risk taking behaviour. He points out that in spite of expensive education programmes and the fact that adolescents are frequently found to be knowledgeable and logical in their assessment of risk, they indulge in many more risk-taking behaviours than either adults or children, including alcohol consumption, drug-taking, unprotected sex and risky driving. However, this risk-taking has a powerful social aspect; it becomes much more frequent in the presence of peers (Gardner & Steinberg, 2005). Risk-taking behaviour at this age may well have originally been an evolutionary function, for example conferring an advantage with risk-takers being perceived as having the potential to better provide food and protection for their families (Ellis et al, 2012). This aspect of neurodevelopment may account for the over-representation of young men in the TBI statistics.

Mentalizing, defined by Bateman and Fonagy (2010) as a "process by which we make sense of each other and ourselves, implicitly and explicitly, in terms of subjective states and mental processes" although Fonagy & Mullins (n.d.) admit to preferring the less technical description of "holding heart and mind in heart and mind" (slide 7), is compromised as development occurs and it grapples with the more complex social behaviours demanded of the emerging adult (Happé & Frith, 2014).

Sebastian (2012) appears to give a good account of the way in which brain development may be implicated in adolescent hypersensitivity to ostracism. She refers to some creative studies by Sebastian et al (2010) and Sebastian et al (2011) following on from the work of Eisenberger et al which suggested that adults process social and physical pain in similar ways, and a study by Masten et al which indicated that there seemed to be differences in processing these types of pain between adolescents and adults. Sebastian (2012) reports that a diminished response in the right ventrolateral prefrontal cortex in adolescents in comparison to adults was identified in both studies, the effect being seen in both in vivo experience of mild social rejection among adolescents playing a Cyberball game (Sebastian et al, 2011), and in a stroop test calling for the processing of rejection related words vs acceptance and neutral words (Sebastian et al, 2010). However, a closer examination of the original papers shows that this work is significantly limited by the fact that all the participants in both studies were female. Sauve (2015) reports that gender differences in response to ostracism have rarely been examined and as yet there seems to be little evidence in relation to males. While Sebastian (2012) seems to suggest that the findings in her previous studies apply to all adolescents, given the significant differences in the context of neurodevelopment between boys and girls e.g. the biological, particularly hormonal, milieu, and the different social and psychological demands placed on males and females even as they are growing up, some caution needs to be exercised when applying findings about one sex to all adolescents.

Peers hold a greater significance in the young person's life and complex patterns of negotiation between self and others begin to take place, balancing a need to belong with growing self-awareness; self-policing with a desire to be different (Happé & Frith, 2014). This is also the time when intimate relationships with those beyond the family begin to emerge.

In a comprehensive overview of issues relating to adolescent sexuality, Moore (2016) highlights that the neurobiological context of adolescence is overlaid with increasing levels of circulating hormones including testosterone, oestrogen, oxytocin and vasopressin which increase sexual attraction and desire as well as promoting the need for attachment and bonding. She points to the work of Ortigue et al. whose review suggests that romantic love is mediated in the brain by the dopaminergic reward system and higher cortical areas which mediate cognition (Ortigue, Bianchi-Demicheli, Patel, Frum, & Lewis, 2010) both of which have been demonstrated above to be undergoing considerable changes at this time. Moore (2016) supports the idea that these early romantic relationships serve to support the development of an understanding of the self and help to shift relationships with parents to a more mature, less dependent status.

Throughout the teens and early twenties there seems to be a complex interaction between the bio-psycho-social contexts of adolescents and young adults played out in their growing need for independence; increased risk-taking; potential for social misunderstanding, and the move away from the family towards the broader social context driven by the need to establish an independent identity. This crucial developmental period has been described as the second individuation (Blos, 1967). For many young men who sustain a TBI it seems that this development, this second individuation, with its inherent “shedding of family dependencies, [and] the loosening of infantile object ties in order to become a member of society at large or, simply, of the adult world” (Blos, 1967) is interrupted by the catastrophic events that overtake them.

The only reference made to masculinity in the original proposal for this research was a study by Schopp, Good, Barker, Mazurek and Hathaway (2006) which suggested that men who adhered to traditional masculine roles prior to their brain injury would have poorer outcomes post TBI if they perceived a decline in their masculinity. They found that men who prior to their injury desired power over women and perceived themselves as conforming to a playboy role had less overall satisfaction with life post injury. This may be relevant to young men who are searching for their social roles.

Methodology

Introduction

In this section I will explore my philosophical and epistemological positions, examine the values I bring to my work as a therapist and look at the way in which these impact on my work as a researcher. I will explore the way in which these have influenced the methodological decisions related to this piece of work, including the development of my research question, and detail the practical steps involved in completing the project.

Philosophical & Epistemological Position

Like many authors, Willig (2013) suggests that a crucial first step in research is to identify an epistemological position which defines the nature of what it is possible to know. However, in order to do so it is first necessary to develop an ontological position.

Ontology is concerned with the nature of being or reality. Ontological positions range from the realist position which asserts that there is one single reality which it is possible to examine and know, to the relativist position which asserts that each individual constructs their own reality in the context of their culture, history and position in society relative to others

The epistemological position flows from the ontological position. Some would argue that what we know and experience is a result of interacting with an independent 'truth' existing in the world which it is possible to know through careful measurement and observation; this is known as the positivist paradigm. In contrast others argue that all experience is mediated linguistically and socially and therefore there can be no independent 'truth' separate from this mediation. Positions such as these fall within the constructivist or interpretivist paradigms.

Ponterotto (2005) gives a scholarly overview of the philosophy of science and the traditional view of the main paradigms within research. He draws the distinction between positivism, post-positivism, and the constructivist-interpretivist and critical-ideological positions. Understanding the implications of these epistemological positions is important both for the endeavour of scientific research and, as Hanson (2004) argued, for the practice of counselling.

Within scientific research there has traditionally been a firm differentiation between quantitative approaches rooted in the positivist paradigm, which Denzin & Lincoln assert “stress the measurement and analysis of causal or correlational relationships between variables” (p. 128, Ponterotto, 2005), and qualitative approaches which Denzin & Lincoln (2005), while recognising the difficulties and complexities in defining them, outline as the “study of things in their natural settings, attempting to make sense of, or interpret, phenomenon in terms of the meanings people bring to them” (p. 3).

My own position as a trainee counselling psychologist lies somewhere between the extremes of realism and relativism, positivism and constructivism/interpretivism. Counselling psychologists are scientist-practitioners. As a scientist I believe that some aspects of the world exist independently and can be objectively observed. As a practitioner I am only too aware that the narratives, constructions and interpretations people build around events can differ wildly and have the power to destroy or to empower them. My entire work focuses on helping my clients reflect on their narratives and develop new positions, perspectives and interpretations in relation to them. In this respect I find Dilthey’s distinction between the aims of natural sciences (*Naturwissenschaft*) and human science (*Geisteswissenschaft*) (Ponterotto, 2005) extremely helpful. Dilthey argued that in the natural sciences the goal of research is scientific explanation (*Erklaren*) whilst in human science the goal is understanding (*Verstehen*). This focus on understanding, and in particular understanding the ‘”lived experience” (*Erlebnis*) from the point of view of those who live it day to day’ (Ponterotto, 2005, p. 129) is the corner-stone of the qualitative paradigm.

Although the qualitative and quantitative approaches aim to produce different types of knowledge, it often seems as if their advocates are trying to establish supremacy over each other, to the point where some authors use the language of conflict e.g. battle and war, to describe the way the relationship between the paradigms is often portrayed. (Denzin & Lincoln, 2005, p. 2; Rafalin, 2010, p. 44).

Whilst it is true that the prevailing culture within the world of science has been to set these approaches up in opposition to each other and force a ‘choice’ between epistemologies, it can be argued that this is false distinction. Willig (2012) points out that epistemological perspectives cannot be easily categorised without significant simplification.   This approach also seems to suggest that the modernist and post-modernist epistemologies exist independently of each other rather than existing in relation to each other and simply privileging different aims (Hansen, 2004). It also points to an epistemological position as a fixed, unchanging truth, itself a positivist assumption which opposes the pluralistic philosophy inherent in counselling psychology.

In the context of counselling practice, Hansen (2004) asserts that these arguments about epistemological positions take place on the “philosopher’s blackboard” (p. 136) and questions whether these clear-cut, esoteric positions can ever reflect the messiness of life. In relation to research, Hiles (2014) highlights that the debate around paradigms frequently gets stuck on the differences between qualitative and quantitative methodology. He contends that the “distinction between qualitative and quantitative methods is a red herring” (p. 49) and that whilst it is crucial to understand the paradigms within which you are working this does not necessarily need to be either fixed or singular even within a given piece of research. He argues forcibly that the most important issues are a coherent logic of inquiry underpinning the work and an understanding of the type of knowledge being pursued.

As I have continued to work on this project I have come to realise that, for a counselling psychologist, there is another important perspective that needs to be taken into account when thinking about methodological issues; that of the participants. Each of the men I interviewed would undoubtedly say that an actual event, something real, had happened, causing significant damage to a very real part of their bodies which we call the brain and which on current understanding is believed to be the centre for control of human bodies, thinking and emotions. They would view this from a very positivist/realist perspective and so would their families; it is something they would say has definitely happened to them and has changed their lives in so very many ways. This very much reflects the dominant medical discourses around brain injury. However, as a counselling psychologist who has worked in the field of neuro-rehabilitation, I am aware that there are also particular narratives and social constructions surrounding brain injury e.g. relating to disability; being a good patient; the reification of determination and tenacity. This reflects what Hansen talks about as the messiness of life as opposed to the abstract arguments taking place on the philosopher’s blackboard about whether a rationalist or a relativist position is more real. An actual injury has taken place in the lives of these people, they would see that as “truth” but now they are trying to work out the “truth” of what it means for them and their families to live with sometimes profound disability.

In undertaking this research I want to honour my participants’ experience, whether that is their ‘truth’ of the physical injury or their ‘truth’ about its impact, and in order to do this I have to recognise that both exist, not in opposition to each other but in parallel to each other.

If the major paradigms begin to be understood as existing in relation to each other, rather than in opposition perhaps it becomes possible to move between differing positions depending on the questions being asked and to move away from what Rafalin (2010) calls the "method wars".

This is significant for counselling psychologists both as scientist-practitioners and in relation to the philosophical underpinnings of the discipline. If the core humanistic values of counselling psychology are to respect other perspectives (Cooper, 2009), then it does not fit to reject out of hand one or other paradigm. Cooper goes on to suggest that although many might see the nomothetic approach of positivist research as antithetical to the idiographic perspective of counselling psychology, it too can open new understandings of our clients.

Counselling psychology is an integrative and pluralistic model of working (BPS, 2012) and this should apply across all aspects of work. Counselling psychologists privilege the understanding of individual experience, but it would be disingenuous not to acknowledge that the discipline is rooted in general psychology, drawing on theories developed in the positivist paradigm *e.g.* personality theory and developmental theory.

Recently a number of researchers in the field of counselling psychology seem to be asserting that methodological pluralism might be a more useful and honest position to adopt (Fassinger, 2005; Rafalin, 2010; Elichaoff, Rodriguez & Murphy, 2014) with Ponterotto (2005) referring to the concept of "counselling researchers as bricoleurs". This is more fully explored by Denzin & Lincoln (2005), who assert that bricolage is strategic and pragmatic, drawing on all available methods, whilst also being self-reflective. Ponterotto (2005) anticipates that:

"As the field of counselling psychology continues to evolve, I expect that more of us will become bricoleurs as we draw on *various research paradigms and multiple inquiry methods, as well as mixed methods*, to answer questions of mental health, healing processes, and quality of life." (p. 134, emphasis added).

There is little previous work in relation to sexuality and intimate relationships in the rehabilitation of young men who have experienced a TBI and thus, in this instance, I want to generate what Hiles (2014) would call discursive knowledge to explore the experience of the young men themselves. However, in order to fully understand the field of study it will later be helpful for positivist and participatory knowledge to be generated. Because there is no previous theory upon which to base a hypothesis I have chosen to employ the grounded theory methodology to make an initial exploration of the topic. A methodology which, as it will be seen, grew out of a synthesis between different paradigms and can in fact still be used within each of them.

Grounded Theory

The use of grounded theory method (GTM)[4] was first described in the mid-1960s (Glaser & Strauss, 1967) and has often been hailed as a radical departure from the predominant positivist paradigm of the time. Rooted in sociology and emerging from the theory of social interactionism (Charmaz, 1996; Fassinger, 2005) GTM embraced the divergent approaches of its two authors – Glaser bringing his rigorous training in quantitative methodology whilst Strauss brought a perspective foregrounding the pragmatist perspective of the importance of language, agency and meaning (Charmaz & Henwood, 2008). While this may seem a strange juxtaposition in the 21st century, it is less puzzling when set against the context of the positivist influence on qualitative research in the mid-twentieth century. It is perhaps, as Charmaz & Henwood (2008) astutely suggest, the diverse nature of the origins of GTM that laid the foundations for the methodology to be subsequently claimed by both objectivists and constructivists.

The method was seen as both a critique of the prevailing epistemology and as offering a systematic, practical guide to the way qualitative analysis could be conducted (Charmaz, 2006). While GTM rejects the hypothetico-deductive approach of testing hypotheses based on known theory and aims to develop theory inductively based on analysis of the data collected, it should be noted that Glaser and Strauss (1967) did not reject the hypothetico-deductive approach in itself, stating that although their emphasis was on generating rather than verifying theory they did not want to divorce the two as “both are necessary to the scientific enterprise” (p. viii).

In the intervening 50 years, as the prevailing epistemological position within the social sciences has begun to shift away from the positivist paradigm, there have been a number of developments in the use of GTM which to date have led to three principle strands: Classical GTM (Glaser & Strauss, 1967), Strauss & Corbin’s later version (1990) and the most recent Constructivist version (Charmaz, 2000, 2006). While there are methods common to each version e.g. theoretical sampling, coding, identification of categories, constant comparative analysis, memo-writing and saturation, there are also fundamental differences in approach stemming from differing epistemological perspectives (see fig. 1).

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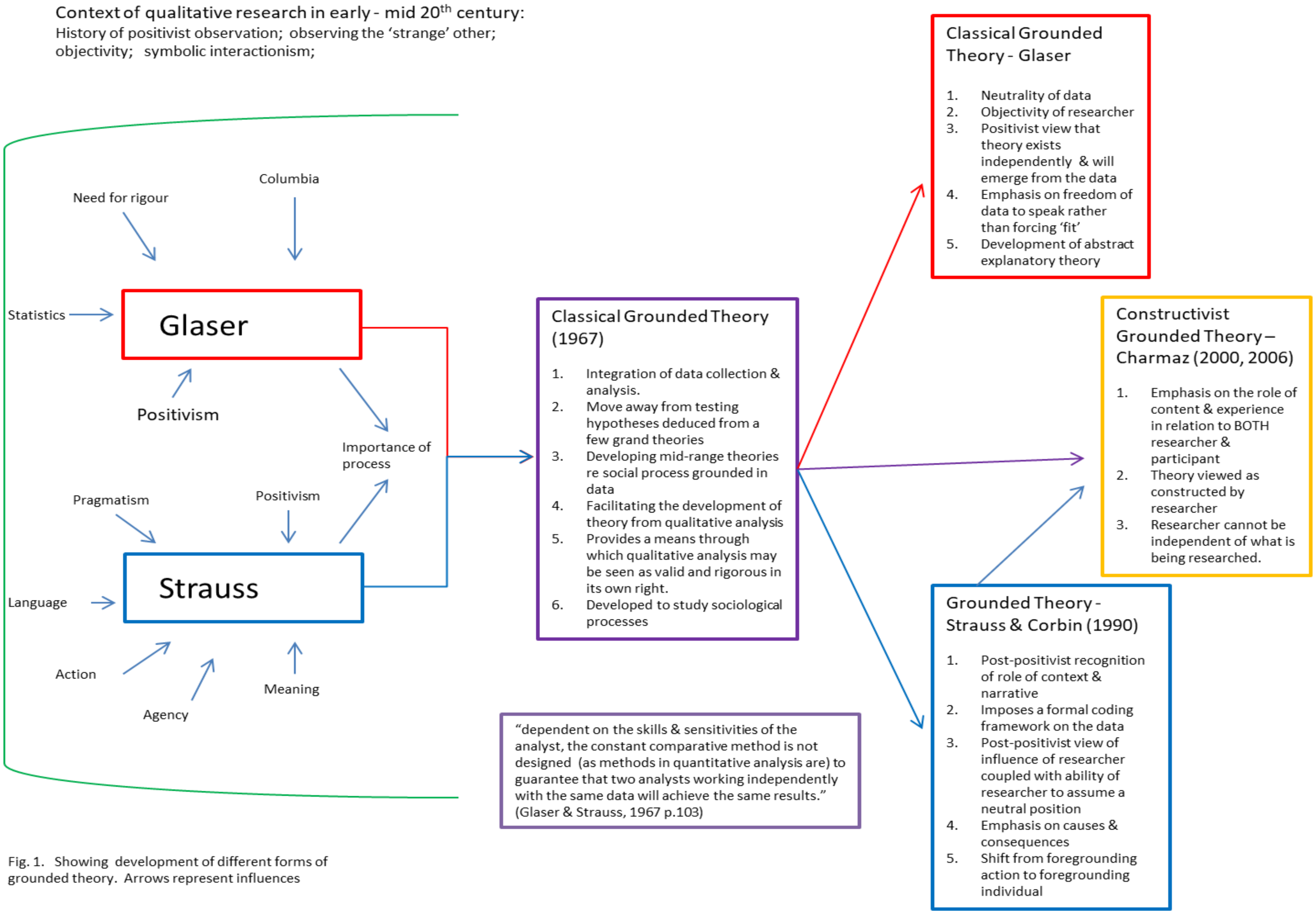
[4] Throughout I will follow the convention of Bryant & Charmaz (2007) and use the term grounded theory method (GTM) to differentiate the method from its potential product, *a* grounded theory.



Context of qualitative research in early - mid 20th century:
History of positivist observation; observing the 'strange' other; objectivity; symbolic interactionism;

Classical Grounded Theory (1967)

1. Integration of data collection & analysis.
2. Move away from testing hypotheses deduced from a few grand theories
3. Developing mid-range theories re social process grounded in data
4. Facilitating the development of theory from qualitative analysis
5. Provides a means through which qualitative analysis may be seen as valid and rigorous in its own right.
6. Developed to study sociological processes

Classical Grounded Theory - Glaser

1. Neutrality of data
2. Objectivity of researcher
3. Positivist view that theory exists independently & will emerge from the data
4. Emphasis on freedom of data to speak rather than forcing 'fit'
5. Development of abstract explanatory theory

Constructivist Grounded Theory – Charmaz (2000, 2006)

1. Emphasis on the role of content & experience in relation to BOTH researcher & participant
2. Theory viewed as constructed by researcher
3. Researcher cannot be independent of what is being researched.

Grounded Theory - Strauss & Corbin (1990)

1. Post-positivist recognition of role of context & narrative
2. Imposes a formal coding framework on the data
3. Post-positivist view of influence of researcher coupled with ability of researcher to assume a neutral position
4. Emphasis on causes & consequences
5. Shift from foregrounding action to foregrounding individual

"dependent on the skills & sensitivities of the analyst, the constant comparative method is not designed (as methods in quantitative analysis are) to guarantee that two analysts working independently with the same data will achieve the same results." (Glaser & Strauss, 1967 p.103)

Fig. 1. Showing development of different forms of grounded theory. Arrows represent influences

Figure 1 - Development of versions of grounded theory (Clark, 2017)

Whilst some commentators have suggested that there is a fit between the differing approaches that have arisen e.g. Mills, Bonner & Francis (2006), others e.g. Glaser (1992), Holton (2007) are quite clear that the original methodology is the only one that should be called grounded theory and are at times 'scathing' of later developments (Dey, 1999). Classical GTM remains rooted in the positivist paradigm with its assertion that there is a 'truth' hidden within the data which, with due diligence, may be found. There is also a commitment to the principle that data should never be forced (Glaser, 1992).

Strauss and Corbin's version of GTM retains some elements of positivism but moves more towards a post-positivist position acknowledging the influence of the researcher. It emphasises formulaic procedures (Charmaz & Henwood, 2008) and, Glaser would argue, a pattern of forcing data to fit preconceived frameworks.

This study employs the constructivist version of GTM (Charmaz, 2000, 2005, 2006) which privileges the phenomena of interest and positions the researcher as central to the understanding and interpretation of the data gathered. This approach has moved away from the positivist position of discovering a hidden truth which exists independently, towards a more flexible position in which the research process is viewed as emerging from the interaction between participant and researcher with an emphasis on the construction of meaning between them (Clarke, 2003; Charmaz, 2008). The constructivist approach asserts that reality is multiple, constructed and process-driven (Charmaz, 2008). The theories and models developed from the research are recognised as being a particular interpretation of the data. They are embedded in a particular context and influenced by the values and assumptions of the researcher as well as those of the participant. This recognition of the influence of the researcher, their context and history means that the reflexivity on the part of the researcher is crucial to ensure that they become aware of the assumptions that they bring to their work and the way in which their analysis is evolving. Charmaz (2006) calls attention to the assertion that because it recognises the influence of all parties, constructivism encourages researcher reflexivity in relation to their own interpretations as well as participants' interpretations.

My own reflexivity during the research process was supported by my experience as a reflexive practitioner; through detailed reflection on my position as a counselling psychologist researcher; through examination of my epistemological and ontological position; through reflection on my values in relation to ethical questions in the research; through supervision and through creating memos in relation to my work.

Due to the constraints of time and resources within a professional doctorate and to the whole project being more time consuming than anticipated due to difficulties in recruiting participants and problems associated with transcribing and analysing interviews generated with people with cognitive difficulties and profound speech impairments, this study uses the abbreviated version of Constructivist GTM (Willig, 2008).

A number of authors have argued that novice researchers choosing grounded theory methodology may quickly become overwhelmed by the task of trying to decide which version to use and may, as a result, use an incompatible mix of elements from all versions (Breckenridge**,** Jones, Elliott & Nicol, 2012). However, clearly understanding the underlying paradigms and establishing one's own epistemological position helps to ameliorate this problem.

In recent years GTM has gained increasing popularity with psychologists. Charmaz & Henwood (2008) attribute this to factors such as the rigour of the method, its flexibility to be used across post-positivist and constructivist epistemologies, and its promotion of the view of individuals and behaviour being set within contexts.

Willig (2013) suggests that the methodology has some limitations for psychologists undertaking research. The first of these is that GTM is rooted in a positivist epistemology and does not adequately attend to reflexivity. This criticism does, however, seem to be specific to the older versions of GTM and Willig acknowledges that constructivist GTM goes some way to addressing these concerns. Her second criticism relates to the issue of applicability to psychology research when the method was developed to explore social processes. Willig argues that using the method to explore the nature of experience means that, while a systematic map of categories of experience which will help understanding may be produced, a theory will rarely be produced.

Whilst it is true that GTM grew out of sociology, Glaser and Strauss (1967) themselves envisaged that the method could "be useful to anyone who is interested in studying social phenomena – political, educational, economic, industrial, or whatever" (p. viii). Henwood and Pidgeon (1995) argue cogently that the goal of deriving a comprehensive theory may be too ambitious for some projects and achievable goals even at post-graduate level may include using GTM for basic taxonomy development, focussed conceptual development and to instigate cycles of interpretation. Charmaz (2006) argues for using GTM more flexibly and returning to what she calls “past grounded theory emphasis on examining processes, making the study of action central, and creating abstract, interpretive understandings of the data”, viewing the methods as being flexible guidelines rather than methodological dogma. This theme is taken up by Charmaz and Henwood (2008) in a critical discussion of the use of GTM to generate rich descriptions and in their (2007) assertion that GTM may be regarded “as a family of methods” (p. 11).

The principle elements of the process of analysing data using constructivist grounded theory methodology are set out below.

The Position of Previous Knowledge

An area of contention within GTM is the place of the literature review and the role of previous knowledge.

Although Glaser and Strauss (1967) said that researchers should “ignore the literature of theory and fact on the area of study” (p. 37), it is not true that they expected researchers using grounded theory to be *tabulae rasae* or that the literature review should be omitted altogether. Indeed they say that existing sources of insight, including theory “are to be cultivated” but not “at the expense of insights generated by the qualitative research”. (p. 253).

Whilst the position of the classical grounded theorists e.g. Glaser (Dunne, 2011) and Holton (2007) is still to assert the necessity of approaching data without the influence of extant literature, with the development of different strands of GTM others have come to different conclusions.

Lempert (2007) acknowledges the concerns expressed by classical grounded theorists but admits that she deviates entirely from the proscription against an early literature review, arguing that researchers need to take a more pragmatic view based on the need to participate in ongoing theoretical conversations and the need to be able to appreciate where there are gaps in the literature and to understand current directions in the research.

Dunne (2011) helpfully identifies two categories relating to the arguments against conducting an early literature review: those concerning ideology e.g. concern that inexperienced researchers might be overawed by existing theory and thus lack confidence in their ability to find their own theories; and those linked to pragmatism e.g. that due to the fluid nature of the methodology, conducting an early literature review may be a waste of time given that what will be most relevant will not be known before the research begins. He goes on to a useful recapitulation of the literature and outlines a number of reasons why a researcher may wish to conduct an early literature review.

Constructivist opinion varies. Charmaz and Henwood (2008) state that in order to avoid tipping into the hypothetico-deductive position of deducing theory or testing hypotheses based on *a priori* knowledge, researchers should avoid positioning their work within the literature until after they have created their own theoretical position thus allowing their ideas to develop fully without influence from prior theories. However, Charmaz (2006) and Bryant and Charmaz (2007) recognise that universities often demand a literature review as part of the research proposal i.e. before data analysis begins. Charmaz (2006) suggests that once a proposal is accepted the literature review is allowed to “lie fallow” until after the analysis.

Strübing (2007) argues cogently that the important factor is not whether previous knowledge is used in the data analysis but that *a priori* knowledge may dominate the researcher’s interaction with the data. He suggests that while there are always ‘taken for granted concepts’ (p. 587) that will influence the researcher’s perspectives, the negative impact of these can be minimised if the researcher uses the knowledge as inspiration while looking at the data but does not regard the theories embedded within that knowledge as being the only answer available. This approach fits very well with the counselling psychologist’s reflective position of holding their knowledge of psychological theory lightly whilst cultivating a stance of open curiosity towards those they work with in order to honour their uniqueness and individuality and not to force them into boxes preconceived from the theory.

Taking all these issues into account I undertook an initial literature review as part of my research proposal, which, as anticipated from having worked in the neuro-rehabilitation, showed that there was no literature relating to the perspective and experience with regard to sexuality and intimacy of young men following TBI. I then set the literature aside during interviewing and initial coding. As I began to formulate ideas in relation to more focussed codes I began to read broadly whilst thinking about my own perspective through a process of continual reflection and memo-writing.

Research Question

The importance of a well-defined research question is often highlighted in the literature (Holliday, 2002; Willig, 2013), however, a well-developed research question has traditionally arisen from the literature review. In a grounded theory study, as previously discussed, the topic of interest is approached with an open mind, not with preconceived ideas or hypotheses derived from the existing literature, thus the study necessarily begins with an open research question which may change during the course of the analysis. Charmaz (1990) states that the research question constructed at the beginning of a study may in fact prove irrelevant, in which case a new question should be constructed.

In the case of this study a research question had to be formulated to satisfy the requirements of the University ethics committee but this was kept as general as possible stating that the area of interest was to ask:

- What are the experiences of rehabilitation and recovery in relation to their sexuality, of young men aged 16-25 who have had a TBI during this period? How can their experiences inform their carers and interventions in neuro-rehabilitation?

Coding

All versions of grounded theory analyse data through the use of coding; the means by which the researcher begins to move from the raw data to a theoretical understanding of the process and context being studied. The process of coding begins with open coding and moves to focussed coding (See Appendix 9).

Open Coding attaches labels to units of data. The units can be of any size - words, paragraphs, pages etc. Within the constructivist approach the preferred unit is line-by-line coding (Charmaz 1996, 2006; Willig 2008, 2013). Categories need to be anchored in the data; in employing line-by-line coding the researcher remains close to the data and is more readily able to identify implicit concerns expressed within the texts (Charmaz, 2006). Charmaz (2006) argues that line by line coding stops the researcher from projecting their own perspectives, fears and unresolved material onto the data and gives distance from the researcher's and participants' "taken for granted assumptions" (p. 55).

Charmaz (2006) provides detailed guidance regarding how to undertake initial coding advising that early coding should be done quickly to promote creativity. Like Glaser she recommends the use of gerunds to keep language active, help identify processes and stay close to the data. The use of *in vivo* codes, i.e. codes using the participants own language, is also recommended. She emphasises the need to remain open; to construct short, simple, precise codes that fit the data, rather than forcing data to fit codes; and to use the method of constant comparison. This lays the foundation for subsequent synthesis of the data (Charmaz, 2005).

Willig (2008, 2013) stresses that in the early stages of open coding the labels given to units of text will be primarily descriptive. She argues that line by line coding is particularly important in studies which use the abbreviated form of grounded theory because it compensates for the loss of breadth associated with theoretical sampling by exploring the data that is available in more depth. Charmaz (1996) highlights the fact that line by line coding may identify an important process in a later interview that would be missed if a less rigorous approach were used. Earlier data can then be re-examined to see if the new process accounts for any of the experiences therein rather than recruiting further participants. This approach is also advocated by Pidgeon & Henwood (2004) as particularly useful where only a small sample is available.

Open coding is crucial because during this phase the researcher begins to identify relationships between some of the codes leading to the formation of broader, increasingly abstract, theoretical categories integrating many of the early, descriptive categories.

Focussed coding is the process of constructing codes which embrace groups of the individual open codes. During this process the researcher actively works to identify the most frequent and significant codes identified during the initial coding process (Charmaz, 2006). Pidgeon & Henwood (2004) discuss the way in which this might involve splitting some of the tentative categories that have been identified and renaming or integrating some of the open codes to form new categories. It is at this point that the researcher begins to make decisions regarding which codes are the most useful and incisive and thus make the most analytic sense (Charmaz, 2006).

Whilst Charmaz (2006) labels focussed coding as “the second major phase of coding”, she also acknowledges that there is not always a linear progression between open and focussed coding, there may be sudden Damascene moments when the researcher apprehends a link between a number of codes or when an occurrence in a later text makes explicit some implicit processes missed in earlier texts.

In this study, to facilitate coding, the interview text was set out in the middle of a page. Open coding was recorded line by line on the left side and early ideas for possible focussed codes were recorded in the right hand margin.

Categories

"Grounded theory involves the progressive identification and integration of *categories of meaning* from data." (Willig, 2013. Emphasis in the original).

Categories are one of the key concepts of grounded theory. They are the grouping together of pieces of information relating to processes or events coded from the data which share core features. The categories are reflective of the codes in that initially they may simply be descriptive grouping together e.g. cycling, swimming and sewing as hobbies, however, as the analysis progresses it is expected that the categories will become more abstract and will have an interpretative or explanatory power. The categories are not preformed entities into which the data must be forced to fit but develop through continuing interaction with the data. Categories are not mutually exclusive and each datum may belong to more than one category.

Constant Comparison and Memo Writing

This is another key concept found across all versions of grounded theory. Writing about the process of coding and creation of categories is necessarily constrained by practical and temporal boundaries. Words appear on the page in a particular order implying a neat chronological progression in the development of ideas within the research. This is not in fact the case and it is constant comparison that saves it from being limited in this way. The method of constant comparison requires that throughout the analytic process the researcher constantly compares different aspects of the research. Statements within an interview are compared with others from the same interview; categories and codes are compared with each other; data from one interview are compared with data from other interviews; ideas within memos are compared with categories. All the time the researcher is searching for similarities and differences within the data and continually questioning their own prior assumptions and perspectives (Charmaz, 2006).

This process is supported through memo-writing which is viewed as a crucial step between gathering the data and developing an understanding of the process under examination (Charmaz, 2006). It creates a written record of the thought processes through which the researcher, as they closely examine codes, begins to develop categories from which theories may be developed (Charmaz & Henwood, 2008). Memo writing ensures that the researcher remains actively engaged in the process of analysing the data. Corbin and Strauss (2008) call memos “working and living documents” (p. 118). They helpfully advise that it is the process which is important, suggesting that researchers allow the writing to be a fluid, creative process rather than worry about the form memos take. A set of sample memos for this study is included at Appendix 3

Saturation

Theoretical saturation, arrived at through the method of constant comparison, is the point at which data collection and analysis may cease.

Glaser and Strauss (1967) defined theoretical saturation as being reached once examination of the data no longer develops the properties of the categories. Charmaz (2006) points out that this is not the same as seeing repetitions within the data; it is instead the point when “gathering fresh data no longer sparks theoretical insights, nor reveals new properties of these core theoretical categories”. Hallberg (2006) and Suddeby (2006) both highlight the fact that the judgement about whether saturation has been achieved is essentially a subjective one. Suddeby asserts that even experienced researchers may have difficulty in identifying when saturation has been reached, although experience is one factor that is helpful in making the judgement. Hallberg points out that it can never be known whether collecting one more interview would in fact change or add to the categories. Equally from the social constructionist perspective I assert that it can also never be known if the same researcher would find additional properties at a later date or if someone else analysing the data would identify different properties within it – a point also conceded by Glaser & Strauss (1967).

Corbin & Strauss (2008) regard saturation as both simple, you stop when you reach it, and complex, actually achieving it is not easy. They acknowledge that it is always possible to find something else if the researcher looks hard enough but sometimes what is found adds very little to the overall picture. They also recognise that it is sometimes the case that “the researcher runs out of time, money, or both” (Weiner, 2007). This more pragmatic consideration has led some authors to question the concept of saturation. Willig (2013) constructively views theoretical saturation as an ideal which should be strived for but is arguably never possible to achieve because perspectives can and do change. Dey (1999) recognises the difficulties in making a justifiable decision to stop collecting data for analysis, as well as the power of the word 'saturation' to suggest ideas of completion. His pragmatic solution is to suggest that 'theoretical sufficiency' (p. 117) is a more appropriate concept referring "to the stage at which categories seem to cope adequately with new data without requiring continual extensions and modifications" rather than the implication of having drained the data of the possibility of generating additional categories or properties and dimensions of those categories.

This study uses the concept of theoretical sufficiency as it fits with the constructionist stance I adopt in relation to this work.

Participants

Sampling

Theoretical sampling often seems to be held up as the gold standard for GTM. However, while Fassinger (2005) acknowledges this influence within GTM she also highlights that some commentators e.g. Charmaz and Cutcliffe, suggest that introducing theoretical sampling too early, particularly where the sample size is small, can result in closing down avenues that may have opened up with a less directional form of sampling. Corbin & Strauss (2008) acknowledge that there are times when "researchers have to be practical" (p. 145) and due to time constraints or the need to travel to collect data, may not be able to use traditional theoretical sampling. However, they assert that the crucial aspect of theoretical sampling is that it is concept driven and thus a researcher can return to the data set looking for concepts that have arisen in later analysis.

Although I had planned to use theoretical sampling, due to significant difficulties with recruitment (see below) and increasing time pressure, the primary means of sampling in this study were convenience and purposeful sampling.

Convenience sampling is described by Richards & Morse (2013) as being such that "those invited to participate in the study are simply those available to the researcher" (p. 222). Whilst some commentators suggest that convenience sampling is one of the least satisfactory methods e.g. Robson, (2002), this does seem to refer to a particular type of process whereby the nearest people are asked to participate regardless of their experience. Richards and Morse (2013) suggest that convenience sampling is a pragmatic first step which enables the researcher to begin exploring the field of interest as long as those within the sample have witnessed or experienced the phenomenon under examination.

An approach was made to local London brain injury charities to see if there was any interest in the project. One group responded and I attended a young persons' group where I talked to the clients about my research. Originally I had wanted to hold a formal focus group to help develop questions and areas for research, however, only 4 young men attended the first group and then the co-ordinator became ill making it impossible to schedule another meeting. The first meeting was useful and the young men told me that no-one had mentioned anything about sex or relationships during their rehabilitation and that there were problems that they felt they had to deal with e.g. "people look down at you", "Girls don't approach you", "they look past you". Some of the young men also talked about how friends who they had known before they sustained their brain injuries were now starting to get married. It was an interesting and useful visit. Clients were invited to participate in the research but only one volunteered.

<u>Purposeful</u> sampling is described by Patton (1990) as selecting "information-rich" participants from which most can be learned about the field of interest. Morse (2007) refers to such participants as "excellent", describing them as people who have witnessed or experienced the phenomenon under investigation; who are able to reflect on it, talk about it and who have time and are willing to share their experience. It is interesting that while Morse acknowledges the usefulness of translators in conducting research with some participants, she insists that an "excellent participant" should be "able to speak articulately about the experience". This presents some difficulty when the field of interest relates to people who may have cognitive difficulties, learning disabilities or speech difficulties and implies that while research may be conducted with them, they might lack 'excellence' as participants. This is not a view that I support. Rich data can be obtained from participants with significant intellectual disabilities, for example, if the researcher takes the time to explore appropriate modes of communication (Brewster, 2004) and adapts the interview process appropriately.

Recruitment

Recruitment proved far more difficult than had been anticipated. The original research proposal had anticipated recruiting 8 – 12 young men between the age of 18-25 who had sustained their brain injury between the ages of 16-25, however, after a year only one young man had been recruited; as a result the criterion was changed to allow men of any age to participate if they had sustained their TBI between the ages of 16-25.

The range and number of organisations approached was broadened and emails were sent to 22 charities and organisations whose stated aims were to work with people who had sustained a brain injury. A website (www.TBI-relationships.co.uk) was also set up to facilitate recruitment. Information sheets, and a link to the website were sent to all the organisations (See Appendix 4). Two men approached me via the website but one of them did not meet the inclusion criteria. Eventually a healthcare professional with an interest in these issues introduced me to the branch manager of a brain injury charity in Wales. As a result of this introduction and with the enthusiastic help of the branch manager 8 more participants were recruited, however, one could not be interviewed as I was ill when the interview was scheduled and another only came forward sometime after the other interviews were finished and it was not practical to return to Wales.

The difficulties in recruiting should be noted. Many organisations expressed their support by saying that this area of research was much needed, however, it was only where a personal contact intervened and promoted my research that participants were able to be recruited. I suspect that this in part due to organisations feeling that they have a duty to protect their clients. Given the apparent reluctance of health care professionals to discuss sex with clients (Dyer & das Nair, 2012), it may be that while they thought it was an interesting piece of research they did not feel able to promote it among their clients; or it may just be simply a matter of not having time to take on additional work on behalf of someone else when their primary function is to provide services to people with complex neurological conditions.

Sample

The sample consisted of 8 men who had sustained a TBI between the ages of 16-25. Although the Headway (2011) statistic referring to the high frequency of TBI refer to males between the ages of 15-29, the age range for injury in this study was adapted with the lower limit being changed to 16, the cut off for classifying the injured person as an adult (NICE, 2014). The upper age limit of 25 was influenced by research showing that brain development in relation to social cognition continues into the early 20s (Blakemore & Choudhury, 2006). The study only interviewed those over 18 for pragmatic reasons relating to consent.

Three of the young men recruited had profound speech difficulties and one had a slight speech impairment. This had a significant impact on both the interviewing and transcribing the data, which both became very time-consuming processes. From the outset I was aware that because of the nature of brain injury some of the participants may have speech difficulties and while I did not fully appreciate the impact this would have on the data-collection process I was committed to including them. In this case the aim of qualitative research giving voice to the voiceless became very literal.

Inclusion and Exclusion Criteria

The inclusion and exclusion criteria for the study were as follows:

Inclusion Criteria

- Male of any age
- TBI sustained between the ages of 16-25
- Capacity to consent

Exclusion Criteria

- No pre-existing mental health problems prior to brain injury
- No pre-existing learning disabilities prior to brain injury
- Acquired brain injury that was not traumatic e.g. stroke

Those with pre-existing mental health problems and learning disabilities prior to brain injury were excluded because these factors may also have an impact on sexuality, intimacy and the ability to form relationships. The focus of the study is TBI so other brain injuries have been excluded.

Participant	Age at interview	Age at TBI	Time since TBI (yrs)	Lost conscious-ness	Length of time unconscious	Taken to specialist unit	Length of time in hospital[5]	Locus of brain injury[6] (if known)	Inpatient rehab	Community rehab	Speech affected	Other injuries sustained	Educational level before TBI	Currently employed/in education	Relationship Status
1	26	23	3	Yes	Participant doesn't know - induced coma	Yes	2 years	Cerebellum & L side	Yes	Yes	Not perceptibly	No	GCSE	No	Not currently in rel'p
2	25	19	6	Yes	1 week	Yes	9 months	Left side	No	Yes	Yes	2x spinal breaks & fractured pelvis	BTEC Cert	No	Not currently in rel'p
3	31	25	6	Yes	approx 2-3 weeks	No	1 month	Front & Left	No	Yes	Not perceptibly	No	GCSE	Work Experience	Married
4	26	19	7	Yes	Couple of months	No	11 months	Left side	Yes	Yes	Yes	Damage to liver & spleen	A Level	In Education	Not currently in rel'p
5	34	21	13	Yes	A few days	Not Known	Participant not sure – more than 2 months	Don't Know	Yes	Yes	Slightly	Dislocated hip, broken bone in neck, numb L side, deaf in 1 ear, hyper-sensitive hearing in other	GCSE	Voluntary gardening & club for children with disabilities	Not currently in rel'p
6	37	19	18	Yes	5 weeks	Not known	9 months	Frontal Lobe	Yes	Yes	Not perceptibly	Dislocated hip	NVQ Level 1-3	Volunteer charity shop	Not currently in rel'p
7	30	23	7	Yes	2½ weeks	Ppt not sure	3 months	Right side	Yes	No	Not perceptibly	No	1st year Undergrad	No	Not currently in rel'p
8	38	17	21	Yes	6 weeks	Yes	6 months	Left side	Yes	Yes	Yes	No	Part-way through A Levels	Yes – IT infrastructure engineer	Sexual rel'p with friend

Table 1 - Demographic details of participants including information relating to their TBI

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[5] Length of time in hospital includes time in inpatient rehabilitation facilities

[6] All details re injury are as reported by client

Ethical Considerations

The research received approval from City University Ethics Committee and new approval was sought whenever an amendment to the original research proposal was made (See Appendix 5).

The B.P.S. Code of Ethics and Conduct (2009) was adhered to in relation to protecting the welfare and dignity of participants, including protecting their identity and maintaining confidentiality. Data was anonymised e.g. using pseudonyms, allocating code numbers to participants' data and keeping lists of participants and codes separately from their data. Specific details which may identify participants when put together have been altered or generalised e.g. not giving exact dates of injuries or only giving general geographical areas, however, in the interests of ensuring informed consent, participants were also advised that due to the small size of the brain injury community it may still be possible for people who have worked closely with them to identify them, an issue also noted by Lewis & Porter (n.d.) in relation to research involving children with severe learning disabilities. Data was handled in accordance to the principles of the Data Protection Act (1998).

Information about the study was written in accessible language and format using an appropriate size and style of font. Consideration was given to providing alternative formats if necessary. Participants were encouraged to discuss their involvement with someone outside the research and to raise any concerns with the researcher. Consent was viewed as a process rather than a one-off event and participants were advised of the right to withdraw up to a month after data collection. Participants were advised that participation would not affect any treatment/contact with the organisation through whom they had been recruited.

Due to the nature of the consequences of brain injury careful consideration was given to issues relating to capacity to consent. I have some training and experience of the Mental Capacity Act (2005) from working with clients with neurological conditions. The NHS Research & Development Forum Guidelines (2008) were taken into account and, in addition to using the knowledge of the professionals working with the participants, informal tests of capacity were carried out to ensure that participants could:

- understand the information they were given
- retain information related to the decision to be made
- use or weigh the information in relation to the decision

- communicate their decision by some means

These are some of the most basic issues in relation to ethical practice in research and were primarily considered before the research began. However, like Haverkamp (2005), I felt it was important to consider ethical practice as an ongoing process related to the philosophy of what I was doing, rather than a tick box exercise which once completed could be forgotten. Therefore ethical issues were held in mind throughout the research.

Interview Design

The interview was organised in two parts (see Appendix 6). The first part was more formal gathering demographic information and general information about each participant's accident and resulting brain injury. Whilst this type of information may be gathered via questionnaire sent out in advance, this was not appropriate in this case given the strong possibility that participants may have cognitive difficulties resulting from their TBI. Including these questions as the first part of the interview allowed the participants to talk about something familiar with the interviewer, this was intended to set them at their ease prior to talking about more intimate issues. It also gave me an opportunity to show the participants that I was familiar with issues relating to brain injury. Initially I had anticipated simply writing notes about their answers, however, I recorded the first interview in full as I had never done this sort of work before. The first part of the interview with the first participant proved so rich that I decided to record both parts of the interview for every participant.

The second part of the interview was semi-structured in nature and explored their experience of sexuality and intimate relationships in relation to the rehabilitation process.
As recommended by Charmaz (2006) the interview was carefully constructed to ensure that more positive, less personal questions were asked towards the end, ensuring that the participant wasn't talking about highly sensitive material immediately before the interview finished. Themes in the second part of the interview included thinking about their experience of relationships before and since the brain injury, thinking about barriers in both contexts, ideas about masculinity, thinking about the way in which these issues were dealt with in rehab and how they might be dealt with, thinking about their feelings.

One element of the interview which differed from other interviews I have seen was the use of pictures to elicit information from participants. The idea of the pictures was to provide a metaphor in relation to the participants' experience. The word metaphor comes from the Greek and literally means "to carry or bear" (*pherein*) "across, over" (*meta*) (n.d. online etymology dictionary). In this case I was looking for a way to carry meaning across any potential gap between experience and language resulting from the TBI. Eisner (2008) speaks eloquently about the role art can play within research reminding us that "words …. are proxies for direct experience" (p. 5) and that moving away from literary forms can open the path to multiple ways of knowing. Like Bagnoli (2009) my purpose was not to use the choice of pictures for clinical interpretation but to aid reflexivity in the participants and provide an alternate means of communicating their experience.

Weber (2008) argues that for many people visual images are pervasive; even with eyes closed in imagining or sleep we may be flooded with visual images which we interpret and create naturally. She refers to Barthes' idea of pictures being both direct reflections of objects in the real world (denotative meaning) but also having abstract codes associated with them (connotative meaning). Weber (2008) insightfully proposes that it is these connotative meanings that make pictures so useful in research, capturing the ineffable and drawing on embodied knowledge, bypassing the intellectual and connecting with a deeper sense of the experience. It was through such connotative meanings that I hoped to gain a deeper understanding of the participants' experience (See Appendices 7 & 10).

The question of whether such a method is valid within qualitative research in general and grounded theory in particular needs to be addressed. While there has long been an interest in the visual within psychology the discipline has tended to privilege the verbal (Reavey, 2011; Frith, Riley, Archer & Gleeson, 2005). However, over the last twenty years there has been an increasing interest in the way in which the use of visual methodologies can be used to "enrich our understanding of meaning-making and experience" (Willig, 2011). Although there has been some concern with the potential lack of shared languages, conceptual frameworks and objectivity in interpreting visual data in comparison with verbal data (Frith et al., 2005) this is not such a problem when approaching qualitative enquiry from an epistemological position that has moved away from a position that asserts that there is one truth to be found (Rouse, 2013). Once a position such as that of constructivist grounded theory is adopted, where the co-construction of multiple realities is acknowledged the apparent lack of objectivity is no longer a problem. The use of non-interview data is also valid within grounded theory methodology. Charmaz (2014) states that grounded theory is not purely an interview method and that the research problem should shape the data collection methods used. She highlights that many researchers use documents as data asserting that these can be both written or recorded visual images. Bagnoli (2009) states that “using non-linguistic dimensions in research…. may allow us to access and represent different levels of experience” while Rouse (2013) reminds us that not all participants can express themselves fluently through the verbal medium.

Interview Process

Each prospective participant was contacted and given a verbal outline of the research. An information pack was sent out to those who were interested and after a week they were contacted to ask if they needed further information or had any questions. Capacity was checked informally at this point. Arrangements were made to interview those who wanted to participate either at the centres used by the charity or at the participants’ own homes. To ensure my safety, the centre manager advised whether participants should be interviewed at the centre. In addition, I gave my husband details of the interview time-table and I rang him as I arrived at each participant’s home and again to confirm that I was safe as I was leaving after the interview.

At the beginning of each interview I checked that the participant understood the nature of the research and was still willing to participate. This was in part to put the participant at their ease and in part to make some further simple checks of capacity. They were reminded that they had the right to withdraw their data up to one month after the interview.

The interviews were designed to last approximately 90 minutes, however, the interviews with those who had speech impairments took much longer due to significant pauses and the need for repetition to ensure understanding. The longest interview lasted 3 hours. Participants were always offered the opportunity to stop the interview or take a break, usually more than once, but no-one wanted to do this.

At the end of the interview there was a debrief when participants were given an opportunity to ask any questions that had occurred to them, to comment on the interview and to add further information. A number of the participants asked what others had said and wanted to know if they had been helpful; they were assured that they had been helpful and advised that they would be sent a sheet summarising the main themes of the research once the work was completed. They were also told that HCPs had not generally discussed issues of sexuality and intimate relationships with any of the other participants during rehabilitation.

Each participant was told that they could contact the researcher following the interview if they needed to or if they wanted to withdraw their interview. They were given information about organisations where they could get further help and advice (see Appendix 8). A follow up phone call was made approximately one month after the interview to ensure that they had not felt destabilised by the interview and to give an opportunity to ask any questions which may have arisen.

Recording and Transcription

All interviews were recorded using two digital voice recorders to ensure no data was lost. Transcription was facilitated using speech recognition software. Short sentences and phrases were listened to and then transcribed verbatim onto the computer including non-verbal markers such as pauses, sighs, coughs etc. Longer paragraphs were listened to more than once to ensure accuracy of transcription.

There was considerable difficulty with a number of the recordings due to participants having profound speech impairments related to their brain injuries. In these cases, some sentences had to be listened to multiple times in the context of the surrounding paragraph before the content could be understood and transcribed. The transcriptions are not an exact representation of the sounds which came out of the mouths of participants with speech difficulties; in order to have done this would have required training in phonetic transcription, therefore it was decided to transcribe the words the participant was trying to say, rather than the sounds which came out of their mouths. In the case of one participant who had no functional speech, the interview was carried out via his use of an augmentative speech system mediated through his smart phone. This necessitated long pauses while the participant input his answer with one thumb using the smartphone keypad. Completed sentences were sent to an output device which spoke the words he had typed.

Use of speech recognition software and participants' speech impediments resulted in transcription taking considerably longer than would normally be expected; 1 hour of recorded interview data took on average 12 hours to transcribe.

Memo – Reflection on Methodology

As I worked through the process of analysing my data I increasingly began to question whether I had chosen the 'right' methodology for my study. I was aware that what I had initially envisaged as an exploration of the process of rehabilitation was actually becoming an intimate exploration of the experience of the young men I interviewed. This worried me. Had I got it wrong from the outset? It is interesting that I use the words 'intimate exploration'. The project is looking at sexuality and intimacy. The young men differentiate between the two, as do I. Even those who have found ways to satisfy their need for sex, talk about wanting to find intimacy. Is it really surprising that when I come along to ask them about it I am given an intimate view of their experience? Watching a video of Kathy Charmaz talking about constructivist grounded theory was a great help. She talks about the way we can never know in advance what will emerge from the process of qualitative research, and grounded theory in particular, if we are being truly open to that process and are approaching the data without preconceived ideas. Within this paradigm it is perfectly acceptable to come with one intention or plan and for it to transform into something else. Thus the aim of this study changed from a mapping of the process of rehabilitation and the journey of the young men through it, to become a study ~~is~~ which explores the experience in relation to sexuality and intimacy, of young men who have sustained a traumatic brain injury, in order to provide a framework through which Health Care Professionals can conceptualise their experience and work with them more confidently and effectively.

Box 1- Reflection on Methodology

Analysis

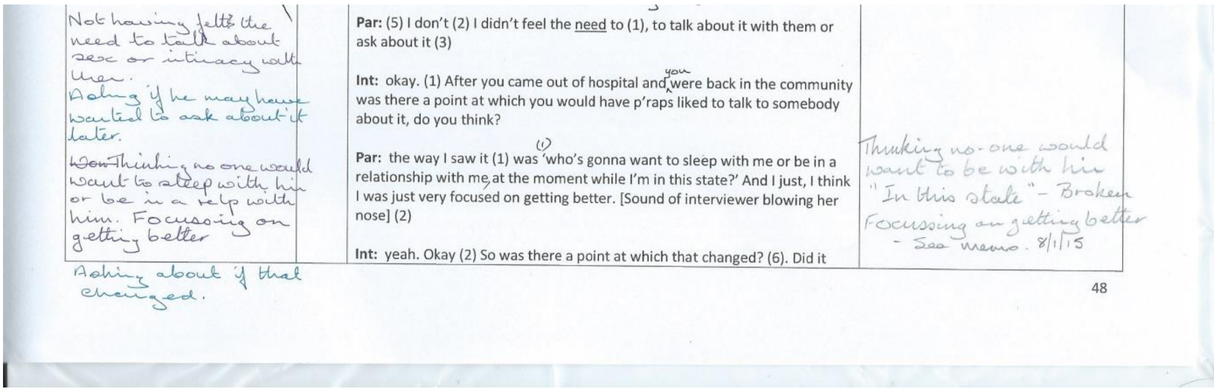
Introduction

In this section of the work I move into what Charmaz (2014) calls an 'interactive analytic space' (p. 109) through the process of coding. Stern (2007) talks about the need to show clearly that any theory developed using GTM is indeed rooted in the data rather than the data having been manipulated to fit pre-existing theoretical frameworks. Coding provides a bridge between the raw data of the interview transcripts and the final abstract concept or theory which is the product of GTM. Star (2007) uses object relations as a metaphor when she talks about coding and developing theory within GTM. She speaks of a process of attachment and separation, as data is compared and codes are generated and tested then retained or discarded, requiring what Winnicott termed a third space:

"an intermediate area of *experiencing*, to which inner reality and external life both contribute. It is an area which is not challenged because no claim is made on its behalf except that it shall exist as a resting-place for the individual engaged in the perpetual human task of keeping inner and outer reality separate yet inter-related" (quoted in Star, 2007, p. 84 emphasis in the original).

She likens codes in grounded theory to transitional objects, being part of that third area, a space where experience is 'held' to facilitate the transition between the concrete world of the data, the place of attachment, and separation into the new world of abstraction in which ultimately a theory may emerge.

Initial coding in GTM takes small segments of the data and labels them. As discussed previously, Charmaz (2006, 2014) favours line by line coding as a starting point and advocates that initial coding is performed through gerunds to ensure that the codes remain rooted in the action of the data enabling the voice of the participant to be heard. A small sample of the way this was achieved is shown below with a further sample in Appendix 8.



Not having felt~~s~~ the need to talk about sex or intimacy with them.
Asking if he may have wanted to ask about it later.
~~Won~~ Thinking no one would want to sleep with him or be in a relp with him. Focussing on getting better
Asking about if that changed.

Par: (5) I don't (2) I didn't feel the need to (1), to talk about it with them or ask about it (3)

Int: okay. (1) After you came out of hospital and you were back in the community was there a point at which you would have p'raps liked to talk to somebody about it, do you think?

Par: the way I saw it (1) was (1) 'who's gonna want to sleep with me or be in a relationship with me, at the moment while I'm in this state?' And I just, I think I was just very focused on getting better. [Sound of interviewer blowing her nose] (2)

Int: yeah. Okay (2) So was there a point at which that changed? (6). Did it

Thinking no-one would want to be with him
"In this state" – Broken
Focussing on getting better
– See memo. 8/1/15

48

		ever become a priority to you? Relationships? Sex?	
Sex becoming an issue when began working again. Friend suggesting it. Seeing it as a transaction. Relps not a priority. Thinking about having one but not how to get one.	1.46.00 Check last section through	**Par:** (3) errm (3) I think sex did only when I was working in X [place name] (interviewer repeats place name) and th (2) when my mate suggested it I thought, yeah, I've got money, (yeah) they want money, I want sex, but I don't think (6) relationships were ever a big priority then (yeah) they've (4) been on my yearly to do list, like, find a relationship (yeah) but not about how I'll do that	Sex becoming an issue when working again. Seeing sex as a transaction Thinking about having a relp but not how to do it
Not having asked + no-one mentioning it Moving on		Right **Int:** Okay (4) ssso it sounds like you never asked anybody, ~~so~~ about, it either. Nobody mentioned it to you (No) and you didn't ask. What was your understanding of the aim of rehabilitation	Not asking. Not being told.
Aim of rehab = getting back to how he was or Getting to stable state to be independent		**Par:** getting me (1) back to how I was x ?previously (1) or getting me (2) back to a (3) stable state I ~~can~~ could be on my own	Aim of rehab – Getting back to how he was before or to living independently.
Clarifying.		**Int:** Getting you back to a stable state where you could be on your own	
Live on own		**Par:** live on my own	
Summarising.		**Int:** yeah. Okay so kind of, getting your independence back (yeah), so what were your priorities in rehab	
Walking + talking priorities Thinking re future when in wheelchair noticing attitudes to him. People avoiding eye contact talking down at him. Not speaking = not having brain Determination. Wanting to show them. Getting out of here. Making a life		**Par:** (3) walking (yeah), talking (yeah), (2) uh (2) my (3) when I was sitting in my wheelchair thinking about, the future, x x now, uhmm I remember thinking people were avoiding eye contact and (2) talking down to me because I couldn't speak (2) they didn't know I had a brain and I thought I'll show them. (yeah)I'll (1) I'll get better, and as soon as, I get out of here I'm making a life for myself (right) and now I walk, talk uhmm (2)	Walking + talking priorities Attitudes of others driving him.* Motivating determination Getting out of there, making a life. * Being spoken down to
Summarising – Focussing on returning to independence.		**Int:** so it sounds like that early stage, the whole, the whole focus, your whole motivation was about, getting your independence and (yeah) getting back to	
		Par: yeah. It never, at that time, I never considered I'd have someone with	

Charmaz (2006, 2014) talks about words not being the only source of data from the interview. She points out that many novice researchers make the error of not recognising the rich data beyond the text e.g. the setting, non-verbal behaviour, the voices speaking the words. West (2011) goes further, advocating the use of the 'tacit dimension', that which is on the edge of awareness, throughout research in counselling psychology. As a Counselling Psychologist I am used to working with what is not said as much as with what is said. I listen for the nuance in what is said, the way it is said, the meaning behind it, and I reflect on my own responses to all this. Although as Charmaz (2014) suggests, initially the text was my main focus, I came to appreciate that when undertaking research I do not cut off the counselling part of myself and become 'purely' a researcher. Just as when I am in the room with a client as a counselling psychologist I bring my whole self to the situation, the same is true when I am a researcher. I bring to the endeavour all of my personal and professional experience, not just that part of myself labelled 'researcher'. Throughout the interviews and analysis I have sought to attend to these less concrete aspects within the interviews and have illustrated my own process by incorporating into the analysis some of the memos I have written rather than locating them in the appendices. However, in order to ensure that I stay true to the participants' experience, where possible I have used the words of the participants (*in vivo* codes) to name the categories.

In the analysis, the participants' words are presented in detail and the journey from their words to categories via the codes elicited by the researcher is explicated. The analysis is the place where the voice of the participants speaks loudest and the process of co-construction of reality with the researcher should be seen most clearly.

Categories

The analysis of the data resulted in identifying four central categories each developed from and containing focussed codes: *I felt like I was sinking at times – wanting my old life back; the aloneness of TBI; a shift in the narrative of time and finally, a wasteland of intimacy*. Overarching these central categories a core category was identified into which the central categories feed. This core category was entitled *From alpha male to omega male – an unwanted, uninvited individuation*. Each of the four central categories and then the core category is explicated below.

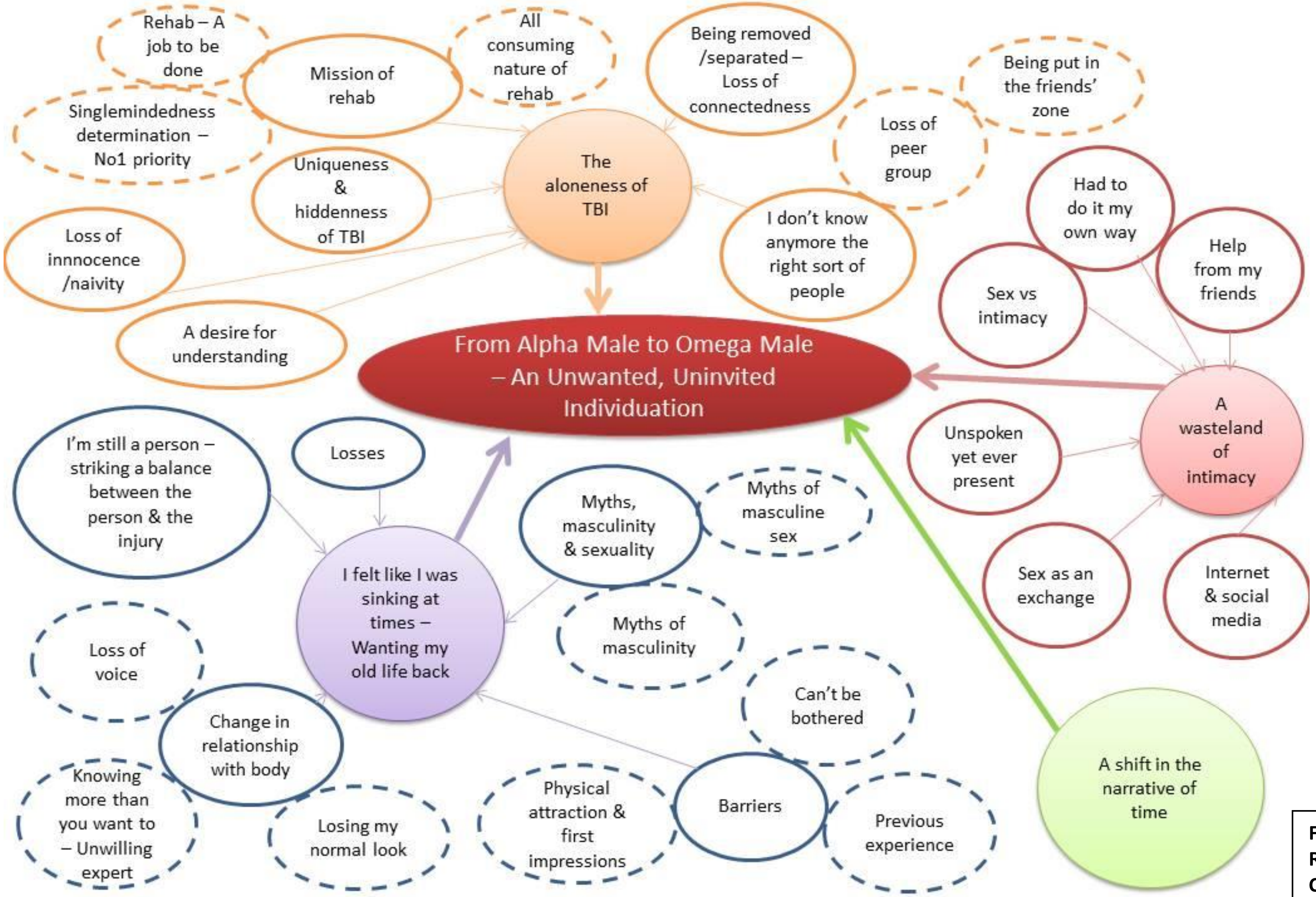
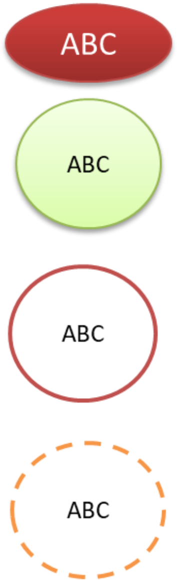


Figure 2 - Schematic Representation of Categories

Key for Schematic Representation of Categories.

Diagram shows links between core category, the 4 central categories and the categories. The focussed codes related to categories are also shown. Note that focussed codes sit closely with their category but also relate to neighbouring categories and in some cases central categories.

Key:



Core category (Filled shape, white writing)

Central category (filled shape, black writing)

Category (unfilled shape, solid line)

Focussed codes

Figure 3 - Key for Schematic Representation of Categories

I *felt like I was sinking at times – I wanted my old life back (Central Category 1)*

The title of this core category is formed by merging comments from two participants. The first comment was made by Jack when he chose a picture of how rehab had felt. He said that rehab had been a struggle and "*I felt like I was sinking at times*" (~~p.~~p. 61). The people in the picture look like they are quite safe and having fun but it's an illusion, the sign in the foreground warns of hidden dangers which brought to my mind the hiddenness of TBI.

The picture Charlie chose was a simply black & white picture of a man with his head in his hands. Charlie didn't want to be in rehab, he didn't even think he had a brain injury. He wanted to be at work. "*I wanted my old life back*" (part 3, p. 8).

Throughout all the interviews there was a strong sense of change and transition to something that wasn't necessarily wanted. There was an awareness of becoming different while trying to hold on to something that was in danger of being lost. This was expressed in many ways from Luke who regarded himself as having moved from being an alpha male to an omega male, to Mike who asserted that he was still the same person. Always there was a powerful sense of what had been lost while trying to find what was left of who they had been; a sense of having become separate and different. It seemed as if there was a sense of waking up in and trying to negotiate a new, strange, unfamiliar, sometimes frightening land. A land where the rules are all changed and no one can tell you what the rules are. Where things you knew before are no longer the same – the way you move, the way you speak, the way you think.

This transition when you have been a young man of some consequence – earning a wage, destined for university, someone with a future, a bit of a catch – entails a significant shift. Finally both literally in some cases, such as for those who now depend on a wheelchair and those whose speech has been affected, and metaphorically, your position in relation to others has changed and you have lost your voice.

Losses

Although rarely overtly mentioned, the theme of loss permeates the interviews. It is perhaps the category that presented me with most difficulty, because having worked in teams providing neuro-rehabilitation, I was expecting this theme to arise. However, the range of loss was much greater than anticipated.

Each interview began with participants being invited to share the story of their injury. In every case loss of time was immediately evident although it was not specifically named. The ways in which time was lost differed. A common theme was time lost through the injury - time spent in a coma, time which was lost being in hospital but it was also manifest in the time consuming nature of rehabilitation and the need to see a range of professionals. There was time which should have been spent doing something else e.g. studying or working; time was lost through delays in achieving qualifications and in the way progression at work was delayed or halted. This was linked with a strong sense of a loss of possibility. For some, jobs were lost because it was no longer possible to cope with the physical, social and/or cognitive demands of the work place. For Charlie this led directly to the loss of the house he and his family were living in.

There was an immediate and sometimes ongoing loss of independence with most participants being to some degree dependent on carers. This was seen not only in terms of physical dependence e.g. needing someone else to do the washing or ensure appointments were remembered, but in the reliance on others for the story of parts of their lives. Most of the participants talked about loss of memory. For some this was a loss of memory around the time of the accident or of the accident itself, e.g. Frankie had built up a picture of what might have happened from the police report, for others it was a more profound loss of greater periods of time before the accident that made them dependent on others for the narrative of their life story. This also represented an abstract loss of time past discussed further, along with the loss of previously imagined futures, in the category named 'A shift in the narrative of time'. Mike had lost a period of three months prior to the accident while Charlie had lost much more:

Int: *did you lose a period of time from before the brain injury or did you just lose that period of time when you were injured in hospital or?*

Par: *just a period of time. I, just a, from when it happened (mmm) to like about a year, two years after.*

(Charlie, interview 1, p3)

Other losses included loss of peer group; loss of stature in the community and a loss of prospects. There was a striking loss of voice, in some cases a literal loss but also a metaphorical loss reflected in their change in status as a result of the brain injury.

During the analysis I explored the idea of a loss of innocence/naivety brought about by coming face to face with death and considered the way in which participants had lost their 'normal look', which arose from talking to a participant who had needed a craniotomy but which seemed to apply to many of the other participants in different ways. There was also the loss of possibility in relation to sexuality and intimacy. All the participants had been sexually active prior to their accident and had at some time been in relationships. Following the accidents only two of the participants was either in a relationship or sexually active; one of these was Charlie, who was married.

The list of losses went on but I found myself feeling increasingly uncomfortable with it as a category (see Box 1. Memo – Developing Analysis).

Memo

Developing analysis – Moving from themes to codes and categories

This category of loss, which I anticipated finding, has caused me most concern because it wasn't explicitly mentioned by the participants. As a result I questioned whether it was something I was imposing on the data. I reflected on my own experience of developing a significant disability; a seizure disorder which robbed me and my family of our freedom in so many ways, and my son's more recent experience of developing a significant long term health condition which has led to life-changing surgery. None of us would have talked about loss but there were undoubtedly many losses. We focussed on dealing with the problem and getting on with life. In fact I am sure we would have thought that ruminating on them would have made matters worse. Perhaps my noticing and focussing on the loss here is a way of making up for my own unrecognised loss?

And yet, the loss is most certainly seen in the data. Perhaps by acknowledging it and making it my first code I can hold it lightly while exploring the other codes and see whether they interact or influence each other? I can also return to analyse this category further which Charmaz (2012) recommends when codes emerge that don't seem to resonate. This is part of the method of constant comparison. Will this code or category hold up in the light of further analysis? Is there a more salient code which could describe what is happening better? And this is one of the strengths of constructivist grounded theory - that the role of the researcher in co-constructing the data and the analysis is openly acknowledged and recognised for what it is. Charmaz states, "Your observations and ideas matter. Don't dismiss your own ideas if they differ from statements in the data. These ideas may rest on covert meanings and actions that have not entirely surfaced yet." (Charmaz, 2014, p132).

This category really is causing me a lot of trouble. I have persisted in writing it up this week but it doesn't seem right. It doesn't seem authentic. Perhaps it is something I have had to explore in order to get it out of the way in order to move on to explore the other categories which are emerging. Perhaps this is why there seems to be such a close link between this idea and so many of the other categories.

I think this is helping me to understand what is meant by interrogating your data. This code of loss is there but it seems to represent~~s~~ a more general theme in the data. Star asserts that grounded theory demands that you move beyond the general themes setting "up a relationship with your data, and with your respondents" (p. 111. Charmaz, 2014) while Charmaz goes on to say that each code should simultaneously categorise, summarise and account for the item of data it is applied to. She goes on:

"you move beyond concrete statements in the data to making analytic sense of stories, statements, and observations. We aim to make an interpretative rendering that begins with coding and illuminates studied life. If you concentrate on taking fragments of data apart and asking what meanings you glean from these fragments, you will move into analysis." (p. 111).

And this is where I think I have to move to and I think why other ideas such as change and something being taken away are pulling so strongly. This theme of loss seems to have taken me away from some of the other ideas I have had. Where is the stuff that I started out with about identity and not being able to relate to their new selves? I remember this being very strong for me immediately after the interviews; the idea of if they can't relate to themselves how can they relate to someone else. This theme or a category developed from it might pull the whole thing back towards sexuality and intimacy, which is where I feel that I am straying from.

Box 2 - Memo - Developing Analysis

As a result of this ongoing process of reflection I concluded that this seemed more like a theme which needed further deconstruction to make sense of the participants' experience.

Another problem with the code of loss is that the language of loss almost implies something active. We use phrases such as "I have lost my coat", "You lost your book" suggesting the person doing the losing has been active in the losing. Perhaps when the verb is used in the continuous form it becomes less active; "I am losing my power of speech" perhaps has more of a sense of something leaching away but none of this fits very well with the sense that I gained from the interviews. The language of the participants very much suggested that they had little control over what was going on, the language of loss therefore 'feels' too active.

Luke talked not about what he had lost but rather what "*had been taken away from me*" (Luke, p30). He talks about having a great deal of energy inside but not being able to do anything to dissipate it, such as going for a run or playing rugby as he used to. He goes on:

"But all that had been taken away from me now, where that side of, that part of my personality was always important the fact that I was tall, and a bit strong and all, all, all that, all what I had focussed on for 19 years (yeah) had all been taken away then obviously after the accident ..hh because I went from being a fit, healthy, strong 19-year-old boy (yeah) to being a (1) disabled person then like (mm) init."

(Luke, p 30)

This seemed to fit with the sense I had gleaned from the interviews of things being beyond their control; of things being done to them and of a removal or separation from 'normal' life.

Another overriding theme in the data was of everything having changed. Many of the participants had physical difficulties they had not experienced before; some had speech difficulties; there were problems interacting with others and the changes in jobs and status in society. This was another theme that demanded more attention and possibly fracturing to uncover the categories within. As a result elements of it can be seen throughout other categories.

I'm Still a person – Striking a balance between the person and the brain injury

I had a growing sense that the idea that everything had changed was being held in tension with an assertion that they were also still the same person they had always been and that person was fighting to be recognised and not taken over.

Charlie talked about not wanting his children to be burdened with his brain injury:

"*My daughter knows I've got a brain injury but she says 'oh yes dad just gets bad headaches' (mm) it's just like I don't (2) class myself as got a brain injury because I don't want the kids knowing brain injury if you understand what I'm trying to say*".

He also talked about how much he enjoyed his volunteer gardening "*because they don't class me as having a brain injury. So I goes there, just forgets about everything, be's myself*" (p. 10).

I said that it sounded as if he was trying to strike a balance between Charlie the person and Charlie the person who had a brain injury, not wanting the one to be taken over by the other. Charlie agreed wholeheartedly.

When I asked Jack about the impact of his injury he replied that while it would have changed some people a lot he still had the same sense of humour (p10). Dave said that his personality hadn't really changed, adding "*you know, I've always been the person I am*" (p. 11).

Mike mentioned a number of things he is unable to do now but also recognised that there were things he couldn't do now that he'd never been able to do, like the moonwalk. Later, when he was talking about how he had changed since his injury he reiterated "*so what, I can't do the moonwalk, I couldn't do it before but I'm still a person*" (p. 7).

In talking about how rehab felt, Frankie asserted that "*you have to be fine with your inner self in order to overcome the difficulties you have because obviously you're not going to be the same guy as before your accident*" (p. 55).

Even here, where he seems to be clearly talking about being radically changed after the accident, there is a sense of some kind of continuity of inner self that might carry you through.

Mike talked about how he presented a "*calm face*" and an "*upbeat attitude*" to those around him. He said that he thought they wouldn't realise how much his injury had affected him, particularly in relation to not having had any girlfriends since his accident. It seemed as if he even fooled himself at times. However, he went on to say that having kept up the smiling face for 3 years, it was all becoming a bit much now and being asked to think about this issue he discovered that it has affected him deeply. Frankie also expressed this idea of presenting different public and private faces in relation to having a girlfriend saying "*What's the point of me sitting here thinking 'I can't believe it I haven't got a girlfriend*'" but then went on "*Which x is kind of the way I feel but I don't show it.*"

In my own work I recall people being jollied along in the rehab unit when they felt down and angry outbursts not being tolerated, behavioural programmes being put in place to control them. I am aware of a sense of there being no space to grieve for what is lost and explore the things that have changed. I wonder if these are glimpses of the old self aching to grieve for what is lost and if being encouraged to do so would strengthen this sense of continuity with the old sense of self?

Change in Relationship with their bodies

Although when questioned directly about it, participants often didn't recognise a change in their relationship with their body, this category did emerge from the data and seemed significant in relation to sexuality and intimacy. Again this was one of those ideas that Charmaz (2014) exhorts researchers not to dismiss, even though it wasn't expressly talked about by the participants and I realised that it arose from my position of having an overview of the data and working to make meaning from it.

Most of the young men had been very active prior to their injury in both their jobs and leisure activities: one had worked with horses, a couple had been employed in the building trade; leisure activities had included team sports such as rugby and football. One had enjoyed surfing, another skateboarding. There was very much a sense of young men who had been physically capable of anything they wanted to turn their mind, and bodies to, and, perhaps more importantly, of not having to think about the way they used their bodies. After the injury this changed completely. For some physical skills had to be completely relearned. When asked what he thought rehab was about, Luke, who had been a builder, illustrated how much his relationship with his body had changed:

"to me at that point it was getting me back walking and getting myself independent where I could feed myself. 'Cos I couldn't toilet independently, I couldn't feed myself, I was 100% dependent on my carers then, my girlfriend (mm) and my mother and obviously the nursing (1) staff at that time like init. But when I was discharged it came down to my mother and my girlfriend like."

(Luke, p. 38)

Prior to the accident he wouldn't have thought twice about going to the toilet or feeding himself, his body just took care of it.

Dave had developed a left-sided weakness following his accident and had visual problems. He talked about having never thought about going out and doing things before but now he did. He had also developed an ability to self-monitor so that he might notice when his body was becoming overtired and his strength deteriorating (p. 24/25). Mike on the other hand stated:

I'm 3 years, 3 years on from the accident and I'm still finding umm still finding things that are changed in my life. (Mike, p. 1, 1st interview)

The young men no longer played team sports but rather went individually to the gym to focus on building strength and stamina, and consolidating the relearned skills, almost as an extension of rehab. For some there was also the issue of ongoing pain.

Int: *you're in constant pain?*

Par: *take painkillers constantly. Tramadol (yeah), gabapentin another trying to find some other tablet cos I've been sort of medication resistant for the last (2) ..hh say 15 years but it's got to the stage now where I cannot function without using painkillers like,*

(Luke, p. 4)

Related to this category of a changing relationship with the body were two significant areas, one related to a change in the way they looked and another related to communication.

Losing My Normal Look

This category arose out of thinking about the young men who had needed craniotomies one of whom mentioned the shock of waking after his accident:

"*you know I literally just woke up and* [interviewer sniffs] *you know, I* (1) *you know, I got half a head and you know, you can't walk tidy* (yeah) *I just didn't really know what was going on*".

(Dave, p. 35)

He had previously talked about how it had been six months before a cranioplasty could be performed to replace the missing piece of skull with a titanium plate. This was because his brain had become very swollen “*so it sort of, stuck out a bit*” (page 3).

A craniotomy is performed when there is considerable swelling of the brain following a closed tbi. It is the removal of a piece of the skull to allow space for the swelling. At a later date, often months later, a cranioplasty is performed during which either the original brain flap is returned, having been frozen in the interim, or it is replaced e.g. with a titanium flap. The image left is of a man post-craniotomy showing the degree to which the shape of the head is altered by the procedure. Patients may need to wear a protective helmet at this time to prevent further injury to the now unprotected brain.

Image from Jerry Pank, used with permission

It was in thinking about this that I realised that most of the young men had lost their ‘normal’ look in some way or other. One of the participants talked about now “*walking with a waddle*” (Mike, p. 8). Nathan who had sustained a spinal cord injury (SCI) was utterly changed in appearance, now having very little control over movement and having become a wheelchair user. Two of the other participants, while not wheelchair users had difficulties with both mobility and producing speech sounds which contributed to them looking very different to the way they had prior to TBI.

These factors were very much seen by the participants as being barriers to having relationships and are discussed further in that section.

Loss of Voice

For some of the participants communication became a struggle to make themselves understood. Jack and Frankie struggled to control the production of speech sounds and Nathan was dependent on an electronic augmentative communication system while other participants had problems with less concrete aspects of communication e.g. prosody, turn-taking and rhythm.

This was one of the areas in which Charmaz’s (2006, 2014) notion that it isn’t just the words of the interview that provide data was extremely pertinent. The interviews were a struggle. Throughout the interview, transcribing and coding, particularly with those whose speech was compromised, I was very concerned about my voice taking over.

With Nathan, although I asked the questions and waited for the answer, he would either try to give one word answers or, perhaps because the process of typing with one thumb was so laborious, would type a brief phrase into his phone. This left me to try to expand and reflect back what he was saying in an attempt to better understand what he was trying to convey.

With Frankie and Jack the interviews were lengthy and took immense concentration in order to understand the words they were saying. The flow of the interview was disrupted by my constant need to ask them to repeat what they had tried to say and then repeat what I heard back to them to check my understanding and accuracy. Even then when transcribing the interviews I found sections that were almost incomprehensible without listening to them repeatedly and tracking backwards and forwards to get clues from the context.

This made me think about the loss of voice these young men were experiencing in terms of the physical difficulty some of them had in communicating but gradually I also came to view it in a metaphorical sense which was bound up in their change in identity; becoming a disabled person; and the loss of freedom and independence experienced.

Knowing more than you want to - Becoming an Unwilling Expert

While there is often a lack of understanding from others and the sequlae of TBI may seem hidden to many, the survivors themselves become unwilling experts in brain injury. The interviews began with my asking participants if they knew which part of their brain had been injured. Most did.

Int: *..hh. Do you know which part of your brain was injured?*

Par: *Frontal (front) frontal lobe, that's the short term memory, and the left side of my brain, that affects movement in the (right side) right side*

(Frankie, p. 7)

Charlie said that he had known nothing about people with brain injury prior to his injury and going to Headway:

"Before I just thought tha' people with brain injury was like a cabbage x x x x (mm mm) you know what they say don't you that's x x? It was. Then when went there I met all different people with brain injury. The people you can't talk, the people you can't walk, the people you can't like feel the left side of their body yeah summing like that (mmm) and it just made me realise how lucky I was and how lucky I am (2) if, that doesn't sound right does it?"

(part 2, p. 32-33)

While Frankie said of TBI:

"*Uhh, if you have one you, involuntarily you know more than you want to."*

While these quotes summed up this experience of becoming an unwilling expert, the concept came over repeatedly when talking to the young men and they gave information about procedures e.g. craniotomy and cranioplasty or about the sequelae of their injury.

Barriers

Participants were asked about what they perceived as the barriers to forming relationships both before and after their TBI. The barriers before TBI were fewer but nonetheless significant for the young men, including race and shyness. However, there was a greater range post-TBI and many of the categories named elsewhere represented barriers to relationships e.g. disabilities, loss of voice and normal look, the all-consuming nature of rehab, being put in the friends' zone. Three codes seemed to warrant uniting to create a separate category of barriers these were: physical attraction/first impressions; lack of previous experience; lack of motivation.

Physical Attraction & First impressions

Perhaps linked with ideas around masculinity, there was an acknowledgement that physical attraction was an important starting point for relationships; it was particularly important to the young men for whom there were physical manifestations of their brain injuries.

Nathan, who had also sustained an SCI felt that his speech would be a barrier to forming a relationship but added:

Par: *[AUG] (26) also being in a wheelchair*

Int: *why, why do you think that is?*

Par: *(70) [AUG] people see me differently and I worry about the scar on my throt (throat).*

Mike said:

"*first impressions are what makes a lot of people's minds up …. If a woman's looking for a partner, look around the room and just look straight past me. They're not gonna think "Oh he could be an interesting guy" (mm, mm) 'cos that first impression when they see me walking with a waddle (1) they think "mm, is that ????"*

(Mike, p. 8, interview 1)

Prior to this in answer to a direct question about what he perceived as barriers to relationships he had said that before his brain injury he may have thought that race was a barrier but now there might be other problems:

"*As soon as like, du, physical attraction is what starts 95% of relationships: it's like you're not gonna go for someone you don't find attractive. I don't really think that's gonna happen, errm, and like girls'd just be, just be looking for a footballer or something …. That's definitely one that I've, I've noticed more. Like it's become more real to me like that is a real barrier I think*". (p. 5-6)

This seemed to link with another idea that arose during the research of sex as an exchange.

In spite of all this, Mike was able to see that there may be an up-side:

"*one thing that I am as a advantage now I know (2) that any woman (3) looking to get involved with me now will be getting involved because, because of my personality (mhum) I can't play football no more, I can't do this and that so anyone wanting to give me a go like will want to give me ago because my personality not cos I can do the moonwalk or anything".*

Previous experience

This was one of the issues that had contributed to my interest in researching this area. Seeing the way my own sons developed their capacity to have intimate relationships with young women made me wonder how men who have had a brain injury in late adolescence or early adulthood might develop the skills they need to navigate the sometimes turbulent waters of complex relationships. The conundrum that underpinned this for me asked how accomplished at intimate relationships could you be at this age and if there is little prior experience is it possible to develop those skills?

Most of the young men had had one or two 'serious' relationships although they may have had more sexual partners. Jack commented on his inexperience with girls a couple of times, saying that he viewed them as separate, almost untouchable. Dave said that there had been a few girlfriends but "*Nothing really brilliant to be honest*" (p. 18)

Luke talked about not having a clue about relationships and how he had been "*courting*" a girl for about 3 or 4 months before it had become a sexual relationship. He said that she was probably "*ready to have sex"* earlier than that "*but I didn't pick up on that"* (Luke, p. 18). His tone of self-criticism prompted me to ask myself again how accomplished can you be at 19 and whether the lack of experience impacts on your ability to build relationships after TBI. I also wondered whether this aspect of development is arrested by TBI and whether and how development can begin again.

Can't be Bothered

Problems with initiation and motivation are well recognised in relation to people who have sustained a TBI (State of Queensland, 2011; Marin & Wilkosz, 2005). Lack of motivation can have a profound effect on the ability to form and develop relationships in a number of ways as demonstrated by the participants of this research.

Due to a misunderstanding, Mike was interviewed over two sessions. On arrival at the second session he had changed his appearance - his hair had been cut, he'd shaved off his beard and he was wearing smarter clothes. During the first session he had commented on the fact that he hadn't been to the barbers for a while and thought he had put on weight due to having been confined to his house because of a leg injury. I made a note at the time that I wondered whether Mike was making himself unattractive for fear of not being wanted, however, there also seemed to be a sense in which he just couldn't be bothered. The contrast the following week was striking and as we talked about the place of sexuality in rehab and how professionals might help he said:

"They could have mentioned that to me, like 'you need to take a bit or pride in your appearance' because if you see me last week I came in with a full Bluebeard on my face and someone should have said to me 'Mike shave that shit off your face, you won't get a girlfriend like that'"

(Mike, p. 10)

He continued:

"*'you will need to try, you're not gonna get your ideal partner just land in your lap one day, like you've actually got to get out there and look, leave no rock unturned' and that (mmhmm) so, think that would've helped*"

At the end of the interview he said that participating had changed the way he was thinking about relationships and made him realise that he needed to be motivated and take action because "*a girl isn't just gonna fall into my lap* (mmm). *Gotta go looking.*" (Mike, p. 28)

Dave talked about the difficulty in people not understanding the consequences of brain injury and when to start explaining about it to a potential partner. While these are clearly very real difficulties he also conveyed a sense of ambivalence and lack of motivation in relation to starting a relationship:

"Cos obviously, I don't see the point in starting something up that's not, that is not gonn (1) that, which is eventually gonna fail (yeah). I'm more of a person who thinks well, if this ain't going anyhow, let's not bother getting started…. if something happens it happens, and if it doesn't it's (1), you know, it's just the way life is."

(Dave, p. 21)

Luke described having had a very active sex life prior to his brain injury and was upset by the subsequent decrease in frequency. Although he had asked for Viagra and valued sex as a source of bonding between partners, he also said, "*I can't be bothered to put the amount of effort in (3) to have sex."*

(Luke, p 26)

Charlie, who was married, talked about the difficulties lack of motivation caused across many aspects of his life and marriage. He mentioned not wanting to get up in the mornings, not feeling motivated to go to appointments, groups or to his volunteer work. He mentioned three times in a short period that this causes massive arguments between him and his wife but perhaps most poignantly he described the impact of his lack of motivation on their sex life:

"even with sex an' that though, I'll be feeling horny laying next to X [his wife] *but I just, can't be bothered* (mmm) *so I just roll over and go to sleep and like I* <u>*knows*</u> *what I does (2) but just can't help it"*

(Charlie, p. 26)

Myths, Masculinity & Sexuality

The participants mentioned a number of myths associated with both sex and masculinity. To some extent I was unsure whether this was surprising or not. I am a middle-aged woman from a large cosmopolitan city who has been working in the field of psychology for some time, the myths were not necessarily ones that I share and yet from my work, from self-reflection and from observing others I am aware of the power myths can have in the lives of individuals and in society as a whole. I also found myself wondering whether lack of experience was a factor here as well.

Myths of Masculinity

It had not occurred to me to ask about changing perceptions of masculinity until the issue arose in the first interview. Prior to his injury, Mike had been employed in a very physical job working with horses. The question about his ideas around feeling masculine or being a man arose out of the discussion about his relationship with his body pre & post TBI. He expressed his concerns about how he would fulfil a traditional role of husband and father acknowledging that he wouldn't be able to teach his children how to play football or fetch things out of the attic saying

"I can't you know do lot of lot of the things that would be down to the man I can't do you know so"

(Mike, p. 8).

He recognised that things had changed and the accident had forced him to think about things he had previously taken for granted. He talked about "*showing off my masculinity*" (p. 2, second interview) prior to the accident running up ramps with heavy wheelbarrows etc. and recognised that his ideas about men being physically stronger and more capable were "*pretty much set in stone for me, that's the way it should be*" (p. 2, second interview). However, he also felt that this was something that was necessarily shifting after his brain injury.

One myth that was particularly prevalent was that of the man as the breadwinner with some participants talking about how they had been working and earning a wage prior to the accident. Those who were no longer able to work found this very challenging. This was perhaps most eloquently expressed by the participant who said that work was important equating it with respect:

"*work for a living like, init, is important, uhmm* (2) *..hh. It probably, uhuh, you're respected by your peers* (mhmm) *and that where I am probably no. I always said like, it's like I went from like an alpha male and now I'm like an omega male* (1) *so that, that's how I would put it like.*"

(Luke, p. 28)

This idea of transforming from an alpha male, in his case a young man who had completed an apprenticeship, got a job, good money and a car, and who was seen as a 'good catch' by local girls, to an omega male, a man in constant pain, who could not manage a job and who struggles with interpersonal relationships, is very moving and captures something of the transition from fit young man to disabled person.

Some of the participants recognised positive changes following on from their brain injury. Charlie talked about how prior to his brain injury he had spent a great deal of time with his mates. This seemed to be considered a male norm where he lived – he would go out to work and then go out with his mates. He described going out clubbing with them while his then girlfriend stayed with his mum drinking tea. He now sees the time he spent with his mates as having been a barrier to developing intimate relationships with women. When he was asked to reflect on the idea of masculinity he said that he thought he was more of a man now than he had been then. He talked about how he and his wife had stuck together through her unexpected pregnancy and his brain injury and compared this with his mates who still behaved as they always had. He wanted to be a guide for his children and a role model for his young son, who he didn't want to get into trouble.

Other participants also felt that there had been changes in their perceptions of masculinity since their accident. Dylan didn't see the need to go to the gym and become muscular or to have sex at the weekend, "*I just think I'm a man, what more do you want?*" (p. 27). He now seemed to feel that it was more important to be able to set his mind to something and achieve it and Dave, felt that he had never conformed to masculine ideals because of his height and said that his priority had always been to achieve the goals that he set himself.

Myths of Masculine Sex

There were myths of masculinity related to sexuality as well. Dylan told me that before his TBI he had frequent one-night stands adding that it is "*a man thing init?"* (Dylan, p. 17). For him sex was an important part of being a man. He reiterated that being a man was associated with physical things like playing sport, having a job, earning a living, and getting plastered/smoking weed and having sex at the weekend. However, he too said that he thought differently about it now explaining that he doesn't want to be a muscle man now but sees his masculinity in setting his mind on something and then pursuing it.

Mike commented, "*yeah well sex for men is like a errm is a, men are supposed to have a healthy appetite for sex in't they?*" (Mike, p. 23)

Luke, who had described himself as going from alpha to omega male, had also seen sex as an important part of what it is to be a man. He claimed to have had a high sex drive prior to his brain injury perhaps masturbating 3 times a day and having sex 5 times a day. He reasoned that most men probably needed to have sex every day, seeing it as a biological or evolutionary drive dating back to caveman times. When I suggested that there might be a continuum he replied "*p'raps women don't want as much sex as p'raps a man would want*" (p. 28). He thought having a low sex drive was natural after sustaining a TBI but felt that this might pose problems in a relationship as he did not have what he considered the sex drive of a normal 36 year old.

This idea about myths and masculinity seems to be about the power of projecting a societally sanctioned narrative or identity to those around you: men are physically strong; men are the breadwinners; men are capable. Moving from being seen as an alpha male to an omega male, either by self or others, represents a loss of control over that personal narrative.

Initially I thought that loss of control of personal narrative was limited to needing help to remember parts of their story, but as I reflected on it over time, I began to realise that this loss of control over your own story and narrative are highly significant. It was not just a loss of the ability to remember a coherent story about your past life, it is also a loss of the ability to project a chosen identity to others. While this was particularly strong for those who sustained physical injuries, it was also present for those who did not. The strength of societal narratives about both masculinity and disability can overpower any attempt to create a distinct identity on the part of the injured person. There is a strong societal narrative about disabled people being asexual and I wondered how much this was impacting on these young men.

The Aloneness of TBI (Central Category 2)

This second central category arose from analysing the participants’ picture choices. Charlie chose this picture to represent the challenges he had faced in relation to sexuality and intimacy. While ~~it~~ one participant chose this to talk about relaxing and having fun, Charlie said “*it’s just like a wall x x and I just want to be on my own (mmm) so*”. ~~”~~ He then continued “*but even when my X [his wife] is there next to me and like I said I felt horny and randy ‘sjust like I said rolled over went to sleep. Felt like being on my own*” (part 3, p. -10).

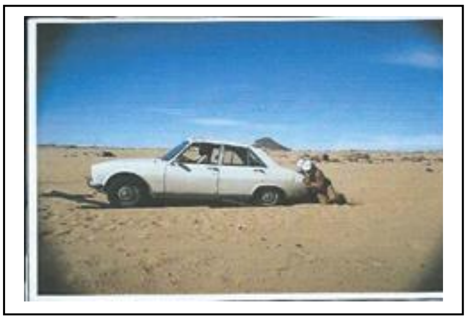
It was this choice and these comments that triggered my thoughts about what I called the aloneness of TBI. It was an idea that wouldn’t leave me alone. Charmaz (2014) endorses the idea of the importance of returning to data and concepts that won’t leave you alone. Other picture choices in the interviews resonated with this concept.

Mike initially chose a picture of a wrecked ship to illustrate how rehab had felt to him but then he changed his mind saying “*but no that’s, that’s more how I felt* [pointing to a second picture] *like although there was lots of staff to help you get through it and that, it just felt really lonely (3) [clears throat]*”.

He continued “*it was like errm very lonely this is a picture of one single tree on its own (mmm) in the sea it looks like (1) like, how many trees do you see in the sea? It's like, that tree is like obviously (3) different from a lot of other trees, me again*” (“me again” meaning he is different to others), and then “*yeah errm and like errm (2) dull and gloomy that's how life just felt at that time*”.

(Mike, 2nd interview p. 16-17)

This picture was chosen by two participants. Jack chose it as representing his struggles in relation to sexuality and intimacy. He referred to “*a barren desert*” and “a wasteland of intimacy”. While Nathan saw himself as the car. He realised people were trying to help but wondered “*what’s the point there’s nothing everywhere?*”.



Memo – The making of a central category

As I reflected on these and other comments I began to realise the power of this category and I am left wondering about the aloneness of TBI. About young men needing to focus on themselves to get through rehab. About people simply not understanding the challenges and the changes they have been through. About the isolating power of the hidden disability. It seems to encapsulate questions about where someone fits in when such a fundamental change has taken place in their power to be, to remember, to solve problems, to learn, to move. Questions about how you fit in when you find that you can no longer observe the social niceties and meet social expectations. How isolating and alone are you when you are slotted in to rehab groups and charities with people you may not have chosen to spend time with before the brain injury?

The category seemed to encapsulate~~d~~ the sense of becoming isolated from everyday life, the life they had led before; the utter focus on rehabilitation as a mission; the sense of not knowing anymore the right sort of people; the wasteland of intimacy and this, this category was raised to become one of the central categories.

Box 3 - Memo - The making of a central category

Being Removed/Separated – Loss of Connectedness

In the aftermath of the accident, the participants had immediately been removed from everyday life; taken to a hospital, usually to the strange world of intensive care. They became a part of a well-oiled machine focussed on saving their lives, ongoing treatment and eventually rehabilitation; there was a sense of separation from so called ‘normal life’ to the rehab focussed life of the survivor as illustrated in the section on the mission of rehab.

The idea of separation is seen in their removal from friends and from the trajectory of their life as it was, while their friends continued on their chosen paths leaving behind those who had been injured.

Perhaps the most interesting insight was from Frankie:

Int: *Okay (5) what, what was your understanding of the role, the aim of rehabilitation?*

Par: (*5) on their part or on real terms?*

Int: *tell me both*

Par: *on their terms is ngh they are trying to reintegrate you in the society.*

Int: *they are trying to reintegrate you into society (yeah) yeah. Okay*

Par: *and the real stuff is they're only trying to*

Int: *sorry the real st/, the real situation is?*

Par: *is they're only trying to*

Int: *they're only trying to. So it's not actually happening in your (mmm) book (mm) your experience?*

(Frankie, p. 34)

He went on to give the example of going to Headway, saying that while they are trying to reintegrate you into society the reality is that you go every week and see the same people with the same types of difficulties as you have. Frankie said that he loves going to Headway but he doesn't see it as the means of integrating into society that he thinks they want to be.

The category of being removed/separated – loss of connectedness manifests itself through the uniqueness and hiddenness of TBI, through a desire for understanding and through a loss of innocence or naivety, although elements are also seen later in the analysis when I explore ideas relating to the change in status from fit young man to disabled person and the loss of connection associated with brain injury.

The Uniqueness & Hiddenness of TBI

Within brain injury rehabilitation there is an oft repeated phrase that "every brain injury is unique". Search this phrase in Google and a number of organisations using the phrase appear including Brainline, Headway and Brain Injury Alliance of Utah. The Headway website states: "Every brain injury is unique, and there is no one particular route to recovery or indeed accurate way to predict how severely a person will be affected." (Headway, 2016). There is no algorithm that says 'if this bit is damaged; this is what the consequences will be'. There are so many mechanisms of injury – shearing, impact, chemical damage, physical damage, primary and secondary injury, bleeding, swelling, starvation of oxygen – so many variations in treatment and in recovery and rehabilitation, in attitude, resilience and perception. All of these things contribute towards the construction of the narrative of one person's unique experience of TBI and their rehabilitation. This idea of uniqueness was something that many of the participants referred to:

"Then when went there I met all different people with brain injury. The people you can't talk, the people you can't walk, the people you can't like feel the left side of their body yeah summing like that (mmm) and it just made me realise how lucky I was and how lucky I am (2) if, that doesn't sound right does it?"

(Charlie, part 2, p. 32-33)

Some of the participants suggested that this uniqueness may cause some difficulties for HCPs working with them. Dave said that he had been told by the doctor that his injury was indeed unique and Frankie summed up the general idea of uniqueness very succinctly. He began by saying that all the people who had worked with him had been extremely knowledgeable but continued:

Par: *I still felt like a kind of lab rat*

(Frankie, p. 54)

Another narrative relating to the hiddenness of brain injury also exists:

"*some in wheelchairs, hundred per cent care and others are walking round, you, you'd never think they had a brain injury, like, they look quite normal because they do say that brain injury is like an hidden, hidden disability init?* (yeah) *It's not always visible thing like."*

(Luke, p. 49)

Charlie said that he himself had not believed at first that he had a brain injury because there are no visible signs of it for him.

This is also a common theme in the brain injury community among both professionals e.g. Kreutzer (n.d.) & Headway (2016), and the injured people and their families, although clearly for some injured people the results of their TBI are all too obvious. However, even in these cases there are symptoms which may not be readily identified. Participants mentioned issues such as fatigue, emotional lability and lack of motivation which impact on them and their relationships but cannot immediately be seen.

A Desire for Understanding

While brain injury is a significant problem within health care, many members of the general population will not have knowledge of brain injury and its sequelae, particularly those aspects which may be hidden e.g. cognitive difficulties such as memory or attention. A lack of understanding was seen as a problem by participants.

"….obviously not everyone understands what a brain injury is. I think they think they know (yeah) *but then when they deal with any, like my friends find some actions a bit strange or something like and maybe not understand why one day you can be great, one day you can be a bit down….."*

(Dave, p. 21)

Charlie had experienced a lack of understanding from some professionals and from other people with brain injuries because of the very hidden nature of the consequences of his TBI. He can still drive, walk and talk. He doesn't look like he has any difficulties but his cognitive disabilities have had a profound impact on his life and his family.

Understanding is seen as key in anyone who might be a potential partner, but there is also a problem about how to broach the subject. Dave continued:

"…. so I think that would be difficult because obviously you'd have to try and meet someone and then explain, without sort of putting them off you know (yeah) *like scaring them off 'Oh by the way now, I got a brain injury and I do suffer from this and that'…. if someone doesn't understand that then I don't wanna know."*

(Dave, p. 21)

The idea of wanting a partner who would understand their brain injury was common:

"It's just a matter of finding a woman, who I'm attracted to and is attracted to me [interviewer sniffs] *that we gonna fall in love with and she's gonna understand my brain injury* (mmm) *and then I'm gonna understand her like init type of thing."*

(Luke, p. 55-56)

Luke suggested that potential partners may be worried that symptoms associated with the TBI might get worse in later life (p. 60). Dave was concerned that they may be put off by not knowing what brain injury really means and may wonder if the injured man might get *"nasty"* or be *"crazy"*.

Some of the difficulties described by Charlie including his low mood, frustration and lack of motivation suggest that any partner would indeed need a great deal of understanding to make a relationship work.

Loss of Innocence/Naivety

Another way in which TBI is unique, and in which those sustaining the injury may become separated from others, is that many of have come very close to death. This evoked in me a sense of loss which was not referred to at all by the participants but which struck me repeatedly as I undertook the interviews with each of the young men. It was a broad category of a loss of innocence or naivety about their own sense of immortality. Hazlitt's (1827) famous essay "On the feeling of Immortality in youth" opens with the words "No young man believes he shall ever die" and later, "Death, old age, are words without meaning, a dream, a fiction, with which we have nothing to do". However, for these young men the reality of death has come very close:

"*I think they gave me 2 hours to live pretty much*." (Dave, p. 2)

"*And I only woke up because a very clever doctor [….] said "Let's try and see how he reacts if we turn the machines off (2) and the first couple of times I didn't react so they had to turn back on. The third time I still didn't react and he left it a bit longer and I suddenly .. HUUUUH gave a big gasp of air and came back to life*."

(Frankie, p. 2-3)

I wonder if perhaps this alters who they are in some fundamental way? These young men no longer have a sense of their own immortality and I wonder if this somehow separates them from other young people? Does it add to that uniqueness, the sense of strangeness Dave referred to?

There also seems to be a feeling that they can no longer be sure that the things that they plan will come to fruition. Frankie was about to begin the long road to getting a degree. He talked about the course which would eventually lead to a degree in business management. He told me that he would complete the HNC and then move on "*to do a proper degree (yeah) and that's my plan*". There was something in the words "*and that's my plan*" which seemed to convey that although it was his plan it may not happen.

The "Mission" of Rehabilitation

Rehabilitation as a job to be done

Rehabilitation was certainly seen as a job that had to be done, even after formal rehab was finished. This was directly expressed by Dave when talking about a boxercise class he attends at a local gym:

"*I go to the gym and I'm (1) focussed on getting myself fit, rather than going there and chatting around to different people. You know, I'm there to do a job sort of thing and that's. So I've become more serious that way but I feel like I've got to do that to get better.*"

(p. 24)

Dylan had preferred working with younger therapists. In part this was because they were on his wavelength but he then went on to say that he could have a laugh with them and "*You can enjoy the job then"* (p. 34) which made time go faster. Having described rehab as a job he later went on to describe it as his mission saying about the professionals:

"*It's just like great, they've done what they had to do (1) so well (mhmm). I mean they, daa, so like they took me (3) how can I put it? (6) Oahhh, well they done as good as they could do (2) as much as they could do, an' I, like, carry on my own like (mhmm). On like, how can I, it was like err, a mission*"

(Dylan, p. 42)

A number of the participants indicated how lonely and what hard work rehab had been through their picture choices including choosing pictures of holidays/relaxation to express how they would have liked rehab to have been.

Linked to this there was a strong sense that working hard now will make things better in the future. As Charlie said:

Par: *But now I feels like, now every day I'm getting better*

Int: *so even after all these years you feel that is still improving?*

Par: *yeah (mm) if I'm better today than I was yesterday (uhuh) then tomorrow I'll be better than I was today (mmm) [vocalisation]*

(Charlie, p. 18)

Almost all the participants saw themselves as having to keep on with the task of rehabilitation even after formal input had ended. They continued in their involvement with services such as Headway which provides on-going support and some informal rehab; most of them also continued with some sort of programme of physical exercise using local gym facilities. I wonder if this is associated with the nature of TBI and a 'not knowingness' about rehab, a sense that if they just work hard enough for long enough they might get better. Physical rehab is also an area where they can gain a sense of control.

All-consuming Nature of Rehabilitation

While rehabilitation was definitely hard work, it also seemed to be all-consuming, particularly in the initial post-hospital phase.

Six of the eight participants received inpatient rehabilitation in specialist facilities but the sense from all the participants was of rehabilitation completely taking over their lives and leaving little room for anything else.

One of the questions asked participants to choose from a list the professionals they had seen during rehabilitation. The purpose of this was to help them think about whether any of the professionals they had seen had mentioned sexuality. Most of the participants had seen a wide range of professionals but it was only as I was coding the final interview that I began to think about the amount of time and energy it would take to be constantly seeing such a range of professionals, even if they were in a residential facility. For Dave this was exacerbated when he left hospital because he lived in a rural area where there were no services for people with ABI. This meant that he had to travel a considerable distance for all his appointments, but only after his family had won the time consuming battle of securing his right to those services in the first place. Luke mentioned the difficulties and time taken in applying for and securing the benefits he was entitled to.

The tasks of rehabilitation were enormous for this group; it was succinctly expressed by Jack who said "*I remembered how to breathe …. and that was, about it.*" (Jack, p. 31)

Jack had been 17 when he had his accident. He woke from a coma after 6 weeks to find that he was unable to move easily due to high tone in all his limbs. During the time he was in a coma he had grown 6", his body had changed completely, he no longer knew his own parameters and boundaries. He was right handed but his right side was very badly affected, in addition he could not speak. He had to relearn walking and talking and learned to write with his left hand. As he put it, "*And now I've had to, well, if you can't talk the one thing you learn pretty quick, how to write*" (Jack, p. 32).

The same was true for most of the participants, after the brain injury nothing was the same as it had been. Most of the participants had to relearn lost skills and this was a long process. Skills lost included physical skills such as walking and talking but also less tangible skills such as memory and social skills.

Through the pictures, Nathan, who had sustained an SCI in addition to his brain injury, indicated that rehab had felt like a slow process, it was a dark time and he felt as if he was going round in circles not getting anywhere.

As previously stated, all the participants were continuing with rehab independently in some way and most of them were going to the gym regularly, even if this was not something they had done before their injury.

The all-consuming nature of rehabilitation, the hard work and the hours of practice seemed to leave little time for other things including relationships. This was not just seen in the initial stages of rehabilitation, for some of the participants once the first stages of rehabilitation were completed, getting back to where they were at in terms of education became the priority and once again relationships were seen as a lower priority:

“*since my injury I’ve been so determined with, getting myself better (yeah) that it sort of (1) there, there isn’t really enough time in, in my life anyway for that. I wanna get my, like I said, with education, I wanna get myself, I wanna get myself on a good path (yeah) so I know what I’m doing. You know, I don’t really wanna get side-tracked …”*

(Dave, p. 29)

Memo – Reflections on separation

Reflecting on this provoked in me the idea of entering ‘a world of brain injury’ and becoming contained within a bubble of rehabilitation. This links with the idea of being removed or separated and becoming isolated. There is something very compelling about the certainty offered by rehabilitation after the unpredictability of what has happened in the accident and its immediate aftermath. I find myself wondering whether this certainty, the predictability of sessions at certain times, of repetition of certain exercises, does something to counteract the unpredictability. It provides a structure, boundaries within which the person can get better. As I reflect on this and these paragraphs, a vivid image comes to mind; it is the face of the foreground figure in The Scream by Edvard Munch superimposed on the face of a person standing on the very edge of a black abyss. I wonder if rehab helps to fence off the abyss, an abyss of things being uncontrolled, of not knowing what you knew before, of no longer possessing a complete narrative about self or a complete life story. As I see this image the sense of the danger of falling into the abyss is palpable for me. Later when I examine the original picture more closely I see that there is a fence in it which has been interpreted by some as holding back “the subjectivised flow of nature” and as protecting the figure from “total absorption into subjective madness” (Edvardmunch.org, 2011). I realise that to enter into relationships, and particularly intimate relationships, means entering into uncertainty and unpredictability again.

Box 4- Memo - Reflections on separation

Single mindedness, determination and being the No 1 Priority

Intimately linked with the concept of the work and time-consuming nature of rehabilitation is a concept of needing a degree of single-mindedness and determination coupled with the necessity of making yourself the number 1 priority in order to get through rehab. This was seen consistently across all the participants and was expressed openly.

All the participants felt that they needed a degree of determination to get through rehabilitation after brain injury and some felt that this was the only reason they had done so well. For some of the participants this single-minded determination arose out of having been given a very poor prognosis which they refused to accept:

“errm… the hospital told me I wasn’t gonnan walk”

(Mike, p. 4, interview 1)

He was subsequently transferred to a private rehabilitation centre having had a payout from an insurance claim and he was determined to walk again:

"I wasn't walking, I went on a wheelchair and errm I used to drive the rehab staff mad like asking to practice walking laps of the centre. Walk, walk, walk that's all I wanted to do and I done it like"

(Mike, p. 9, interview 2)

Dylan told a similar story reflecting both the singlemindedness needed and the way in which he felt he had to make himself the number one priority:

"Par: *I think, well, because aww, when I was in hospital they said "you ain't gonna like walk again, be in a wheelchair*

Int: *you weren't going to walk again?*

Par: *Yeah but I just thought "I'm not having that. I don't care what you say." And that's how it's gone I don't care what no one else says, I'm gonna listen to what I say and what I want. So far as I'm concerned, sod them. It's me and me only (mm) (2) Ah and that's how it's always been (mm) or now anyway."*

(Dylan, p. 28)

He later said that the key thing was mental strength and a belief that if he set his mind on something it would happen eventually.

Singlemindedness and determination were seen as the strengths that would carry them through into the future. Nathan saw becoming independent as his highest priority and when asked what personal strengths would carry him forward replied "*In stubbine*" (I'm stubborn. P. 45).

It was this motivation and continued determination to improve that kept them going even after formal rehab had finished:

"Int: *Do you still get any rehabilitation?*

Par: *err no. I go to the gym three times a week. I got my*

Int: *but that's under your own steam rather than*

Par: *yeah I've got my own programme*".

(Dave, p. 15)

The need for this focussed approach meant that certainly in the initial stages there was no time for sexual partners and it almost seemed that there was no room for thinking about them. Mike, who had had a number of girlfriends before the accident and for whom sex had been very important (he had said his main difficulty had been staying faithful) said,

"…. *people's motivation gets affected when they've had a brain injury* (yeah) *and my motivation to get better and really, and really if anything it increased, like I've always, I've always been on it and errhm but my motivation to find girlfriend (1) had (2) slacked off a bit*".

(Mike, p. 7, interview 2)

When Jack was asked if he would have wanted to ask about sexuality at any stage replied:

Par: *(5) I don't (2) I didn't feel the* <u>*need*</u> *to (1), to talk about it with them or ask about it (3)*

Int: *okay. (1) After you came out of hospital and you were back in the community was there a point at which you would have p'raps liked to talk to someone about it, do you think?*

Par: *the way I saw it (1) was (1) 'who's gonna want to sleep with me or be in a relationship with me at the moment while I'm in this state?' And I just, I think I was just very focussed on getting better.*

(Jack, p. 48)

Frankie admitted to having similar thoughts and Nathan wondered what part sexuality and intimacy were ever going to play in his life again.

Dylan was asked if he would like to have a relationship with a woman, he replied that he would but then went on:

"*yeah.* (mmm) *But I don't want like a woman well, being in charge of my life* (right) *yeah because that wouldn't feel right to me* (mhmm) *as far as I'm concerned there's only number 1 and I'm the number 1".*

(p. 20)

It was interesting that when asked what they saw as the purpose of rehab many of the participants has some idea of it being about a return to 'normality'. Dave talked about its aim being to get him physically stronger and getting "*back to as normal a life as I could possibly get*" (p. 30). Jack suggested it was about:

"getting me (1) back to how I was x (1) or getting me (2) back to a (3) stable state I can be on my own" (p. 49).

And yet somehow, as identified by Frankie, rehabilitation also seems to play a part in separating them from normality.

Memo – Reflection on rehabilitation

Since completing the interviews and working through the coding and analysis I have often found myself reflecting on the nature of the rehabilitation these young men undergo and wondering if it really is the best way forward for them. There is something about the way in which they talk about and my own experience of working in such settings which has made me question whether this pursuit of facilitating function and promoting independence in fact makes them too independent and somehow jeopardises the ability of these young men to form relationships.

I remember talking to one of the managers at Headway about this when I was interviewing and I first wrote about it when I began coding in 2014:

"As an assistant psychologist I was aware of how intensive rehab was, and in some ways the attitude was the more intensive the better. However, I'm not sure that I really appreciated how the texture of what this means and how it takes over your life in the way it does. The setting of the priorities for rehab is also important, who sets them and what is seen as being a priority? But I think I need to explore this idea of the rehab taking over. Rehab seems to separate rather than integrate and yet the aim would be to reintegrate into society isn't it? And yet how many of these young men do manage that? So many are still going to places like the Headway clubs and although the rehab has worked in that they can walk and talk again what does it rob them of and how do they manage relationships afterwards?"

I have reflected on it a great deal since but of course now I realise that I am not the only one to have been asking these questions and that Bowen, Yeates and Palmer (2010) have explored the idea that there are other important aspects that should also be the focus of rehabilitation in depth.

Box 5 - Memo - Reflection on Rehabilitation

"I don't know anymore the right sort of people"

This phrase is a quote from one of the participants. It seemed to encompass a number of aspects of what happens to young people post TBI. There is often a loss of peer group coupled with a sense of them being left behind or becoming isolated and they find that their relationships with potential sexual partners changes.

Loss of Peer Group

I don't know anymore the right sort of people is a phrase that has haunted me. Frankie, who sustained his TBI three days after finishing his "A" levels, said it. He was a lively outgoing young man who had been studying, working and who enjoyed socialising. Then he was in a car accident. Before the accident he had worked at weekends. His shift would finish at 11.00pm on Saturday night and he would go off to a party or club, he then would get a couple of hours sleep then go to work on Sunday morning. I asked:

Int: "*You don't go to parties anymore? [Participant shakes his head]. No (2)*"

Then he added:

"*I don't know any more the right sort of people*"

(Frankie, p. 25)

He explained that the friends he had at the time of his accident had all gone their separate ways. I realised that they would have all gone on to university and he added that some had gone on from there, e.g. one was now in China and another in London. Dave also talked about his mates moving on (p. 21). This would seem to be a particular problem for this age group. It is a time of great mobility, particularly for those who are destined for university. They are left behind while friends leave their home town and go away.

Those who were not planning to go to university find that friends move away for work or to get married. Even when friends stay in the same area, their lives are no longer similar and so contact may be lost. Charlie said that he no longer felt that he fitted in with the group he had associated with prior to his brain injury; the experience of having a brain injury had changed him, he had grown through it. He felt that his friends were, comparatively, very immature and didn't take their responsibilities seriously (p. 20). However, Charlie also felt that he didn't really fit in with the brain injury community because his injury was not as severe as that of many others attending the local brain injury group. Dave too identified with this sense of having grown in ways his friends hadn't:

"*Cos like me and my mates, you know you're young, bit childish and having a laugh, joking and all that but then after my accident I was sort of (1) serious and not so jokey (mmm) but it wasn't really a big problem for them, it's just sort of like I was nn, (1) I was just more sort of grown-up sort of thing in more serious*." (Dave, p. 20)

Dylan could no longer socialise with friends from prior to his injury because his hearing had become hypersensitive and thus he could not go to a pub with them as he was unable to hear them when they spoke to him (p. 15-16). As explained elsewhere, many of the young men had played team sports prior to their TBI; after their accident this was no longer possible for any of them representing another peer group lost.

With Nathan I had a strong sense of his social circle having shrunk to encompass only those who were also members of the disabled community, his care staff and family.

Post-TBI the focus of rehabilitation is very firmly on getting things back to normal and yet the normal that is offered by our society for those with severe disabilities is not the normal these men were used to prior to their injury. There is a sense of the shrinking of their world. Post-TBI they may become involved in groups run by local health services or charities as part of their rehabilitation but these groups are composed of other people who have sustained a TBI. It may be difficult for them to socialise with their former friends for a number of reasons and so socially their horizons shrink, there are fewer opportunities to meet new people who are not disabled because they may find access a problem in many ways, and this means fewer opportunities to meet a potential partner.

Within the TBI groups meeting a partner is also problematic. For heterosexual men the difficulty is that young men are far more likely to sustain a TBI than young women so relatively few young women will belong to the groups, and for homosexual men, because they already belong to a minority, the chances of meeting with someone else from that minority are slim.

Being put in the Friends' Zone

Almost an extension of no longer knowing the right sort of people, was the idea that following a brain injury, something changes in terms of sexuality and the young men end up in what two of the participants called "the friends' zone". They recognised that their interactions with women were different, as if they were no longer seen as potential partners but automatically categorised as being somehow non-sexual.

Mike thought that perhaps he projected himself differently following his brain injury and noticed a real contrast with the way things had been prior to his brain injury:

"*I feel that when I, when I wanna talk to girls who I think might be attractive like, not intentionally like, I might come across as though I just wanna be good friends with them and I get put into what's known as the friends' zone (2) (mm) like I think that's, that's happened to me a lot since, like since the accident. (mm) (3) That definitely wouldn't have happened before*".

(Mike, p. 26)

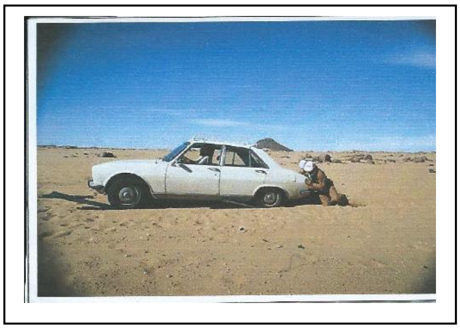
I made a note in the margin while I was analysing this interview asking "is it the way he comes across or is that where girls put disabled men, in the 'friends' zone'"?

This phrase was also used by Frankie who had significant difficulties with speech production. He said, "*Because some girls may go "ohhh talking is tough." Automatically you're thinking they park you to the friends' zone*" (p. 71).

The friends' zone is understood to mean that you are not seen as potential boyfriend material, you are somehow asexual although Frankie did say that prior to TBI his best relationships had gone through a friendship stage before becoming romantic relationships and thus he hoped that once someone got to know him as a friend things might progress to something else.

A Wasteland of Intimacy (Central category 3)

The term "a wasteland of intimacy" is a direct quote from Jack. When he was asked to choose a picture that represented the struggles he had faced in terms of sexuality since his brain injury, he chose two pictures:



He focussed primarily on the second picture and I asked him how it represented his struggle. He replied:

Par: *(3) haa, not {feeling} well in a barren desert (mhmm)*

Int: *that's how it felt sometimes?*

Par: *mm (4) [speech slightly less clear], a wasteland of intimacy*

(Jack, p. 64)

About the first picture he simply commented *"not knowing where to turn".*

When asked whether sexuality was something he had ever wanted to talk about Nathan said that he had. I asked what sort of things he had wanted to ask:

Par: *[OV] uh. [AUG] (20) Given the confused and will it ever happen again*

Int: *that you feel confused? (yeah) And will it ever happen again (yeah) okay. Okay.*

(Nathan, p. 16)

Talking further about this he indicated that he questions what part sexuality and intimacy are going to play in his life in the future. Frankie talked about being *"simply dead"* in terms of sexuality having not had sex for 8 years, since before the accident (p. 39).

This seemed to be a fundamental question facing all the participants. Without exception, all the participants wanted to be in a stable intimate relationship at some point in the future. They had all been sexually active prior to their brain injury and most had been in a stable relationship at some time, however, this changed post-TBI when only Charlie who was married considered himself to be in a long term intimate relationship. All but one of the participants had been sexually active, either alone or with a partner at some stage since their brain injury, and said that sex was still important to them.

Seeing an overview of the data I came to realise that all the participants are trying to work out, in their own way, what the place for sexuality and intimacy is in their lives now. Some pursued ways of satisfying their sexual needs; some have set them to one side in pursuit of other goals – education or work; some are trying to negotiate the changes that have taken place either with partners or alone but all feel that at some stage they will want to have an intimate, physical relationship with someone, even if at present they don't know how, with whom or when. And all of them seem to have found themselves in a wasteland of intimacy since their brain injury in one way or another

Unspoken and yet ever present

The subjects of sex and intimacy as a normal part of life were almost never mentioned by staff during the course of rehabilitation, in spite of the fact that all the participants saw a range of professionals on numerous occasions and that in most cases rehab was lengthy. There were two exceptions: Charlie, said that a psychologist and possibly an OT had talked to him about sex, and Mike thought he had attended a psychology group where sexuality was mentioned. It transpired that Charlie's wife had spoken to the psychologist saying that they were having relationship problems following his TBI and in particular that their sex life had diminished. Immediate suggestions included not spending so much time together which Charlie said helped at first. He thought that they had been offered couple counselling but then:

"She {the psychologist} *said it would be too awkward with me in the room as well and she started doing single ones with X* {his wife} *and then me separate like* (right, okay). *It worked, for a bit then it just went back to normal then."*

(Charlie, p. 28)

When I asked Mike to tell me more about the group, he remembered that it was in fact about confidence. At the time his confidence was low but he was trying to pretend it wasn't so he jokingly asked the psychologist out to dinner.

While sex was rarely mentioned during the rehabilitation process by professionals it was certainly very present for the young men.

"*'Cos there's like a ward, I was on a ward of young boys and you know you could see them all, you could watch (2) like Jimmy over there, he'd be havin' a wank like, Simon there he'd be havin' a wank like, you know you, you'd have a ward full of like teenagers, like 19 year-old boys like (1) and we'd all be playin' with our willies like. That's what a ward is isn't it? You imagine a ward, a ward of men (..hh) who's on there long term, they gonna have to init? They gonna have to masturbate*."

(Luke, p. 44)

Another participant talked about asking to be pushed to the quiet room where he would "read" the Daily Sport. Being invited to elucidate he replied, "*Yeah. I would yeah, have a wank in there*," (Jack, p. 55)

There was a striking contrast between this masturbating in secret, with masturbating publicly and almost trying to provoke a response. He went on:

Par: *"I do remember having a wank, well, not all the way, but masturbating in my bed and then calling the nighno*"

Int: *and then?*

Par: *"calling the nurse (3) and (2) just putting the cover over me and then when she came over and she just said "Jack, that's a hard on"* [smiling. Interviewer exhales loudly] *and I started masturbating again"*

Int: *in front of the nurse?*

Par: *"Yeah (4) and she just said "Jack, what are you like?" and walked off (1). Yeah, I don't think I ever (3) really offended anyone (3). No="*

(Jack, p. 56-7)

There was, for me, a sadness and poignancy about this young man who had been unable to walk or talk expressing himself in this way, and no-one taking any notice.

In the time since their accidents, some of the participants had become concerned about diminished sex drive but seemed to feel that there was no-one they could turn to for advice and that perhaps this was, after all, only to be expected.

Complexity of Relationships & struggling with boundaries

Relationships are not easy, they require considerable hard work to maintain them. They require an ability to 'read' and interpret both situations and the thoughts feelings and emotions of others; and they require the ability to do it quickly, in real time. Not only can these skills be compromised following a brain injury, processing speed can be compromised too. There is also the difficulty in the early stages of talking about what are deemed socially 'appropriate' things; making small talk. A number of participants commented on issues which connect to coping with the complexity of all stages of relationships.

Mike talked about the difficulties of knowing how to get things started:

"*Uhmm well yeah, I mean I'd struggle to instigate things because you can't just errm approach a woman and just (1) kiss or touch them straight away (uh mm). Police tend to frown on behaviour like that (just a bit) uhmm. So like everything's gonna start with a conversation and I just don't feel like my, my mind is working as it should. You know, I would struggle with uhmm striking up conversation. What would I talk about? Uhmm ……. Can't think of nothing [par laughs] (mmm), that's how it would be*".

(Mike, interview 1, p. 8)

The difficulties of how to talk to a woman were reflected upon by Dylan when asked about barriers. He now saw "*chit-chat*", as he called it, as a form of lying and preferred to get straight to the point:

"*ah like, it's just like the speech (right) err I'd say to 'em. It's probably just more like straight the point now (3) How can I put it? I prefer just to say (2) what I want there and then instead of like talking your way into it".*

(Dylan, p. 18)

Disinhibition is not uncommon after a brain injury but I found myself wondering whether having an encounter with death might make you impatient with niceties and social convention. I also wondered if there was an element of him seeing things as they really are without the veneer of social convention. Is this another aspect of sex as an exchange? If I am charming, if I talk to you really nicely and compliment you and say the right things does that make it more likely that you will have sex with me? However, disinhibition causes considerable difficulties for those who experience it. As we talked together about this he went on to say that he felt scared of speaking to girls because he was afraid that directness might frighten them off forever but he was also worried about how he might interpret their intentions fearing that he might erroneously think "*they're taking the piss out of me*" (p. 20) and making the distinction with friends who he would know were "*just having a laugh like*" (p. 21).

Dylan said his mother was very concerned about this problem, worrying that he might get into trouble with a girl's male relatives. She spoke to his psychiatrist and as a result he spent some time taking the drug benperidol which he clearly found very disturbing.

Jack, who was 21 years post-injury and held down a full-time professional job, still encountered difficulties with impulsiveness at times. He talked about how he had noticed that he would sometimes feel driven to say something inappropriate to a woman but discovered that his already compromised speech would desert him completely. He came to view this as a self-correcting mechanism and learned that if his speech went he shouldn't say what he was thinking, however, email was a different matter and "*I've really got to control that myself (yeah) without relying on my speech*" (p. 15).

Luke had met a number of women via online dating sites. He told me that at times he had become quite nasty with a woman he had met, complaining bitterly about those who care for him and that this had led to the break-up of the relationship. He said that he felt very bitter and frustrated over his TBI and the way things have changed for him since then. He added

"*I, I probably come across as all right but if you got to know me and we spent time, then obviously, especially in an intimate relationship (mmm) then obviously that side of my personality would come out then like x x*"

(Luke, p. 7)

This seems to be a significant problem for people who have sustained a brain injury and while work on social skills does happen in rehabilitation, in my experience the focus tends to be on surface interactions with others rather than working at depth.

The issue of making yourself the number one priority also had the potential to cause problems in ongoing relationships and Mike pointed out that since his injury he had become a lot more organised, he now keeps his keys on a particular hook for example, and likes to keep things tidy. Later in the interview he said that a lot of people were pissing him off and he wondered if this would happen if a girl came into his life and his home. He said that he couldn't bear for someone else to make the place untidy or move his things because

"*that would that would frustrate me and that will properly mean the end of the relationship so (3)*"

(2nd interview, p. 21)

While Dylan said quite forcefully:

"*I don't want like a woman well, being in charge of my life (right) yeah because I wanna x x me (mhmm) as far as I'm concerned there's only number 1 and I'm the number 1*." (p. 20).

A number of the young men became confused at times over the use of the word sexuality and took it as a suggestion that they might need to talk to someone about whether they were gay or straight following their brain injury. One participant in particular suggested that he hadn't been 100% sure prior to his brain injury. While most of the participants were pretty clear that they are heterosexual this does raise the question of how concerns over sexual orientation might be resolved, or not, post-TBI given the lack of willingness on the part of HCP to discuss issues.

"I had to do it my own way".

All the young men saw sex as still being important to them either now or in the future and all but one said that they currently have sexual needs. In the absence of any advice, help and support from HCPs they had, on the whole, made their own arrangements to satisfy their sexual needs. It was Jack who had said that ideally the issue should be raised by HCPs but he wasn't really sure what, in practice, they could do to help adding *"I had to do it my own way"* (p. 52).

While most of the young men hadn't realised that their brain injury might cause problems with regard to sexuality and intimate relationships and all had masturbated since TBI, one of the key questions for them post-TBI was whether they would still be able to have sex with a partner – put succinctly, could they still do it? And if they could get an erection, would they be able to maintain it and not experience an orgasm too quickly?

This was especially important for those with physical injuries. When asked what he would have wanted from someone helping/advising him in relation to sexuality Nathan said:

"*I would want someone who could tell me what to do and push me to my limits*".

(Nathan, p. 18)

Later explaining that he literally needed someone to tell how he could overcome his disabilities in order to physically have sex.

Frankie's concern was slightly different

"*I don't mean to be rude or anything but I am wondering how long could I last in bed?*"

(Frankie, p. 32)

Jack had experienced similar concerns the first time he had paid for sex:

"*Uhm I was young at the time, so err being clever I thought 'ah I'm gonna shoot my own, (2) I'm gonna ejaculate too quickly (mhmm) if I don't do something first so before I went I ..hh masturbated and then went and I was lasting longer than she was*".

(Jack, p. 40)

Dylan had visited a sex worker to see if he could still have sex:

"*don't get me wrong, I've done it* [visited a sex worker] *but x enough. Oh bloody hell, it's just like, to make sure I was doing the job like*".

(Dylan, p. 47)

Help From My Friends

In the absence of professionals talking about sexuality and intimacy, it was friends whose advice was sought.

"*I can talk, talk to my best mate Jay, or my mate that I met in rehab, Jack, and we'd talk about girls and stuff*".

(Mike, p. 6, interview 2)

Most of the young men recognised that friends had tried to help even if this had not always been helpful. Friends had sometimes tried to 'set them up' with a partner.

Par: *Yeah, uh, I mean my mates have tried, they tried*

Int: *what try to fix you up with somebody and?*

Par: *Yeah*

(Dave, p. 22)

Friends were also seen to some degree as a possible source of sexual intimacy. Mike had jokingly made the suggestion to a friend that they might get together to see if he could still have sex:

Par: *…. I have said to a friend I like errm I 'cos she, she hasn't had a serious relationship and I haven't had a serious relationship and she's got a kid now so I said well why don't, why don't we be, why don't we be buddies like and errm like we can just call it physio [both laugh]*

(Mike, p. 14, interview 2)

Jack had an ongoing sexual relationship with a married friend whom he described as a "*good friend who sleeps over a lot*". He felt that they were both clear that this was a temporary, mutual arrangement, that this was about satisfying a sexual need but that ultimately what he was looking for was a relationship that met his combined needs for both a sexual relationship and a more permanent, long-term intimate relationship.

Par: *she helps me a lot and (3) her, and one thing led to another and we'd been sleeping together for a while now*

Int: *Mmm, okay*

Par: *but she knows I'm looking for a girlfriend and she says (1) yes, you must*

(Jack, p. 26-27)

Internet & Social Media

Another way in which sexual needs were being met was via the internet and social media. While for some of the participants it was difficult to get out on their own, without exception they could all use computers and mobile phones independently. Even Nathan, who was most physically challenged, was able to access a computer independently and indeed, his mobile phone was his only means of effective communication. Internet access opens up a range of possibilities in relation to sex. It is perhaps obvious that sexually explicit videos & pictures can be downloaded but what was less obvious to me, was the availability of other people online who are willing to share sexual talk and fantasies. It is possible to pay to watch someone masturbate in real time. A number of the participants had met people through online dating sites and some had used such websites to connect with women and had then shared sexual fantasies and sexually explicit images.

Luke illustrated graphically the difficulties this can cause for someone who struggles with the complexities of social interaction. He had met up with a woman he had contacted via a dating website. They had shared explicit texts "*where she had said that she was gonna, like, have sex with me and suck my willie, and different bits and pieces like*" and she had sent him pictures of her feet and her breasts. She had invited him to her house and he had assumed, perhaps not unreasonably, when they started "*fondling and playing*" that they were going to have sex, so he had

"*undone my jeans and got my erection out and I started, I didn't do it to completion like, but I sort of (1) made a joke about it like and I never saw her again either.*"

(Luke, p. 35)

He seemed slightly confused that another woman, who had also sent him pictures of her feet and breasts, wouldn't send him a picture of her vagina. This is a complex area and these young men are negotiating it unsupported.

Sex vs Intimacy

This demonstrates that in some respects sexual needs can be met relatively easily. However, it was striking that although there were lots of comments about not wanting someone to interfere with their lives, all the young men expressed a yearning for a long-term intimate relationship and they seemed to distinguish between a purely sexual relationship and intimate relationships.

Jack talked a lot about how he had met his need for sexual satisfaction, he had previously visited sex workers and was in an ongoing sexual relationship with a friend but he talked about looking for someone who would be his girlfriend. I commented that it seemed as if he was identifying two 2 separate things that were important for him. One was the need to express his sexuality in whatever way was available but the other was a desire for a relationship where sex was part of a whole package. Jack said that he had never thought about it in this way but recognised that this was how he felt.

Nathan also recognised this separation. He was enthusiastic when I talked about the care home that had allowed sex workers to visit residents but went on to say while the advantage of that was that you would get to have sex, a girlfriend

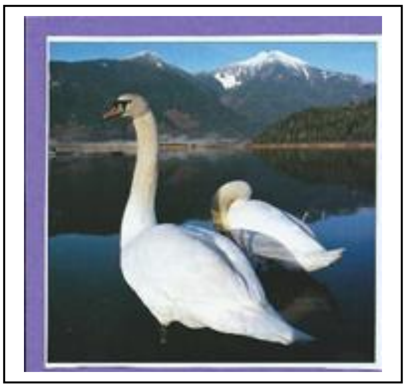
"*would be better because you have someone out to help you through life.*"

(p. 33)

Two of the participants chose a picture of a couple walking hand-in-hand to represent their hopes for the future. Dave chose the picture because "*it looks sort of normal*" and of the life ring he said,

"*well it's safe init…. You know you're safe*" and then "*I like to be sort of like (1) comfortable basically (mm) you know as long as I'm happy and comfortable that's great for me that is*" (p. 43-44).

Luke talked about the couple being in love and the life ring representing something they were working on together to ensure they look after themselves and stay healthy.



Mike chose a picture of two swans saying, "*they're swans, they mate for life don't they?....that's that's that be me hopefully one day that male swan (mm)* [both laugh a little] *I'm looking for someone who's gonna be serious and someone who'll wanna get involved and wanna stick around.*" (p. 21)

He noted that this was different to the way he had felt prior to his injury.

Sex as an Exchange

The idea first struck me when I interviewed Luke and he talked about when he lost his virginity. He talked about having had a 'proper' apprenticeship, earning good money and having a car. Someone told him that one particular girl would have sex with him if he gave her a lift home:

"*So that's what I done like I gave her a lift home, she grabbed hold of my willie and we went up on the mountain and I had sex with her*".

(Luke, p. 16)

It occurred to me that if he had not owned a car he wouldn't have had sex that evening and so I began to think in terms of having the means to have sex or sex as an exchange. This is the same participant who talked about going from an alpha male to an omega male.

This idea of having the means to have sex arose again with Jack who talked about visiting a prostitute when he was in work and earning a salary, he commented:

"*Yeah I know why I did it, because I was earning money. I had money (mm), I wanted sex (2) and if you got money you can get sex*".

(Jack, p. 41)

The comments made by these young men made wonder how far you need to have the means to have sex, or sex is an exchange, if you are not disabled. If you think about the context of dating within sexual relationships, it is not too long before you realise that being taken out to dinner, pubs, theatre trips, being bought presents and complimented may all constitute an exchange and all these things require the means to procure them. I wonder how far a person with the kind of disabilities and limitations frequently found after brain injury might have the means to do this.

A Shift in the Narrative of Time (Core category 4)

From quite early in my work a phrase that came frequently to mind was that the participants had experienced a 'catastrophic event' – but catastrophic in the sense of "a sudden and large scale alteration in state" rather than the definition that has become more common-place in recent times as relating to something being "extremely unfortunate or unsuccessful". The phrase stayed with me but I didn't know what to do with it.

Almost two years after first writing about this phrase, I came across some notes in Charmaz (2014) about an *In Vivo* code "Living one Day at a Time" and its relation to time perspective for her participant Teresa (p. 180). Just as Charmaz (2014) recognises Teresa's cancer and surgery were a significant moment separating her life, so too with my participants the point of the brain injury was pivotal.

My choice of language here is important. Charmaz (2014) uses the words 'significant' and 'separating' in relation to the event in Teresa's life. These words don't resonate for me in relation to my participants. They are not strong enough. I choose the word pivotal because there is a sense of their life turning or pivoting about that point. What comes to mind to replace 'separating' is 'rending asunder'; a powerful, biblical phrase conveying the energy of the moment; the tearing apart of life that I identify within their stories.

Charmaz (2014) identifies the concept of past futures - futures which were dreamed of, planned for and possible before the onset of illness. This resonates with the way my participants talk but again I want to develop the idea.

I noticed in working with these young men that there isn't the continuous narrative flow of past present and future usually present when people recount their histories. When my participants talk, they do talk about past futures – the trajectory they were on before the accident –a place at university; the prospect of earning good money; assumptions about sex, relationships and having a family. Towards the end of his interview Luke talks about how different his life might have been saying he might have got married and had children *"had a normal life really"*. He goes on to say he might have been *"a respected member of society (1) instead of being on the fringes of, of, of society as I am now….." (p. 52)*

As I reflect on this concept of past futures and my own data I realise that their time perspectives have altered further. There are narratives of two more futures and three pasts within the data. There is the immediate post-injury future and the present future. There are the past past; the splintered past and the present past.

The immediate post-injury future, might also be termed the shattered future. It was a future filled with unknowns when the prognosis was unknown. It was a future where you might not walk or talk again; a future where you might not be able to be independent; where you may never learn to go to the toilet or feed yourself. This future was not talked about very much but it seems as if it might have been terrifying and unthinkable. When Jack came round from his coma he would wail because he didn't know who he was or what had happened and he was unable to do anything. Mike and Luke would not even countenance a future where they were unable to walk. For these participants this gradually gave way to the present future, a future which opened up as they recovered but which is very different from the past future of before the accident. For this group, while the present future does seem to hold hope, it seems it cannot be planned for, or perhaps plans can be made but there is no certainty about whether or not they will come to fruition because life itself has become uncertain.

In relation to the past there is the past past, which might also be thought of as the 'normal' past. This is the pre-injury past. The narrative of this past is of a comparatively normal life; a life ignorant of brain injury. The narrative of this past may be held by the injured person or by another who was with them during that time, a parent or sibling.

The second past is the 'splintered' past of the time of the injury and rehabilitation. I have an image in my mind of someone looking into a mirror that has been broken. Hit at a single point, the cracks caused emanating outward from the point of impact, the shards of glass reflecting back an almost unrecognisable image. For these participants this is a time of gaps in memory, sometimes disconnected images or a narrative pieced together from what other people know or have surmised. This period may stretch from sometime before the accident until some point during or after rehab.

Finally there is the present past. This is the post-injury, post initial rehab past when life begins to settle back into some routine and a sense of normalcy begins to be found again. This is a new past of what constitutes normal life post-injury. For this client group, there is not a sense of returning to what was before but a new normal does seem to emerge eventually.

Core Category

From Alpha Male to Omega Male – An Unwanted, Uninvited Individuation

When I began this project my title was the somewhat lengthy:

A study of sexuality and intimate relationships in the rehabilitation of men who sustained a traumatic brain injury (TBI) between the ages of 16-25

Looking back at the original schedule of questions, I think I expected to somehow be able to partition off both the rehab period and the participants' experience of sexuality and intimacy in order to produce a neat, focussed solution to something that I anticipated to be a problem i.e. that sexuality and intimacy were rarely addressed in rehabilitation.

While the research has strengthened the idea that these aspects of being are indeed neglected during the rehabilitation process and beyond, the results are not as circumscribed as anticipated; sexuality and intimacy cannot be partitioned off from the rest of life and I am no longer sure why I ever thought they would be.

Looking through my own experience of being with the participants, my analysis and the memos I wrote as part of the process, I see references to change, to movement, journeying, to loss, to finding the old self and creating something new. Words from the participants that have been very present include determination, single-mindedness, unique, hidden, loneliness. And from me aloneness, cataclysm, catastrophe, rend asunder.

My growing sense was of a journey into a strange unknown land, a land where nothing was as it had been; the rules had all changed. Luke's comment that he had gone from being an alpha male to an omega male connected strongly with this sense and the final block fell into place when my supervisor and I were discussing this transition and the concept of individuation arose.

The term individuation was coined by Jung (1923) in relation to the development of the individual personality and then adopted by Mahler (Mahler, 1963; 1974) in thinking about the transition and separation of the infant from the primary care giver. Adolescence is seen as the second individuation (Blos, 1967). Akhtar (1995) used the idea of a third individuation to describe the experience of immigrants moving to a new permanent country although the term has also been used in other contexts (Colarusso, 1990). The sense of separation and moving to a new, unknown country were such strong undercurrents in my data that it made sense to begin to think of them in terms of individuation, but this is not a normal developmental process, there is no preparation for this individuation, it is not something that can be done with others. This is a wholly unwanted, uninvited individuation in which the very foundations of who you are and what makes you, you, may be utterly and irrevocably changed and yet it is an individuation which must be embraced in order to journey on.

The central categories described above account for different facets of the core category detailing different aspects of the process that the young men have undergone post-TBI and while only one of these categories specifically refers to sexuality and intimacy, they all relate to it through the medium of identity.

In this core category it is possible to see the leap from the concrete phrase uttered by the participant, to the abstract concept developed by the researcher; a concept which embraces and accounts for all the other categories within the data.

Discussion

The position of much of the research in relation to sexuality post-TBI is neatly summed up by Incrocci & Gianotten (2008):

“TBI may change sexual functioning in three different ways: a complete loss of sexual desire, development of sexual dysfunctions, or the expression of deviant sexual behaviour” (p. 312).

The research has tended to use quantitative methods to examine the statistics related to these categories (see Moreno, Lasprilla, Gan & McKerral, 2013 for an overview) and yet this misses so much of the beauty and complexity of sexuality, reducing it to the lowest common denominator of a behavioural function that works or doesn’t, if you want to do it all, and is either within or outside ‘the norm’. With my own research I wanted to move beyond the quantifying of problems and begin to explore the experience of those who have sustained a TBI.

In 2011, when I began my research journey by writing the proposal, the research questions driving this study asked:

What are the experiences of rehabilitation and recovery in relation to their sexuality, of young men aged 18-25 who have had a TBI between the ages of 16-25? How can their experiences inform their carers and interventions in neuro-rehabilitation?

And I listed my aims as:

- Using a qualitative approach, to explore experiences, difficulties and changes relating to sexuality and intimate relationships in men aged 18-25 who have experienced TBI between the ages of 16-25.
- To review any practical and emotional support they have received during the rehabilitation process in relation to sexuality and explore whether it could be improved and if so, how.
- To address some of the gaps in the literature relating to this area.

Over the course of the research there has been a subtle but significant shift in focus. Initially I considered rehabilitation to be the structured period of focussed work aimed at restoring function following the brain injury and I wanted to know what, if anything was done by professionals to support young men in relation to their sexuality and intimate relationships.

However, as the interviews were gathered and I reflected on the data, it became apparent that things could not, and should not be so tightly circumscribed. My hunch that sexuality wasn’t dealt with during formal rehabilitation was correct in relation to my participants but I felt that I needed to take a step back in order to broaden my view and look at their experience and the context within which these issues are located; that a broader approach would facilitate a fuller exploration and understanding of the issue.

This shift might have worried me when I began the research but now it pleases me. I have followed the lead and voice of my participants. I have allowed the data to speak and have worked to hear what it was saying. This is what Charmaz (1990) tells us to expect in qualitative research from her earliest work. Willig (2013) goes further suggesting that “one of the outcomes of qualitative research should be an understanding of what would have been an appropriate research question to ask in the first place” (p. 27) because the researcher cannot know the relevant concepts and language to use in relation to the participants’ experience until the data has been gathered and explored. This is the mark of qualitative research and is particularly important in grounded theory methodologies which were originally conceptualised as a way of developing theory from the data rather than testing ideas and concepts generated in advance of data collection and analysis (Dey, 2004).

The analysis has been a complex co-construction between the words and thoughts of the participants and my own words, thoughts and way of being. The discussion moves the analysis further, developing it and situating it in the context of relevant literature and previous research. Stern (2007) quotes Burton: “… a dwarf standing on the shoulders of a giant may see farther than the giant himself” (p. 123) and goes on to say:

> “When you write up your grounded theory, you may feel like a giant when in reality you are the dwarf; it is because of everything you have read, seen, heard, and felt that you have been able to pull your thesis together. Therefore it is important to situate your work within the body of related literature, both because it’s academically honest to give credit to other researchers, and because you need to demonstrate how you built upon it so that you *can* see further” (p. 123).

Charmaz (2014) exhorts researchers to pursue the constant comparative method beyond the analysis of data and into the discussion using relevant theoretical frameworks and literature to extend the analysis and facilitate further comparisons. With the early literature review having only outlined some of the most obvious literature relating to the field of interest, this is an opportunity to look in depth at related concepts arising from the analysis. Charmaz (2014) continues:

> “Through comparing other scholars’ evidence and ideas with your grounded theory, you may show where and how their ideas illuminate your theoretical categories and how your theory extends, transcends, or challenges dominant ideas in your field.” (p. 305).

Thus within the discussion I propose to explore and develop the categories further through situating them within the extant literature and using that literature to triangulate my own findings. This is particularly important with a small sample where it has not been possible to return to the field repeatedly or to be entirely faithful to the ideal of theoretical sampling.

The discussion begins by exploring individuation, the central concept of the core category, it then moves on to explore aspects of some of the central categories.

From alpha male to omega male: An unwanted, uninvited individuation

The overarching, core category within this study is that of an unwanted, uninvited individuation. This abstract category was developed and elevated to this central position within the analysis because of its ability to account for and contain all the other categories embedded within the data.

Individuation might be defined as a process through which the individual separates or becomes distinguished from those about them. In this section I explore the way in which the process of individuation has been understood in both developmental terms and in relation to migration. I then examine the similarities between this individuation and the unwanted, uninvited individuation identified in this study.

The concept of individuation in psychology was first identified by Jung although as a philosophical concept it was known to Aristotle and Plato (Kincel, 1975).

Jung's understanding of the process of individuation has been described as "the psychological equivalent of a spiritual journey" (Wagenseller, 2012) and points of congruence have been identified with Christian and Jewish mysticism as well as Eastern philosophy (Grevatt, 2016; Drob, 2005; Coward, 1979).

Jung saw the ego as being the conscious part of the psyche which develops from the self (Schmidt, 2016). Jung (1923) describes the self as "the subject of my totality" which includes the unconscious psyche. Individuation is the means by which the individual personality is developed and differentiates from the collective, which Jung defines as being those aspects of the psyche which are not unique to any one individual but which are shared by a people, a society or by human beings in general (Jung, 1923). He states that the collective includes general concepts such as religion, science and the state, as well as feelings and ideas e.g. God, fatherland and justice. Jung (1923) described the individual as consisting of the ego and the self, with the self being an unconscious phenomena that the individual needs to work towards uncovering across the course of their life. There was a clear spiritual, rather than religious, aspect to this process of individuation. Although initially Jung viewed individuation as primarily occurring during the second half of life, he came to view it as a lifelong process involving an inner journey through which the individual reaches their full potential, becoming who they were truly created to be (Wagensellar, 2012; Grevatt, 2016). The process of individuation allows a shift from a position where only the conscious ego is known, to one where the unconscious self becomes more known and more distinctive.

Since Jung's early work on individuation the concept of individuation has become an important one in the field of developmental psychology used to describe specific moments of significant shift in ways of relating to others.

Margaret Mahler adopted the concept of individuation to account for the aspect of infant development which sees the baby become increasingly more separate and autonomous from the primary caregiver. Mahler (1974) viewed the newborn infant as existing in a "twilight state of existence" (p. 89) without the sensory capability to connect with the external world and thus totally dependent on a symbiotic relationship with the mother. Her theory of separation-individuation describes two separate but interlinked processes of systematic growth through particular stages that lead to what she termed the "psychological birth" of the infant as one who recognised his/her separateness from the mother and emerged as an individual from the symbiotic state of early infancy. Blom & Bergman (2013) describe Mahler's concept of object constancy as the hallmark of a successful separation-individuation process. While never perfectly achieved, this is the point where the child has developed a consistent predominantly benevolent, internal image which provides the same sense of security to him/her as the real mother had. They highlight that embedded within this is self-constancy where the self is experienced as consistently unique and separate regardless of the level of intimacy being experienced.

While Mahler has had her critics, particularly in relation to her sometimes confusing choice of language to describe the separation-individuation process (Tyson, 2004), recent empirical data have also cast doubts on her assertions about a period of “normal autism” in early infancy i.e. a supposed lack of responsiveness to sensory stimuli and about the lack of memory capacity in the early months of life (Brandell, 2010), however, these authors also acknowledge Mahler does provide a useful framework for understanding infant development and there is a degree of congruity between her work and that of currently more popular theories such as Bowlby’s attachment theory (Tyson, 2004; Brandell, 2010).

Blos (1967) further developed the concept of individuation and used the term “second individuation” to describe the whole period of adolescence, recognising the shift in orientation from dependence on the family to a focus on the individual’s place in wider society as mirroring, although not identical to, the first individuation from mother-infant duality and symbiosis, to separation and the emergence of an individual character (Bendicsen, Palombo, & Koch, 2009). He regarded the second individuation as a pendular process requiring both regressive movements as well as progressive ones in order to achieve the necessary maturation. Crucial to this maturation is disengaging from the parental ego as a framework for or extension of the adolescent’s own ego which has up until this point been available to extend his or her own ego structures. This functions to help control anxiety and regulate self-esteem (Blos, 1967). While disengaging from this parental support is what ultimately facilitates the development of the mature ego, it does leave the adolescent ego temporarily weakened.

Blos does not seem to have borrowed the word “individuation” from Jung but was certainly aware of Mahler’s use of the term in her theory of development (Bendicsen, Palombo, & Koch, 2009). Blos viewed the transition phase of adolescence as being rooted in a healthy latency period although the onset of the psychic development of the second individuation was viewed as commencing with the onset of puberty.

Blos (1967) described the tasks of the second individuation as “the shedding of family dependencies, the loosening of infantile object ties in order to become a member of society at large or, simply, of the adult world”. That is, in order to facilitate finding love objects outside the birth family, the adolescent must successfully disengage from the internalised infantile objects that enabled him or her to establish “a stable sense of self and the capacity to relate to others” (p. 179. Colarusso, 1990). Blos (1967) viewed both the first and second individuations as having “in common a heightened vulnerability of the personality organization” (p. 163). This bears a striking similarity to some of the descriptions of the processes of adolescent development described by those researching social cognitive development e.g. Sebastian 2012.

The concept of separation-individuation was subsequently further developed with a focus on the role within adult development. Colarusso (1990; 2000) theorised a third, fourth and fifth individuation to account for the experiences undergone during early, middle and late adulthood. While agreeing with Mahler that the early separation-individuation experience of infancy provides a foundation for all future relationships, Colarusso (2000) asserted that the later separation-individuations are not merely a recapitulation of the first individuation but that the issues of closeness and separation can only be understood within the context of the complex primary relationships of adulthood e.g. spouse, co-workers, children etc. The third individuation takes place in late adolescence/early adulthood and, as described by Colarusso (1990) encompasses the move to sexual maturation and biological parenthood being built on the second individuation and the independence achieved there. This third individuation moves to ameliorate the intense intrapsychic loneliness which results from the disengagement from being able to "rely on the real parents or their diminished intrapsychic representations for emotional sustenance, guidance, and direction" by developing new deep relationships founded on the increased capacity for intimacy developed during the second individuation and may lead to the formation of a "family of procreation".

Colarusso's (2000) fourth and fifth individuations encompass the tasks of middle and older age; the redefinition of self as the position within society and the family shifts, loss of parents and the change in relationship with children as they themselves become parents; growing awareness that the ultimate separation of death comes ever closer and the focus on future generations and the desire to fuse with loved ones through the legacy that might be left through sharing one's wisdom and possessions (Colarusso, 2000).

These five processes of separation-individuation might be viewed as an expected series of life-course transitions, however, when a TBI occurs to a young man there is a profound disruption of this developmental trajectory.

Akhtar (1995) recognised the power of the concept of individuation and used it to describe a different sort of developmental journey, that of the migrant from his/her country of birth to their adopted country.

Akhtar (1995) chose to use the concept of individuation to describe the psychological processes undergone post-migration because he asserted that the culture shock experienced by the migrant, coupled with the ensuing mourning for all that had been lost in relation to the homeland and native culture, disturbs the migrant's sense of identity to such a degree that it creates a "state of psychic flux, reminiscent of the 'second individuation process of adolescence'" and also echoes the original separation-individuation phase of infancy (Akhtar 1995). However, like Colarusso (1990), Akhtar also emphasised that his use of the term individuation does not signify a recapitulation of the childhood processes but rather a significant "adult life reorganisation of identity, a potential reworking of consolidations in this regard and a semi-playful extension of a useful psychoanalytic metaphor" (p. 1053).

Akhtar called his individuation the 'third individuation' and openly acknowledges within the seminal article (Akhtar 1995) that, having named his concept thus, he was advised that the phrase had already been used to name the separation-individuation challenges associated with becoming a parent. Akhtar decided to retain his title for the reasons set out in his paper.

Within his paper Akhtar outlines the factors affecting the outcome of migration and subsequently describes four facets of identity change in migrants. The first is a move "from love or hate to ambivalence" towards the new homeland and culture. This represents a move away from the splitting of self and other objects associated with the move into oppositional loved or hated concepts, to a more settled, whole object representation, as the country of origin and the new country cease to be perceived as either wholly good or bad and more realistic, balanced representations are formed.

The second facet, “from near and far to optimal distance”, relates to both the external reality of the distance from the ‘motherland’ and also to new acceptable boundaries that the migrant has to negotiate in terms of physical, social and psychological space in the new homeland.

Next, “from yesterday or tomorrow to today”, describes the repair of the “temporal fracture in psyche” (p. 1065, Akhtar, 1995) of the migrant who may initially long for the “lost paradise” of his country of origin and yearn for the better times which will occur “someday” in the new land. Again, the gradual synthesis of these positions together with the formation of more realistic object representations leads to the possibility of living more fully in the present.

The final facet is that of “from yours and mine to ours” which describes the process whereby the familiarity with and assimilation of the new culture and moral values leads to development of new ego and superego boundaries which facilitate the possibility of moving from the split ‘yours and mine’ position to a position where the new culture can be perceived as belonging to the migrant as much as to those who are already there and alongside the old culture – an ‘ours’ position.

In the current study, as previously stated, I was frequently struck by threads of ideas relating to changing and being different, yet somehow staying the same; of movement or a journey from one way of being to another; of having no choice about when and how those changes were initiated; of waking up and finding yourself a very different person, in a very different set of circumstances, almost a sense of being in a new and unfamiliar land.

The concept of individuation accounts for some kinds of separation: the separation of the infant from the primary caregiver to facilitate becoming a more autonomous individual; the separation of the adolescent from their family of birth to facilitate the move towards independence as an adult; the separation of the migrant from their country of birth in order to forge connections with their new homeland and, for Jung, the separation of self from ego, the individual from the collective. In each case the individual is catapulted into a new and unfamiliar territory which must be successfully negotiated and in each case, the potential for what Blos (1967) called a heightened vulnerability of the organisation of the personality can also be identified.

In the same way as the infant, the adolescent and the migrant, a process of accommodating the often overwhelming, catastrophic changes following TBI must be negotiated in order to facilitate the person who has sustained the brain injury to emerge from its shadow to live and grow again. There are strong similarities between the facets of Akhtar’s (1995) process of individuation for the migrant and the process seen in the participants of the current study post-TBI.

It would seem almost inevitable that, where sufficient memory of life pre-TBI remains, splitting will occur and the evidence from data in this study would certainly seem to support this. Participants expressed a longing for their ‘old’ lives and, particularly in the immediate aftermath of the TBI, the ‘new’ life compared unfavourably to it. This is reflected in many of the categories that were constructed from the data e.g. wanting my old life back; loss of voice; changes in body. In much the same way as the migrant may idealise the life and culture of the homeland these participants were perhaps unsurprisingly likely to idealise their former lives.

For those outside the situation, it may be difficult to see how it would be possible to do anything other than split off the old, idealised 'good' self from the new traumatised, post-TBI 'bad' self and yet these participants were showing signs that they had certainly begun the process of synthesising these two aspects of their lives and being. This is particularly seen in categories which indicate that some aspects of personality/self has stayed the same and that there have been areas of growth and positive change.

Achieving this synthesis is vital to ensure psychic stability. Akhtar (1995) asserts that the vulnerability to splitting of self and object in the immigrant reflects Mahler's rapprochement phase of the first individuation and the regressive movements of the adolescent in the second individuation.

Mourning is an important aspect of the process of individuation for migrants, particularly in the facet of moving from love to hate but also to facilitate the repair of the temporal fracture which facilitates the move into being able to live in the present (Akhtar, 1995). Shifts in time perspective and the place of loss are also important in the experience of the young men who have sustained a TBI and are discussed later. This suggests that mourning/grieving may be an important part of coming to terms with TBI and yet support to be able to do this successfully does not seem to be generally available for these young men. None of the participants in this study seem to have had access to psychological support that focused on loss, grief and moving on. My own experience in both inpatient and community rehabilitation was that this was rarely available and this is also supported by other evidence (Lowe, 2015; Kinsella, Walsh & Muldoon, 2015). The losses associated with brain injury are particularly complex and a section of the discussion has been set aside to consider them.

Increasingly I have come to understand the post-TBI journey as another form of individuation.

Apart from Akhtar's third individuation, the other theories of separation-individuation have a common thread of being related to life course development. Akhtar's individuation, like the individuation proposed in relation to the post-TBI experience and explored here, refers to a special set of circumstances outside the generally predicted pattern of growth and development seen across the life course. However, what they all have in common is the need to negotiate a new, unknown landscape (Gulina, 2017, private conversation). The infant must learn to relate to others without the physical presence of the mother; the adolescent must learn to negotiate life without the scaffolding provided by the parental ego; the young adult must find a way to fill the resulting psychic void and eventually may take their place as a parental figure; the older adult must adapt to the changing landscape of life and their position within the family and community, eventually coming to terms with facing the ultimate separation which will manifest with their own death. Finally, the migrant has to negotiate both external landscape of the new country and the unknown intrapsychic landscape that accompanies it.

One model for understanding the post-TBI experience of the young men who participated in this research is to think in terms of an unexpected, unpredictable individuation that disrupts the separation-individuation of the normal life course and catapults them onto a different trajectory. For many of these young men the TBI has happened at the time of expected transition from the Blos' (1967) second individuation to Colarusso's (1990) third individuation. The TBI precipitates a regression from increasingly complex networks and relationships beyond the family of birth, which lead to the possibility of genuine intimacy and becoming intra-psychically anchored to others in place of their real parents or their intrapsychic representations (Colarusso, 1990), to being thrown back onto the support of that family or a small group of focussed carers. This severing of the second and third individuation opens up the possibility of the new trajectory of engaging with the unexpected, unpredictable individuation which might be seen as having parallels with Akhtar's (1995) third individuation. It is an individuation in which loss and mourning hold a more prominent position because of the ambiguous losses it entails, including the loss of the expected third individuation.

A brain injury isn't generally part of the life course; as previously discussed it is a shocking, catastrophic event that shifts the landscape of a person's life. Somehow, when the dust has settled, sense has to be made of the events and their aftermath and the losses incurred. The way in which that sense is made and the course and outcome of that process of sense making is unpredictable and dependent on many, many variables including the nature of the injury sustained; biological factors; the medical and rehabilitation support; family and social support; the personality and social and developmental history of the person sustaining the injury and the complex interactions between all these factors. It is a significant change and to quote Volkan (1999) "People cannot accept change without mourning what is lost to the past. Whether the loss is of a homeland, as it is for immigrants or refugees, or of a person or thing, the process of adapting to life after loss is necessary and sometimes complex." (p. 169)

There are many facets to the process of this unexpected, unpredictable individuation and these are illuminated by close examination of the other categories, which I have called the central categories, which have emerged, been developed and co-constructed from the data. These central categories are: I felt like I was sinking at times – wanting my old life back; the aloneness of TBI; a wasteland of intimacy; a shift in the narrative of time.

I felt like I was sinking at times – wanting my old life back

Throughout the interviews the participants expressed a yearning to get their old sense of who they were back. This section examines some of the factors which may be associated with that yearning.

The Place of Memory

Many of the participants in my study had memory problems following their TBI, however, there seemed to be something else troubling them which related to a sense of both being the same person they had always been and yet also being different. After reviewing the concept of the SMS I will look at the way in which this may be associated with the experience of the participants in this study.

In a comprehensive paper, Conway (2005) describes not only the neurobiological foundations but also the conceptual underpinnings of a cognitive system he calls the "Self Memory System" (SMS). He argues cogently that this system is fundamental to an individual's formation and maintenance of a sense of self.

In the paper Conway provides intricate theoretical models to account for the way in which episodic and autobiographical memory interact to create the SMS and gives a detailed account of the neuroanatomical basis of the SMS. Whilst this makes it obvious that memory might be affected by a head injury due to the physical insult to the brain, and indeed there is copious evidence to support this (Headway, 2016; Hannay, Howieson, Loring, Fischer & Lezak, 2004), what is most salient in relation to the current study is the way Conway draws out a more abstract, esoteric understanding of the way in which this might impact an individual's sense of self.

From the earliest days of the study of psychology, as detailed by Ownsworth, 2014; Conway, 2005, memory has to be recognised as an important component of the self, providing the necessary continuity that allows a person to understand that in some way they are the same as they were yesterday and will be tomorrow. The concept of the SMS originated in the work of Conway and Pleydell-Pearce (2000) and arises from the intersection of two principle, independent components, *the working self* and *the autobiographical memory knowledge base*, which can interact to create specific autobiographical memories that build a comprehensive knowledge base which forms the foundation of an individual's concept of self and supports long term goal planning congruent with that self.

They describe the autobiographical knowledge base as consisting of three components which reference different levels of specificity: lifetime periods; general events and event-specific knowledge. These components interact to facilitate recall of particular autobiographical memories. The working self can be described as a goal-driven, internal model that modulates cognition, including memory, and thus directs and inhibits behaviour to conform to a model or understanding of the self (Conway and Pleydell-Pearce, 2000).

This concept of cognition being goal driven is not a new one. Both Ownsworth (2014) and Conway (2005) refer to the idea in William James' seminal work *Principles of Psychology.* Rapaport (1961) in the classic text 'Emotions and Memory' refers to number of early psychologists, including Uexkuell and Dewey who all suggested that memory far from being an exact record of what actually happened, is influenced by perspective. Rapaport himself asserted that not only are memories integrated into an individual's personality they are revived in accordance with the needs of the personality.

Conway uses these aspects of memory to develop the rationale for, and expound the nature of the SMS in his later (2005) paper. He bases his conceptual understanding of the system on Russell's distinction between coherence and correspondence in relation to theories of truth within philosophy.

Conway (2005) argues that coherence is a process by which memories are made to fit or be "consistent with an individual's current goals, self-images, and self-beliefs" and acts at all stages of encoding, retrieving and re-encoding memories. By way of explanation he refers to the work of Hastorf and Cantril which showed the way that football fans remembered the way their team play a football match as being consistent with their view that the team was highly skilled and sporting, in spite of the match having in fact been very physical and unsporting. Ruptures or violations of coherence are seen as an indication of psychological illness.

Memory also needs "to correspond with experience" this is extremely important for learning and to ensure the survival of the species but it is necessary to do this efficiently and without overwhelming the system with unnecessary detail. Coherence and correspondence are presented as competing demands on the cognitive system and one of the fundamental principles of the way in which the SMS works is to create a compromise "between the separate but competing demands of coherence and correspondence" (p. 596). Perhaps an illustration of this might be to think about the way in which someone who considers themselves to be an excellent driver might think about a crash that they have had. They remember the incident but may create a narrative around it and about how other factors such as the weather or other drivers caused the crash thus retaining their own sense of being a good driver.

This concept of the SMS may have profound implications for young men who have sustained a TBI. This concept of the SMS may have profound implications for young men who have sustained a TBI and seems particularly relevant for the participants in this study. All the participants had memories of being fit, healthy, capable, independent young men and this no longer fitted with who they were perceived to be or who they saw themselves as post-TBI? This made me question how this dissonance is resolved and what the potential problems might be if it isn't?

It is Conway's underlying concepts of coherence and correspondence that I assert are so crucial to the sense of self post brain injury and while it is clear that a brain injury can impact on the biological aspects of memory, literally taking parts of it away or preventing the formation of new memories, it is also important to consider the potential esoteric impact of such an insult even when the organic foundations remain undisturbed. Coherence and a sense of continuity are thought to be powerful factors in the maintenance of a sense of self. Post TBI, even when memory remains organically all but unaffected it is possible that coherence can be torn apart and a sense of continuity of self disrupted which may have significant repercussions for the injured person.

Self and Identity

The issues arising from this research in relation to staying the same and yet being somehow different and the concepts of coherence and correspondence in memory clearly map directly onto ideas relating to the self and identity which are explored here.

The concept of the self is complex and there may different ways of understanding it (Hollan, 1992). In a helpful introduction to the concept of the self and self-identity Ownsworth (2014) provides a concise overview of the philosophical and psychological history of the concept, highlighting that as early as classical times Aristotle asserted that there is a core essence of every person and asserted that both self-knowledge and relationships with others were crucial to an understanding of the self.

Markus and Kitayama (2010) define self as 'the "me" at the center of experience'. They view the self as constantly changing and developing under the influence of both biology and environment, including culture. They argue that an individual is shaped by and a shaper of their immediate environment; that no self can develop in isolation or exist without a context. The self is always situated and develops "through symbolically mediated, collaborative interaction with others and the social environment" (p. 421). The way in which context influences the development of self leads to differences in behaviour and cognition across cultural milieux.

The concept of loss of self is one that can be identified readily within much of the literature on brain injury and has often been recorded as a central feature of the post injury experience

(Myles, 2004; Nochi, 1998). However, there are some researchers who have argued that it was not a significant aspect of their data (Medved & Brockmeier, 2008).

Within my own data, my sense was that neither position told the full story. Life is complex and the data from both my own study and others (Beadle, Ownsworth, Flemming and Shum, 2016; Gelech and Desjardins, 2011), suggests that it would be naïve and perhaps overly simplistic to expect that post-brain injury life will either be a disaster, with a totally lost or shattered self, or a triumph over adversity where a new courageous self emerges from the ashes. In a comprehensive, systematic literature review Beadle, Ownsworth, Flemming and Shum (2016) found that although the majority of studies suggested that the impact of TBI on identity was predominantly negative, there were also some factors which were not perceived to have changed e.g. friendliness and optimism, and some which were seen as having changed positively e.g. being more mature and becoming more appreciative.

As with the present study, Gelech and Desjardins (2011) also struggled with the dominant narrative of the lost or shattered self but found narratives that present a stable, enduring sense of self which persists across the experience of severe trauma or chronic illness equally problematic. They too identified within their data a dissonance between a continuing sense of self and a significantly changed sense of self.

Gelech and Desjardins (2011) accept a view of the self as constructed through interactions with others and with the symbols, signs and systems of meaning found in the context within which that self is located; a view consistent with Markus & Kitayama (2010), the social-constructionist approach of this current research and with the view of self expressed in the earlier work on PTSD, culture and the self in this portfolio. It is a stance which perceives the self as being “under continuous reconstruction in light of new connections and interactions with others” (p. 63).

Gelech & Desjardins suggest that there are in effect 2 selves available, a public self and a private self. They argue that it is the public self that changes and is seen to change after a profound experience such as TBI but the private self, the core of who I am, is perceived as remaining the same. This may account for some of the tension I identified between a separation from self and so much that contributes to the notion of self, and the idea of there being some sort of continuity/stability. This model of a public and private self very much resonates with comments from my participants along the lines of “I’m still the same person” while accounting for the comments they also made which illustrate that change has occurred.

Gelech and Desjardins (2011) suggest that post-TBI the injured person’s links with society are radically changed and it becomes very difficult to form relationships. This connects with my participant’s comment “I don’t know anymore the right sort of people”. It also connects with Conway’s work because it is the public self where the most significant rupture of coherence seems to be experienced.

This important paper also talks about the way in which this group has their rights compromised:

“paradoxically, it is the modern concept of the person associated with contemporary human rights in the West (a predominantly egocentric view of the person as autonomous and independent) that leads us to dehumanize this group and to suspend some of their fundamental rights" (p. 70).

The priorities in formal rehab for my participants were all around things that would make these young men independent walking, talking, self-care etc., all the things that contribute to that prized Western independent self. I wonder if the single minded focus on rehabilitation seen in these young men and their striving to make themselves the number one is part of an attempt to reclaim that prized western autonomous, independent self that was so much a part of their former public self.

Loss

As stated in the analysis, the concept of loss was one which I anticipated finding within the interview data, however, interestingly, although it was anticipated it was not something I explored in the initial literature review and preparation. Although I was initially unsure whether to include it, as a category within the research, quite simply, in spite of the ability to fractionate it, it makes sense as a category and this is an important factor in assessing the quality of qualitative research. Any single story of loss or triumph over adversity seems too simple to reflect the complexity of what is happening in the lives and experience of these young men and this category reflects that complexity.

In clinical terms loss and grief have held a central place within the canon of psychotherapy since its earliest times e.g. Freud's 1917 paper, Mourning & Melancholia (Freud, 1989). Much of the more recent literature on loss has been in relation to bereavement and strongly influenced by Bowlby's work on attachment. Models have included Kubler-Ross' (1973) five stage model, Parkes' four phase model (Worden, 2010), Worden's (2010) four task model and Stroebe & Schutt's (1999) dual process model of grieving. Each of these has presented the process of loss and bereavement as a series of stages which need to be negotiated before returning to a so called normal life, although Stroebe and Schutt's (1999) model does talk about oscillation between loss and restoration oriented coping.

Not all grief is related to loss of a person through death, however, and whilst it is attractive to think in terms of a process which needs to be negotiated this does not sit entirely comfortably with the kind of losses that have become apparent in the significant changes which occur when one develops a disability in later life and loses what might be called the former life. Yates (2003) gives an informative overview of the literature on psychological adjustment after brain injury. He refers to Wright, who almost 60 years ago suggested that adjustment to disability was influenced by emotional maturity, self-acceptance, values system, mental health status and the interaction between these factors. Yates (2003) goes on to acknowledge the role of stage or mental health models, such as those mentioned above, social cognition models, and, unusually in the psychology literature, the social model of disability. This sits well with the idea of a need for negotiating mourning and loss related to brain injury within a broader process of individuation suggested here.

Pauline Boss (1999) developed a theory which she calls the Theory of Ambiguous Loss. The theory emerged from her work as a systemic family therapist in the mid 1970's (Boss, 2004). Boss' theory proposes a model to account for loss where no bereavement is involved, where there is no death. She asserts that the theory is needed to account for the emotional and psychological processes people go through at times of significant but unclear loss. Boss' dual aspect model asserts that an ambiguous loss is said to have occurred where a loved one is physically present but psychologically absent or, conversely, psychologically present although physically absent (Boss, 2010). Two cases can clarify these circumstances. The first scenario, where the individual is physically present but psychologically absent is clearly illustrated in the case of a family member, say the father, who develops dementia. Here the family copes with a situation where the man is still physically present in their lives but gradually becomes increasingly psychologically absent. The person with dementia might begin to forget things; an organised person might become unable to plan or execute tasks that would have previously been simple for them; they may cease to recognise people and places and not remember recent events. The family may also experience distress over anticipating or not knowing what will be lost next and the fear of not knowing if it will happen to them. The person is still a part of the lives of those around him but is somehow changed, no longer the same husband, father, grandfather they knew, and yet at the same time, is also still that person. The second case, where the loved one is psychologically present while physically absent can be illustrated by cases where someone goes missing but a body is never found e.g. a soldier who is deemed missing in action. In this case the family or loved ones keep that person psychologically alive because they may reappear, the soldier is still considered the father, husband, lover, and the hope continues that he will return one day. There are of course many other scenarios where this applies e.g. when a child goes missing, where people are lost in natural disasters, in the aftermath of 9/11 (Boss, 2004), or, as was seen recently, where a flight disappears without trace (Boss, 2014).

Boss describes Ambiguous Loss as an externally caused relational disorder, which is at once both traumatic and unclear. She also describes it as an "*uncanny* loss" (Boss, 2010, emphasis in the original) i.e. a loss that is confusing and incomprehensible. Unlike the loss of death, with ambiguous loss there is no possibility of closure.

This theory is clearly very useful in understanding the loss endured/process experienced by family members of someone who has sustained a TBI (Kean, 2010; Giovannetti, Cerniauskaite, Leonardi, Sattin & Covelli, 2015). It is clear that when a person survives a brain injury their loved ones undergo a complex process to try to come to terms with what has happened. Relief at survival may quickly turn to despair as the level of injury sustained is realised and a new way of living is negotiated. Even where a comparatively mild brain injury is sustained there may be sense that, even after an apparent recovery, the injured person is somehow no longer the person they were (Landau & Hissett, 2008).

While ambiguous loss is usually talked about in relation to a person who would be counted as bereaved if a death had occurred, there have been some tentative suggestions in the literature that those sustaining the injury or developing a chronic condition may themselves experience a form of ambiguous loss. Boss & Couden (2002) mention that people who develop chronic illnesses may experience ambiguous loss because "They are here, but no longer as they once were" (p. 1352), however, the main focus of the article is on the ambiguous losses experienced by the family unit. Kreutzer, Mills & Marwitz (2016) conducted a comprehensive review of the theory of ambiguous loss as applied to TBI and although they found an extensive literature on ambiguous loss, identified only four papers where ambiguous loss was explored in the context of adult TBI. In the most part these papers explore ambiguous loss from the perspective of the family and caregivers although Godwin, Chappell & Kreutzer (2014) identified four distinct types of ambiguous loss in the context of couple relationships: the loss of you, me, us; loss of security; loss of connectivity and loss of future. In each case these types of ambiguous loss were said to pertain to both the survivor and the caregiver although the emphasis in the article seems to be on the caregivers' perspective with only 2 of the 9 quotes relating to ambiguous loss being from survivors and their perspective is not explored in any depth. Throughout the article there seems to be a privileging of the caregiver's perspective.

Although the theory of ambiguous loss arose from a family systems perspective and seems to have proved very useful in the context of understanding a variety of complex losses, I would argue that this can now be extended to facilitate understanding of loss endured by an individual in relation to themselves and propose that the concept of ambiguous loss can be developed and extended into 2 distinct categories: systemic or interpersonal ambiguous loss and intrapersonal ambiguous loss.

The term systemic or interpersonal ambiguous loss is used to refer to the type of ambiguous loss so thoroughly and articulately described in Boss' work (2004, 2007, 2010) where one person is lost either physically or psychologically to another, creating confusion and where there is no possibility of closure or of the situation being resolved.

The new term I am proposing, intrapersonal ambiguous loss, would be used to describe my newly proposed concept of losses and individual experiences in relation to the self. The sense of change and loss experienced by many people with acquired brain injury (ABI) where they may feel like themselves but changed, or the loss of the sense of self due to the many physical, psychological and social changes resulting from brain injury, would fit into this new category of intrapersonal ambiguous loss.

It may also be that within the category of interpersonal ambiguous loss there are in fact intrapersonal ambiguous losses which coexists alongside the loss of another person either physically or psychologically. Boss refers to role ambiguity in each of these cases e.g. is the partner of a woman with a significant brain injury still able to regard himself as a husband and lover if his relationship with her has significantly changed because he now has to provide personal care, watch her constantly and is unable to share significant decisions with her; similarly as time goes on and the missing soldier does not return how does how does his wife define herself? How is she viewed by other military spouses and her social circle? As the child of the person with dementia increasingly parents their parent, how is their role as a son or daughter affected? In each of these cases the roles that are impacted are often central to the sense of self of the person experiencing the loss and thus the losses are both interpersonal i.e. in relation to who the lost person was and what they meant, and intrapersonal i.e. having a direct impact on the identity of the one who is grieving.

The Aloneness of TBI

This is one of the central categories in this research and encompasses categories such as the being removed or separated/ loss of connectedness; the uniqueness and hiddenness of TBI and not knowing anymore the right sort of people. Many similar themes have been identified in other research papers. Sander & Struchan (2011) identify social isolation as one of the most profound changes for people following a TBI with both immediate and long term impact on friendships and marriages (Burridge, Williams, Yates, Harris & Ward, 2007; Salas, Casassus, Rowlands, Pimm & Flanagan, 2016).

Loss of connectedness

In a recent paper Salas, Casassus, Rowlands, Pimm & Flanagan (2016) undertake possibly the first examination of friendship from the perspective of those who have sustained a TBI. They undertook a thematic analysis of interviews with 11 survivors of TBI which focused on their experience of friendship and social isolation during the post-acute phase. They identified four main themes arising out of the data: the impact of long term cognitive and behavioural problems in social interaction; losing old friends, they could not handle the new me; difficulties making new friends, outsiders and the loss of normality; relating through sameness, you need to make friends who have had similar problems.

This paper provides an important source of triangulation for the current research with properties of three of the themes mapping on to categories identified within this research. Within the first theme mentioned by participants in the Salas et al., (2016) paper participants talked about the impact of cognitive and behavioural difficulties on friendships, with cognitive difficulties being seen as particularly problematic. This is reflected in the current research with difficulties such as poor motivation, communication difficulties; the ideas around the hiddenness of TBI and those related to a desire for understanding from a partner.

The second theme, the loss of old friends, is also represented in some ways in this present study. Some of the participants mentioned both losing friends and losing partners they had at the time of the injury. Sometimes this was because they couldn't cope with the 'new' post-TBI person e.g. girlfriends who left when they were told the extent of the injuries, but sometimes it was the person who sustained the brain injury who felt that they no longer fitted in e.g. Charlie feeling that his old friends were too immature, however, there was also a sense of some of the friends having naturally moved on by going to university or moving away for work, something which is quite natural within this age group. This concept was explored in the category of no longer knowing the right sort of people.

The theme around difficulties in making new friends, particularly potential intimate relationships is also reflected in categories in the present study. In the Salas et al., (2016) paper there is talk of insiders and outsiders (in relation to TBI). This sense is also seen in the current research being felt in categories around being removed and separated and in the conversations around the difficulties faced in getting a girlfriend, being put into the friends' zone and not knowing the right sort of people anymore.

The final theme of relating through sameness is not reflected so strongly, although some participants mentioned that they thought they might now go into a relationship with someone with a disability. In some cases there was a sense that rehab and being involved with a brain injury charity stifled opportunities to meet other people. This was overtly expressed by Frankie "they only think they are reintegrating you into society" and more subtly by others, including Nathan from whom I had the strong sense of a world that had shrunk to encompass only his family carers and other disabled people. Salas et al., (2016) highlight that their cohort of participants was recruited from a particular therapeutic milieu that works specifically to break down social isolation through encouraging survivors of brain injury to socialize together so this theme may be a particular product of their experience.

All of this also fits with the concept of going from alpha male to omega male and may be triangulated with the words of a participant in the Gelech & Desjardins (2011) study who said:

“Friends just don’t happen for me no more . . . . Before my brain injury, you ask who was on the “A” list all the time in the social things, well, I was in there and now I’m not. Now I’m on the loser end of things. I dunno what it is, but they’re not interested at all. (Tom)” (p. 66-67).

One of the factors that was particularly striking in the current study was the way in which the all-consuming nature of rehabilitation acts to separate the participants from everyday life and people. The profound impact of the changes in brain function, the behavioural concomitants of this, and in some cases, the physical injuries means that rehab almost has to be all-consuming because of all the relearning that has to be done in order for the injured person to be able to function well independently. However, conducting this research has made me question whether this whole-hearted focus on independence does lead to something being missed. Perhaps there also needs to be rehabilitation and learning concerned with relating to others? This might be conceptualised as 2 factor rehab – one focussing on the practical everyday living tasks and then another focussing on the higher order cognition and relational aspects living. Similar suggestions are beginning to be made by others, perhaps most prominently by Giles Yeates and colleagues (Yeates, 2014; Bowen, Yeates & Palmer, 2010) who propose that a social cognition and relational approach to rehabilitation would be most helpful. This has important implications for research, little of which has been conducted in this area to date (Yeates, 2014).

Finally, the idea of having to ‘do it my own way’ is an important one within this journey through the unfamiliar landscape of this unwanted, uninvited individuation. The sense of aloneness is perhaps compounded by the sense of uniqueness of the injury, of no-one, including the professionals, really being an expert on their particular brain injury and of no-one really understanding their experience.

Masculinity and Disability

Closely aligned to issues of self, identity and loss both visible and ambiguous, are issues around disability, and for this group, masculinity.

Disability is a complex area of study in its own right and thus it will not be possible to give more than an overview as it relates to masculinity and sexuality.

Under the Equality Act (2010) a person is classified as disabled if they “have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on [their] ability to do normal daily activities”.

Disabled World (2010) defines no fewer than 11 models of disability including the moral model, the tragedy model and the market model. Perhaps the two models which have been most frequently used to understand disability are the traditional medical model and the social model of disability.

Broadly speaking the medical model has tended to view disability as a problem to be fixed, has viewed that problem to be located within the individual, and has resulted in the segregation and exclusion of disabled people by society. In contrast the social model has seen society and the way in which it views and treats disabled people as the problem (Beaudry, 2016). It distinguishes between impairment, which is physical, and disability, which is social (Shakespeare, Gillespie-Sells & Davies, 1996). In other words, prejudice and oppression within society are the primary problems rather than any physical impairment an individual may have (Beaudry, 2016).

What is masculinity in the 21st century? Most of the participants in this study come from what would have traditionally been considered working class areas of the UK and the majority from an area that had until comparatively recently been a centre of heavy industry. Within the interviews some of them talked about how their understanding of masculinity had changed post TBI. For most of them being able to be the breadwinner was important, some talked about how their masculinity had been expressed through spending time with their mates. Manual work was seen as a male domain and men were viewed as generally having a high sex drive. Their pre-TBI views of masculinity very much conformed to what has been termed “hegemonic masculinity” a term which emerged in the 1980s and defines, not the majority enactment of masculinity but the masculinity that is normative; embodies the most honoured way of enacting masculinity within a society; requires all other men to position themselves in relation to it and legitimises male domination of women (Connell & Messerschmidt, 2005). Not conforming to this socially sanctioned concept of masculinity leads to an “othering” of those who do not meet its demands (Shakespeare, 1994: Barrett, 2014).

However, since the 1980s, there has also been a growing recognition within the literature that in reality there is no “static, singular male gender identity, but rather in the plural form of “masculinities”” (p. 38) (Barrett, 2014).

The intersection between disability and gender is an interesting and complex area. Gender is often seen as the social and cultural aspect of the implications of binary physical sexed bodies (Meekosha, 2006) and is a key aspect of identity. From the moment a baby is born and identified as either a boy or girl, it is generally expected to conform to a culturally defined set of beliefs about what it is to be male or female. These gender stereotypes include all aspects of being including appearance, occupations, physical appearance, interests, attitudes and psychological traits (Golombok & Fivush, 1994; Lehmiller, 2014).

The quote from Incrocci & Gianotten (2008) at the start of this chapter fits very well with longstanding stereotypes of disabled sexuality i.e. disabled people are seen as either asexual and lacking in sexual potency or potential, or somehow sexually deviant (Shakespeare, Gillespie-Sells & Davies, 1996; Taleporos & Bowden, 2006). While the work of Shakespeare, Gillespie-Sells & Davies, (1996) is now over 20 years old it still has resonance today with disabled people; Christina Crosby in her book A Body Undone says powerfully “I no longer have a gender. Rather, I have a wheelchair” (Partridge, 2016), while the participants in this study talked about being put in “the friends’ zone” suggesting that they no longer felt that they were viewed as possible sexual partners. This is also recognised by Tepper (1999) who states that following his return to college after a spinal cord injury (SCI) he had no trouble making female friends but they assumed, because he was in a wheelchair that he was ‘safe’ (asexual). What they were interested in was male friendship free from the pressure of sex.

Meekosha (2006) argues that while, because of the traditional views of disabled people as asexual, gender may be seen to have little bearing on the nature of their identity it is in fact a significant aspect which may intensify the perception of disability. Disabled women are seen as having an intensified sense of feminine “passivity and helplessness”, while men are perceived as having “a corrupted masculinity generated by enforced dependence” (p. 765).

A number of authors have identified that disability and the feminine are mutually reinforcing, while disability and masculinity are in conflict (Shakespeare, 1999; Shuttleworth, Wedgewood & Wilson 2012) – disability is seen as synonymous with being vulnerable and helpless. This has led to the concept of conflicted masculinity in disabled men.

Writing in 1999, Tepper describes powerfully the influence of the narrative of hegemonic masculinity on his development as a young man in the West prior to his spinal cord injury (SCI). It is a narrative of independence, self-reliance, success and dominance that fits neatly with the highly valued, predominant Western aspects of the self as autonomous, private and highly independent (Gelech & Desjardins, 2011). Tepper (1999) also talks about the myths of masculine sexuality: men are always ready for sex; the best sex is spontaneous; sex always involves penetration, and points out that the ‘sex education’ that promotes these myths is everywhere in daily life. It seems particularly prevalent on the internet.

In a thorough and insightful review of the literature, Barrett (2014) questions the veracity of this narrative of a dilemma of disabled masculinity. Examining Gerschick’s five interrelated themes of masculinity - sport, sexuality, access to work, embodiment and independence – Barrett (2014) asserts that disabled men negotiate the so called dilemma in active and creative ways and like Gibbs (2005) uses Gerschick & Miller’s (1997) framework of reformulation, reliance and rejection. Reformulation considers the way in which men use their own terms to redefine the hegemonic characteristics of masculinity; reliance, the way in which they sensitively adopt certain facets of that hegemonic masculinity; rejection, as the name suggests involves the rejection of the standards imposed by hegemonic masculinity, the denial of its importance in one’s life and the creation and adoption of alternative principles of masculinity. These strategies can be used in complex combinations to serve the need of the disabled man. Tepper’s (1999) paper is a strong rejection of hegemonic masculinity in relation to sexuality in which he rejects not only the myths of sexuality centred on spontaneity and penetration but also other enactments of masculinity such as being the primary wage earner and being responsible for DIY.

A notion which occurred to me in relation to disabled masculinity is that, within the narrative of the dilemma of disabled masculinity, both disability and masculinity are viewed as homogeneous concepts. Barrett (2014) also highlights this difficulty with the extant literature and calls for future research to be more nuanced particularly in relation to exploring the experience of men with different types of impairments – does the experience of someone with an SCI really reflect the experience of someone who is visually impaired or has a cognitive impairment? Even respected authors, such as Shakespeare (1999; 2000), use an undifferentiated category of disability when talking about sexuality although he has argued that to do otherwise is to deny “the common social experiences which unite disabled people, and [a] focus on medical dimensions of difference” (Shakespeare, 1996).

My personal experience of chronic illness forces me to question whether those with an acquired disability or chronic illness fit easily into the central political narrative from which the social model of disability has emerged. While Crosby (2016) acknowledges the achievements of the disability rights movement and the power of the social model of disability in achieving a measure of equality for people with disabilities, she also highlights the way in which she feels it denies the right of those with acquired disabilities to grieve the loss of their former life because it is seen as reinforcing the old pathologising and tragedy focussed models. However, she goes on to say:

"Chronic pain and grief over loss nonetheless remain as unavoidable facts of lives shaped by catastrophic accident, chronic and progressive illness, or genetic predisposition. Despite their strategic elision in disability studies or transcendence in happy stories in the popular press about trauma overcome, bodily pain and grief persist, to be accounted for as best one can". (Crosby, 2016)

Interestingly, Sophie Partridge (2016), someone born with a disability who reviews Crosby's book for Disability Now, says she is nervous of approaching books written by someone with an acquired disability, wondering "Will it be a testament of endless woe to their marvellous [sic] life before the disabling moment of evil enchantment? Once Upon a Time becomes a more than Grimm Fairy-tale, cloaked in triumph over tragedy, ending with a usually somewhat desperate `happy' resolution".

These contrasts between "born" and "acquired" are significant. To become disabled is to enter into a new and very different world. Shakespeare (1994) describes the 'othering' of disabled people by society in general. These young men who have sustained a TBI may in the past at best have not really considered disability or, in the extreme, admit to having been repulsed by it e.g. Luke when asked if his attitudes to disabled people were different before replied: "Definitely. Disabled people made me feel sick. They were freaks". However, now they themselves have become disabled, become viewed as 'other' by society, and perhaps also by themselves. Chinnery (1990) says in his astute, personal reflection on 'the process of being disabled' that it is 'the previously unchallenged, discriminatory values' of the person who has acquired the disability that feed the idea that they are now an inferior person. This is very much reflected in Luke's statement that he has moved from alpha male to omega male.

A shift in the Narrative of Time

Research exploring the concept of time perspective is comparatively recent (Zimbardo & Boyd, 1999). Time is perhaps more complex than it seems at first. A number of authors point out that time is ubiquitous, our lives are boundaried by and embedded in time but this very normality of it means that it is often overlooked and escapes the critical gaze (Daly, 1996; Shirani & Henwood, 2011; Zimbardo & Boyd, 1999). Daly (1996) points out that time is pervasive and taken for granted and yet it shapes both our daily lives and the longer term trajectory of our lives going on to delineate different 'types' of time – natural or scientific time which is uniform and absolute compared to social time which has no ontological status but is an artifact of our mode of social organization". She argues, along with Fraser, for the importance of thinking of temporalities rather than time such as circular time which is connected to nature e.g. seasons, weather and tides, and linear time, which became widespread during the industrial revolution and marks past, present and future. Odih (1999) outlines the concepts of masculine/linear time which has been seen in opposition to feminine relational time. She then goes on to effectively deconstruct these premises.

This category, when it arose in the analysis, was most surprising and it was not an area that I knew anything about prior to undertaking this research. It arose from reading a memo by Charmaz (2014) which referred to the way time is experienced differently by people with chronic illness or significant injury and in particular the loss of past futures. This led me to think about the way time was referenced in the interviews I conducted and from this I constructed the following categories:

Past		**Future**	
Title	**Description**	**Title**	**Description**
Past Perfect	Pre-injury past. Narrative of normal life; ignorant of brain injury. Held either by the injured person or by another e.g. a parent or sibling.	Past Futures	Futures which were dreamed of, planned for and possible before the TBI.
Splintered Past	The time of the injury and rehabilitation. Characterised by gaps in memory, disconnected images, narratives pieced together from what others know or surmise. Period may stretch from sometime before the accident until some point during or after rehab.	Shattered Future	Immediate post-injury future, filled with unknowns. A time when the prognosis was unknown.
Present Past	Post-injury, post initial rehab past when life begins to settle back into some routine and a sense of normalcy begins to be found again. A new past of what constitutes ‘normal life’ post-injury.	Present Future	A future which opens up during recovery. May be very different from the Past Future of before the accident. Seems to hold hope, difficult to plan for because life itself has become uncertain.

Table 2 - Categories for narrative of time

Charmaz (2011) talks about the life changing surgery of her participant in terms of "biographical disruption" an idea first posited by Bury (1982) in relation to chronic illness. Bury (1982) contends that chronic illness disrupts both the structures of everyday life and the knowledge underpinning it. He goes on to say that it demands "a recognition of the worlds of pain and suffering, possibly even of death, which are normally only seen as distant possibilities or the plight of others" (p. 169). I recognise this sense in relation to my participants and the categories of becoming an unwilling expert and loss of innocence/naivety.

In a detailed book drawing on over a decade of work, research and conversations, Charmaz (1997) makes a comprehensive exploration of the meaning of time for those who live with chronic conditions and concludes that time structures and perspectives change radically as they learn to live with their conditions and cycle through periods of flare up and remission. Charmaz (1997) asserts that chronic illness forces people to make changes to the way they organize, frame and use their time i.e. their time structures, and this results in changes in their time perspectives. Time structures are very much anchored in the present and strategies such as living one day at a time or existing day to day are adopted to cope with the most challenging times when old structures based on multiple time commitments no longer work. Perspectives on both the future and the past change. Hopes and goals for the future may change completely or be laid to rest until such a time when the situation changes and it might be possible to connect with them again. This is sometimes accompanied by a yearning to recapture the past, resuming past occupations and pursuits and regaining a past self. Charmaz (1997) highlights that these changes in time perspective can have a significant impact on an understanding of the self which necessarily exists and is understood through its location within a particular timeframe. While people who have sustained a TBI are not categorised as having a chronic illness, there are distinct similarities and what begins as an acute condition frequently results in chronic, long-term problems. While this current research did not set out to explore changes in time perspective in any way it does appear to suggest that this may be a significant factor in learning to live with the aftermath of TBI and have a profound impact on the understanding of the self.

Shirani & Henwood (2011) also examine the way in which unexpected events influence temporal experiences. Their novel work focusses on the experiences of men and unexpected events related to parenting e.g. unplanned pregnancy and delayed conception. In a concise overview of the literature Shirani & Henwood (2011) set forth the idea that people are generally future orientated and encouraged to be so from an early age. This future orientation encourages us to plan and prepare for the future and thus we begin to think that we can know and control the unknown. We make assumptions that the future will follow a particular trajectory; disruptive events are not anticipated because they are viewed as too rare to impact on our plans. This planned future influences present behaviour, a notion which reflects Lewin's life space model (Zimbardo & Boyd, 1999). However, when temporal trajectories do alter unexpectedly "an individual's ontological security derived from a sense of continuity regarding one's life events" (p. 50) is challenged and this has implications for a person's identity, even if this is an imagined identity based on future trajectories that have not yet come to pass. The research suggested that because events had proved that the future was no longer predictable, it became difficult for these men to think about the future. As a result they focused on immediate short term goals and milestones rather than planning for a long term future and in many cases this became a long-term strategy for dealing with the future. Odih

(1999) suggests that a linear sense of temporality is a more masculine trait, with the feminine sense of temporality being more relational, which would explain why men are profoundly affected when notions of linear progression are challenged by unexpected events.

Again this links with the current research in which I often experienced a nagging sense of the participants no longer being able to plan effectively for the future, no longer feeling that they have any control over what might happen even when they do make plans. Remember Frankie telling me that he wanted to do a proper degree and my disquiet over the way he said "*and that's my plan*" and my sense that he felt that even if it was his plan, it may not happen.

No discussion on time perspectives would be complete without mention of the work of Zimbardo and colleagues. In their seminal paper "Putting Time in Perspective", Zimbardo & Boyd (1999) set out a basis for the measurement of time perspective as an individual difference. They define time perspective as "the often nonconscious process whereby the continual flows of personal and social experiences are assigned to temporal categories, or time frames, that help to give order, coherence, and meaning to those events" and further assert that the time frames may be repetitive, cyclical or linear in nature. The measure they developed, the Zimbardo Time Perspective Inventory (ZTPI) has been useful in understanding and working with those with psychopathology (Van Beek, Berghuis, Kerkhof & Beekman, 2011; Davies,2014), however, like Molinari, Speltini, Passini & Carelli (2016) and Davies (2014) my own impression is that it does seem to fall short of being a comprehensive measure with only one, positive, measure of future orientation which takes no account of the possibility of a more negative anxious/worry orientation to the future (Molinari et al, 2016; Davies, 2014) and present measures related only to hedonism or fatalism, both of which are cast in a slightly negative frame allowing for no measure of a mindful connection to the present which is increasingly a perspective used in treatment, particularly in relation to depression and anxiety.

The time perspectives identified by Charmaz (1997) in relation to people with chronic illness and those identified herein in relation to those who have sustained a TBI differ significantly to those identified by Zimbardo and Boyd. This is clearly an important area which would benefit from significantly more research. If time perspectives are as influential as suggested by many of these authors I would assert that they may have a significant role to play in facilitating the rehabilitation of those who have sustained any disabling injury.

A Wasteland of Intimacy

There was a poignancy about this phrase, used by Jack, that kept returning to me and was eventually used as one of the central categories in the analysis. Focussed codes that contributed to the category included the sense of issues relating to sexuality and intimacy being frequently in the thoughts of the participants but never mentioned, particularly by carers and healthcare professionals and so the young men had to find their own way around the issues. Many of the codes related directly to their own experience such as the difficulties in negotiating the complexities of relationships and boundaries. Two of the codes are discussed in some detail here because they seem particularly significant with regard to taking the issue of sexuality and intimacy in this client group forward.

The Place of the Internet

The place of the internet as a source of connection by people who have sustained a TBI was significant among this group and certainly merits further investigation in its own right. It is less than 50 years since the first message was sent over the internet and just 25 years since Sir Tim Berners-Lee developed the World Wide Web and made it available to everyone (Computer Hope, 2016). In the ensuing time it has grown exponentially - it is now estimated that there are over 4.5 billion webpages (De Kunder, 2017) and has become an increasingly popular means of both general social interaction (Parks & Floyd, 1996; McKenna, Green & Gleason, 2002; Malta, 2007) and of interactions of a romantic or sexual nature (Ben-Ze'ev, 2004; Malta, 2007; Griffiths, 2012).

Shakespeare (1994) describes the 'othering' of disabled people by society. People who have developed a chronic illness or condition or sustained an injury that leads to disability have frequently been part of the othering performed by mainstream society, even if unknowingly. These young men who sustained a TBI may well have previously not considered disability at all or, in the extreme, like Luke, have been repulsed by it, however, now they themselves have become 'other'.

In his comprehensive overview of romantic relationships on the internet, Ben Ze'ev (2004) describes cyberspace as both an egalitarian space and a seductive space. He explains that cyberspace is egalitarian because the physical limitations of the real world such as race, physical appearance and disability may be temporarily left behind. As the participant in one piece of research, who had Tourette's, ADD and Learning disabilities said: "I am normal on the 'Net" (Lupton & Seymour, 2003). According to Ben Ze'ev (2004) the seductiveness of the space arises from the characteristics of "imagination, interactivity, availability and anonymity".

The Internet provides a space which at the same time has the potential to be both 'safe' and 'risky'. It is a 'safe' space where old identities and sexualities may be left behind and new ones explored and embraced without the potential for physical and social danger presented in the real world (Griffiths, 2012). The risks associated with this behaviour include the potential for a lack of satisfaction in real-world relationships created by the illusion of finding a 'perfect' relationship in cyberspace (Ben Ze'ev, 2004) and the risk of addiction (Griffiths, 2012). Online sexual activity has been compared to drug use, and described as stimulating the pleasure centres of mind, in terms of its addictive potential (Ben Ze'ev, 2004). There is also the risk of becoming trapped into dangerous relationships.

I would suggest that these risks may in fact be magnified in young men who have sustained a TBI and this was seen to some degree among the participants in this study e.g. James showing his erection in real life, to the woman he had exchanged explicit texts with. In interesting and insightful reviews of the way people engage in cyberspace, Ross (2005) highlights that electronic communications facilitate "intimate discussion shorn of most of the social cues present in face-to-face interactions" (p. 342). While communication on the internet is thought of in popular culture as fast, the removal of social cues may make it easier for young men who might be struggling with this as a result of their injury. Suler (2004) explores the concept of the 'online disinhibition effect' which refers to a phenomenon whereby people say and reveal things online that they would not normally do in the real world. Again this has a particular significance for young men who have sustained a TBI and may be struggling with problems related to disinhibition as a consequence of damage to the prefrontal cortex (Lezak, 2004). While online this disinhibition may not be seen as a problem behaviour, where relationships have the potential to shift from the virtual world to the real world, where social cognition and judgements play a far greater role and need to be deployed at tremendous speed, and where disinhibition is not as acceptable, the online experience may give rise to additional difficulties - as James found out, what is said and done in cyberspace is not necessarily acceptable in real time and space.

There are other potential risks in the use of cyberspace which are increasingly becoming recognised. While many people will have heard of the possibility of children being groomed online through campaigns by organisations like NSPCC (2017) & Childline (2016) many will not perhaps be aware of the potential for adults to be groomed. Recent police figures show that 3889 people were the victims of fraud perpetrated via dating websites in 2017 (BBC, 2017) leading to a loss of financial resources of £39 million, a significant increase since 2013. A BBC (2017) programme talks about a professor who lost over £140,000 and a business woman who lost in excess of £300,000 because they were groomed by professional fraudsters. Young men who have sustained a brain injury may have significant financial resources due to compensation payments and may be even more vulnerable to such attacks due to their cognitive difficulties.

Finally we return to the issue of many of these young men not having been very experienced in terms of sexuality and relationships. Bridges, Condit, Dines, Johnson & West (2015) highlight the fact that highly sexualised material is freely available on the internet with approximately 12% of internet sites estimated to be pornographic; 35% of all downloads being of a pornographic nature and a quarter of all search engine requests being related to sex. There is increasing evidence that adolescents and young adults, are increasingly turning to online pornography as a source of information about sex (Bowater, 2011; Crabbe, 2014) and exposure to such material becoming a normative experience (Sabina, Wolak & Finkelhor, 2008). This presents a problem because over recent years the content of online pornography has become increasingly violent and research in the UK suggests that boys aged 11-16 may view such images as being a true representation of sex in the real world (Martellozzo et al, 2016). Crabbe and Corlett (2010) argue convincingly that young people need to be given the critical skills to deconstruct what it is that they are seeing and to understand the perspectives advanced in these films. It is arguable that with the potential for disinhibition and cognitive difficulties this also applies to young men with TBI.

While much of this research looks at the impact of pornography on people younger than the participants in this research, it must be remembered that they sustained their injuries prior to the age of 25 and that the cognitive difficulties many of them sustained may make it difficult for them to make critical judgements about the content of what they are watching.

It is important that further research is undertaken in this area and that HCPs are made aware of the issues relating to cyberspace and online activity, particularly in relation to sex. Many people who have sustained a brain injury are still able to use computers, or are retaught skills to enable them to use them again but may be oblivious of the risks to both themselves and others that may be present when they engage in online activity.

Health Care Professionals (HCPs)

In spite of the fact that all the participants in this study said that the issue of sexuality and intimacy was important to them, not only talked about masturbating in private while in hospital but in some cases drawing the attention of staff to the fact that they were doing it e.g. Jack p??, the issue was never directly addressed by any HCPs. All the participants thought that HCPs had an important role to play in addressing the issue post-TBI and their very reticence to address sexuality contributes to some of the dynamics identified within this study e.g. the participants having to find their own way to deal with their needs and difficulties or relying on friends.

'Sexuality is a central aspect of being human throughout life' (WHO, 2002) and there is considerable evidence that sexuality is not only important to people, it improves health and quality of life contributing to psychological, physical, spiritual and intellectual well-being (Bauer, McAuliffe & Nay 2007; Whipple, Knowles & Davis, 2007). However, a number of studies have shown that sexuality is ignored by HCPs across a range of populations e.g. those with Alzheimer's disease (Davies, Zeiss, Shea & Tinklenberg, 1998). There are clear societal factors that impact on the willingness of anyone to discuss sex. In many Western societies sex has traditionally been a taboo subject, and while sex may have become ubiquitous in modern Western society, there has long been a sense that it really is only the domain of the young, fit and healthy (Bauer, McAuliffe & Nay 2007), with disabled people, as previously discussed, being viewed as asexual or a potential sexual menace (Shakespeare, Gillespie- Sells & Davies, 1996; Taleporos & Bowden, 2006) and it must not be forgotten that HCPs exist within the context of their society.

Dyer and Das Nair (2012) conducted a thorough literature review to examine why HCPs do not address the issue of sexuality when many acknowledge it as an important aspect of holistic healthcare. They identified 19 interconnected themes in eight papers in their rigorous review and critically appraised the value of these themes using the Quality in Qualitative Research Framework. The themes identified fell into three categories – personal, structural and organisational. These included issues such as a fear of 'opening up a can of worms', lack of time and training, fear of appearing intrusive, and personal discomfort with addressing the issue. Dyer and Das Nair (2014) went on to conduct research exploring the experience of professionals specifically working within rehabilitation post-TBI.

This subsequent study used thematic analysis to explore data from 24 HCPs. It used appropriate measures in relation to qualitative methods to ensure the quality and rigour of the analysis including triangulation, and keeping an audit trail and reflective memos throughout the process. Six main themes were identified: HCPs believed that sexuality after TBI is a specialist issue requiring specialist skills, training and knowledge in order to address it; that sexuality is a sensitive subject and HCPs were concerned that in raising it they may offend clients who may regard them as being intrusive or inappropriate; significant practicalities in relation to discussing sexuality were identified such as when would be an appropriate to raise the issue e.g. raising it too early might trigger anxiety for the client over something they didn't realise was a problem while leaving it too late may mean it was never addressed. It is notable that the HCPs were mostly in favour of a reactive approach i.e. only talking about it if the client mentioned it. The theme of roles and responsibilities identified the tension between not wanting to make sexuality the preserve of any one discipline while also recognising that if it was no-one's specific responsibility then no-one might raise the issue; dilemmas about risk and vulnerabilities revealed concerns that HCPs might precipitate sexual risk-taking behaviour if they discussed sexuality with clients e.g. accessing pornography, as well as concerns that talking about it may undermine efforts to manage hypersexualised behaviour and inappropriate sexual behaviour; finally the theme of organisational and structural issues identified concerns about 'opening a can of worms' e.g. not knowing where they could refer on to if a client did have difficulties, as well as the issue that it was not a priority because sexuality is not among the measured outcomes for rehabilitation.

Some of these issues are reflected in the data from the current study. After thinking about the issues many of the participants said that it should be the responsibility of HCPs to bring up the issue of sexuality because they themselves had no idea that it might potentially be a problem after TBI. While HCPs tended to think a group setting would be a good milieu in which to address the issue of sexuality (Dyer & Das Nair, 2014), most of the participants in this study felt that they would want to talk to someone privately. Participants in both my study and that of Dyer & Das Nair (2014) suggested that having written material around might invite discussion, and participants in this study felt that just being told it can be an issue and they were free to talk about if they wanted to would have been helpful. This reflects a development of the PLISSIT model called Ex-PLISSIT (Taylor & Davis, 2007) which suggests that explicit permission to ask about sexuality should to be given at every stage before anything else can happen.

With the growth of the internet and increasingly easy access for all people I would suggest that it has become a matter of some urgency that HCPs are given the skills they need to address these issues. The HCPs in the Dyer and Das Nair study were concerned that talking to clients might precipitate risk-taking and yet the evidence from the current study is that NOT addressing the issue precipitates risk-taking with clients accessing online sexually explicit material, visiting prostitutes and joining online forums and dating sites without any support or preparation. This raises the concern that by not addressing the issue of sexuality and intimacy they are effectively facilitating the vulnerability of clients to potential abuse.

I would posit, however, that there is a more general problem relating to discussing feelings generally post-TBI.

Over the course of this research I have frequently found myself wondering "Where is the anger?" It is a question my supervisor has also asked. During the course of the research only one of the participants expressed any real ongoing anger but also expressed a profound dislike of himself because of it "Very nasty I am. Very nasty inside like…. Yeah, I am, I suppose yeah deep down I'm very angry and very bitter with the world like" (Luke, p. 6). And yet doesn't anger seem like a natural response to the catastrophic events that have overtaken them? This led me to think further about the way emotion is dealt with, including the role of gender in rehabilitation.

While I fully appreciate that it would be difficult, if not impossible, to deliver any kind of rehabilitation programme if all the participants were constantly in a state of raw anger, my own experience of working in an inpatient rehab unit is that anger is deemed unacceptable. Angry outbursts were dealt with quickly and behavioural methods such as time out on the spot (TOOTS) were used to curb and control it; and if anger became extreme there was always, in the worst case scenario, the option of restraint and sedation.

While there is certainly a pragmatic aspect to this, what is striking is that the anger was stopped, labelled unacceptable, extinguished, rather than being explored and the patients being taught alternative, more acceptable ways of expressing it. Chinnery (1990) sees this removal of anger as part of the way in which society disempowers disabled people

Anger, particularly when expressed as aggression, is generally seen as a more masculine trait (Golombok & Fivush, 1994); it is acceptable in men but far less so in women, although there is increasing evidence that it is the expression of anger that differs (Archer, 2004; UCSF, 2000). With the majority of rehab staff being women (HCPC, 2017) and the narratives of corrupted masculinity which may be attached to disabled men, I can't help but wonder if this impacts on the patients' 'right' to be angry. Is it part of the way in which they lose their voice? This seems to be particularly important given that in a thorough meta-analysis, which included testing for effect sizes, Archer (2004) found evidence to suggest that the biggest surge in male aggression was between the ages of 18-30, which viewed from a sexual selection perspective is the peak time for reproductive activity. A reference to Cox's work suggests that males may feel less effective and less instrumental when forced to constrain their anger (UCSF, 2000). Again this may be particularly salient when looking at rehabilitation.

I wonder if the strong focus on the gym and physical rehabilitation seen in many of the participants is in part a defence mechanism, providing a physical outlet and converting the anger/aggression into something more acceptable through sublimation. Not only is it an acceptable way of venting difficult and unacceptable feelings, it is also an acceptable and accessible expression of masculinity and a place where they may feel effective and in control; perhaps one of the few now available to these young men. It should also be noted that this is helpful for HCPs as well; if anger is converted to something more acceptable then HCPs do not have to deal directly with that anger, or face the pain underlying it.

Anger is not the only feeling which seems to be ignored during rehab. Most of the participants couldn't remember having seen any kind of psychologist or counsellor during the course of their rehabilitation. This fits with the experience of others such as Niamh Lowe, a psychology graduate who writes movingly of her disappointment with the discipline after she sustained a TBI and describes how many neuropsychological examinations were performed while her mental health was utterly neglected; "I longed for one of the psychologists to ask me 'How are you?'; 'How are you coping?'; 'Would you like to talk?';" (Lowe, 2015). Kinsella, Walsh and Muldoon (2015) outlines concerns that while neuropsychological knowledge Is becoming more and more refined, the resulting focus on injury and deficits is in danger of "interfering with a more holistic understanding of the equally important social processes that can both contribute to and detract from rehabilitation" (p. 130).

These are important considerations in neurorehabilitation with evidence suggesting that 65% of those sustaining a TBI receive a psychiatric diagnosis post injury (Whelan-Goodinson, Ponsford, Johnston & Grant, 2009) primarily major depressive disorders and anxiety disorders, more than two-thirds of which were new post-TBI. The conditions are undertreated and there is little evidence base concerning the most effective treatments (Fann et al, 2015).

When thinking about the role of HCPs, it is important to remember that they do not act in some kind of professional vacuum, utterly separated from the pain of their clients. HCPs are human and many of them are the same age as those who are injured. Perhaps there is a fear of loss which is also at play, a sense of “there but for the Grace of God go I” or my son, or my brother. The pain and ambiguity of loss is so great for many of these young men that perhaps the entire rehab system is defending against plumbing the depths of the loss and suffering. It is so much easier to test function, build equipment and teach lost skills, than to sit with the loss and accompany someone as they face their darkest fears both real and imagined.

Limitations of the Research and Suggestions for Taking it Forward

Perhaps one of the main limitations relates to the composition of the sample in this piece of research. Participants were difficult to recruit and thus in this sample 6 of the 8 participants were recruited from the same day centre and had lived in the same geographical area since prior to their TBI. This raises the possibility that the research and the categories that were constructed from it may reflect something of the experience of rehabilitation in that particular area. However, it should also be noted that the other 2 participants came from very different areas, one lived in an urban metropolis, the other in a small city in a rural county and their experience did not differ vastly from the main cohort. As seen within the discussion section of this thesis, triangulation with other research strongly suggests that elements of their experience has been noted in other studies and it is certainly the case that sexuality and intimacy are not generally discussed either post-TBI (Dyer & Das Nair, 2014) or with other clients with disabilities. Future research could examine whether participants from other areas have similar experiences.

The participants were also a homogenous group in terms of the fact that they were all white males, would probably all identify as working class and all identified as heterosexual. A number of recent studies have highlighted that men from non-white and non-English speaking backgrounds have poorer outcomes in relation to both general health (Brown, Hargrove & Griffith, 2015) and in relation to brain injury (Arango-Lasprilla & Kreutzer, 2010; Saltapidas & Ponsford, 2008). There is a small body of evidence that cultural beliefs impact on outcome after brain injury as well (Mbakile-Mahlanza, Manderson & Ponsford, 2017; Saltapidas & Ponsford, 2008) and so it would be both interesting and useful to conduct research to examine sexuality and intimacy post-TBI in these populations. I was unable to find any studies relating to the experience of participants who identified as LGBTQ+. Strizzi et al (2015) identify their study as the only one looking at sexuality in women post-TBI. Their study is a quantitative comparison of sexual functioning, desire and satisfaction between women who have sustained a TBI and healthy controls so again there is a need for research to explore qualitatively the experience of women’s sexuality post TBI.

While I acknowledge that this is a small scale study, I am reluctant to list the size of the sample as one of the limitations. Sample size, though often key in quantitative studies, is not deemed to be so in qualitative which by its very nature is:

“*idiographic* and *emic* (focusing on one or a very few individuals, finding categories of meaning from the individuals studied) as opposed to *nomothetic* and *etic* (focusing on standardized methods of obtaining knowledge from large samples of individuals, using categories taken from existing theory and operationalized by the researcher)” (Morrow, 2005, p. 252).

It feels as if to list this now as a limitation would be to fly in the face of all that I have said about the value of qualitative research. There has been no pretence that the results of the study would be generalisable but rather that it provides insight. This is discussed further in the examination of the quality of the research.

Like Robinson (2011) I found that the breadth and scope of the analysis which emerged was far greater than I could have anticipated at the outset of the project and I am concerned that it has not been possible to do justice to the data gathered and ultimately to the experience of the participants. The gold standard for research using grounded theory is to reach saturation (Glaser & Strauss, 1967). I do not think that this has been possible thus far and although Dey (1999) suggests that this is rarely possible and a more realistic goal is theoretical sufficiency it would be good to have the opportunity to undertake theoretical sampling to try to come closer to a sense of completion.

It saddens me that because of my personal circumstances and the length of time it has taken to complete my thesis I have not been able to go back to my participants and ask them whether they feel that the research does accurately reflect a sense of their experience. I think that ensuring that the participants have a voice in this way is important within qualitative research. I intend to send them a summary of the findings and hope that some of them will remember their participation and want to comment on what I have produced.

Taking the research forward

The issue of time perspectives was a completely unexpected category and as outlined within the discussion is a fertile area for further research in many areas.

Godwin, Chappell & Kreutzer (2014) state that generalizability is not the main goal of qualitative research, however, the goal of the grounded theory methodology is to construct a theoretical framework where possible. It is hoped that others find appropriate ways to test the core category from this research as well as some of the central categories to see whether they make sense and most importantly, whether they have any clinical utility in the treatment of young men who have sustained a TBI. This might be achieved by conducting further qualitative research or perhaps a larger mixed methods study to explore other factors that might be correlated with experience of sexual and/or intimate relationships.

The issue of the use of social media and online resources has been discussed elsewhere. With the continuing growth of the internet and social media it would seem to be an area where there is a significant need for further research to discover the ways in which people with a TBI are using it and the potential difficulties they may encounter as a result.

Quality of the Research

While some may question the strength of a theoretical proposition based on a small N study, this concern tends to arise from a preoccupation with a positivist approach to research and a narrow definition of what theory is. Nochi (1998) suggests that a small N study can be considered useful in the same way that a clinical case study is useful – while every patient would not be expected to manifest all the symptoms recorded in the case study it can serve as a useful guide or comparator when new patients are examined. However, there is also a case for arguing that research should be judged within the framework of the epistemology from which it arises.

At the first annual conference of the special group in counselling psychology, Emmy Van Deurzin (1990) dared counselling psychology to be different, to resist the influence of “the spirit of experimental psychology” (p. 8) and aim to “fill the immense gap left open by a psychology too devoted to narrow scientific principles to pay proper attention to what it means to be human” (p. 9). There is a danger in falling at the last hurdle in qualitative research and that the researchers will allow themselves to be hijacked in a bid for ‘credibility’ within the ‘scientific’ community and shoe-horn their work into the positivist frameworks that have dominated for so long by using inappropriate criteria against which to judge it. Denzin & Lincoln (2005) point out that constructivists, along with other members of the critical theory perspective, now view positivist and post-positivist criteria as irrelevant when evaluating qualitative research as these criteria continue to silence voices that do not fit with their version of science. They assert that among the alternative means of evaluating their research, these researchers should look to an ethic of caring, verisimilitude, personal responsibility and emotionality.

Fossey, Harvey, McDermott and Davidson (2002) also highlight that the criteria used to judge research must be consistent with the paradigm in which it is embedded. They give a comprehensive review of the way in which qualitative analyses might by ‘rigorously’ judged, however, in a provocative article Forshaw (2007) questions whether strict methodology and judgement of rigour is ever appropriate within qualitative research given the fundamental rejection of the notion of pursuing the discovery of an unquestionable truth that exists independently. However, the very nature of undertaking a doctoral thesis is to invite judgement, regardless of the epistemological stance one takes. Fossey, Harvey, McDermott and Davidson (2007) suggest that the key marks of quality within qualitative research are authenticity in the both the representation of participants’ perspectives and in the interpretations made from the data generated; that there is a coherence to the findings arising from the ‘fit’ with both the data and the context from which they emerge; the need for openness and honesty in data collection and analysis along with an acknowledgement of the power relations at play in the research situation; finally they suggest that there is a need for “criteria for quality [to] profoundly interact with standards for ethics” (p. 723).

Abend (2008), in an interesting and stimulating paper, suggests that within sociology one of the main difficulties associated with judging the value of a theoretical proposal is a lack of concurrence about the definition of theory. Abend (2008) identifies 7 different definitions of the word and while his focus is on the field of sociology it can be argued that there is a similar difficulty within psychology. Certainly some of the definitions he outlines seem to be relevant to psychology and in particular the first three. Abend (2008) argues that while a small N study can never derive the first type of theory a “general proposition, or logically connected system of general propositions which establishes a relationship between two or more variables”, they can yield explanations of social phenomena which may explain causality (the second type of theory) and they can also offer original readings and interpretations of particular aspects of the empirical world which while not necessarily explaining causality can lead to a better understanding of something (third type of theory). Abend (2008) is talking particularly about historical and ethnographic studies within the field of psychology but I would assert that the same is true within certain qualitative psychological studies.

I hope that I have succeeded in holding these things in mind in the current research. Certainly it arises out of an ethic of caring, a passion for working in the field of brain injury and a desire to embrace and promote a holistic approach to the care of these young men. There have been ethical dilemmas with which I have had to engage (see Appendix 5) and I have endeavoured to bring my own process into the project to ensure there was openness and honesty in the data collection and analysis. This has been achieved by being reflexive throughout and elevating some of the significant memos from the appendices to the main body of the work in order that it should not be hidden. The rest is for others to judge.

Conclusion

To conflate Ellis and Bochner (2000), with Martin (2011) – the purpose of research is to encourage compassion and to promote dialogue; it is of no use unless it sparks thinking and understanding.

Head injury is the commonest cause of disease and death in the UK for people under 40 (NICE, 2014), and, as previously discussed, young men are over-represented in this statistic. The majority of people recover without specialist rehabilitation but a significant minority are left with significant disabilities. This has an impact not just on the individual but on their partners and families. Late adolescence and the early twenties is a time when young people are moving away from their families of birth and learning to negotiate new relationships with others, including those of a sexual and intimate nature. When a young person sustains a TBI this process is significantly disrupted. While previous research has looked at those in long term relationships, sexual dysfunction and so called inappropriate sexual behaviour following brain injury, most of it has been quantitative and this may be the first piece that examines qualitatively the experience of sexuality and intimacy from the perspective of the injured person.

When I was selecting the sample memos for the appendices I noticed one which talked about my concern that I might know all the answers in advance. This anxiety was present because the idea for the research had arisen from my experience of working in neuro-rehab and observing the reluctance of staff to discuss sexuality and intimacy with clients. I discussed my fear with Professor Carla Willig. She said that it is not unusual to have strong suspicions about some of the issues that might arise for participants as it is our interest and passion about particular subjects that leads us to research them. Her suggestion was to write a memo noting the fear but then to take a stance of actively looking for differences from my own position when analysing the data and allowing myself to be 'surprised' by the data. At the time I wrote:

"I like the idea of being surprised by the data very much but this whole position of acknowledging my stance and then looking for the differences fits very well with the way I work as a counselling psychologist; if we think of the client as presenting us with data (their story) and as a psychologist working to develop a hypothesis or formulation relating to their difficulties, we then have to go through a process of constant testing and revision of the formulation, checking it out with the client and adapting it in the light of their experience and understanding of their problems and of emerging data. That sounds to me very like the method of constant comparison."

I hope that I have been able to do this. The research has certainly produced unexpected results with three areas where I have proposed developing and extending theory: individuation, time narrative and intrapersonal ambiguous loss.

At times I have been concerned that there wasn't enough of a focus on sexuality and intimacy but while I think it might be premature to develop a complete theory in this area, there are significant and clinically useful findings in relation to it:

- Sexuality and intimacy do seem to be important to these young men.
- Sexuality and intimacy are impacted in many ways post-TBI beyond the obvious physical/biological repercussions, particularly including psychological and wider social factors including societal attitudes to disability and masculinity.
- Issues of identity and adjustment associated with the process of an unwanted, uninvited individuation have a significant impact on the ability to form and maintain intimate sexual relationships.
- As anticipated, and in line with the findings in other areas of healthcare, the issue of sexuality is an area which is neglected by HCPs for a range of reasons.
- As a result of this neglect young men find ways to negotiate their own solutions but this can lead to vulnerabilities and risky behaviour e.g. visiting sex workers and use of the internet and social media to meet sexual needs.

These are all rich areas for further investigation.

When the issue of identity became so strong in this research I was concerned about the apparent move away from sexuality and intimacy, in part concerned that I too was avoiding the issue. Reflecting on it further now it seems little surprise that identity was such a strong theme. While I have not used the term 'love' in this research, Solomon (1990) asserts that it is an emotion through which we create both ourselves and a new world arguing that "the self transformed in love is a shared self, and therefore by its very nature at odds with, even contradictory to, the individual autonomous selves that each of us had before." (p. 146). Whether or not you regard love as an essential component of them, sexuality and intimacy requires a level of trust, an ability to open the self to another and that is always a risky thing to do. Perhaps the place that this can begin again is through the medium of the therapeutic relationship. After all if you can no longer recognise and relate to yourself, how on earth can you expect to relate to others?

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Appendix 1

Overview of Brain Structure

The brain is arguably the most important organ in the human body. Weighing 3lbs (approx. 1.3 Kg), it is located in the head protected by layers of skin, bone, space and fluid (Alzheimer's Association, 2011). When removed from the protective layers the brain looks somewhat like a walnut, wrinkly with an apparent central division, and has the consistency of firm blancmange (Pinel, 2009).

In higher animals the brain is an essential part of the central nervous system and as such plays a crucial role in maintaining homoeostasis within the organism; sensing, moving in and learning about the environment; communicating and enabling the organism to survive. However, in human beings the brain also enables a human being to, plan, dream, imagine, and create art and music.

In this section I give a brief overview of the structure of the brain.

The brain is constructed of millions of neurons and various glial cells. Neurons are highly adapted cells which are specialised to enable them to generate, transmit, conduct and receive electrochemical impulses. The structure of the neurone is specifically adapted for this task consisting of the cell body containing the nucleus; an axon of varying length encased in a myelin sheath; and protuberances known as dendrites, which contain receptors, and terminal arborizations which end in terminal buttons.

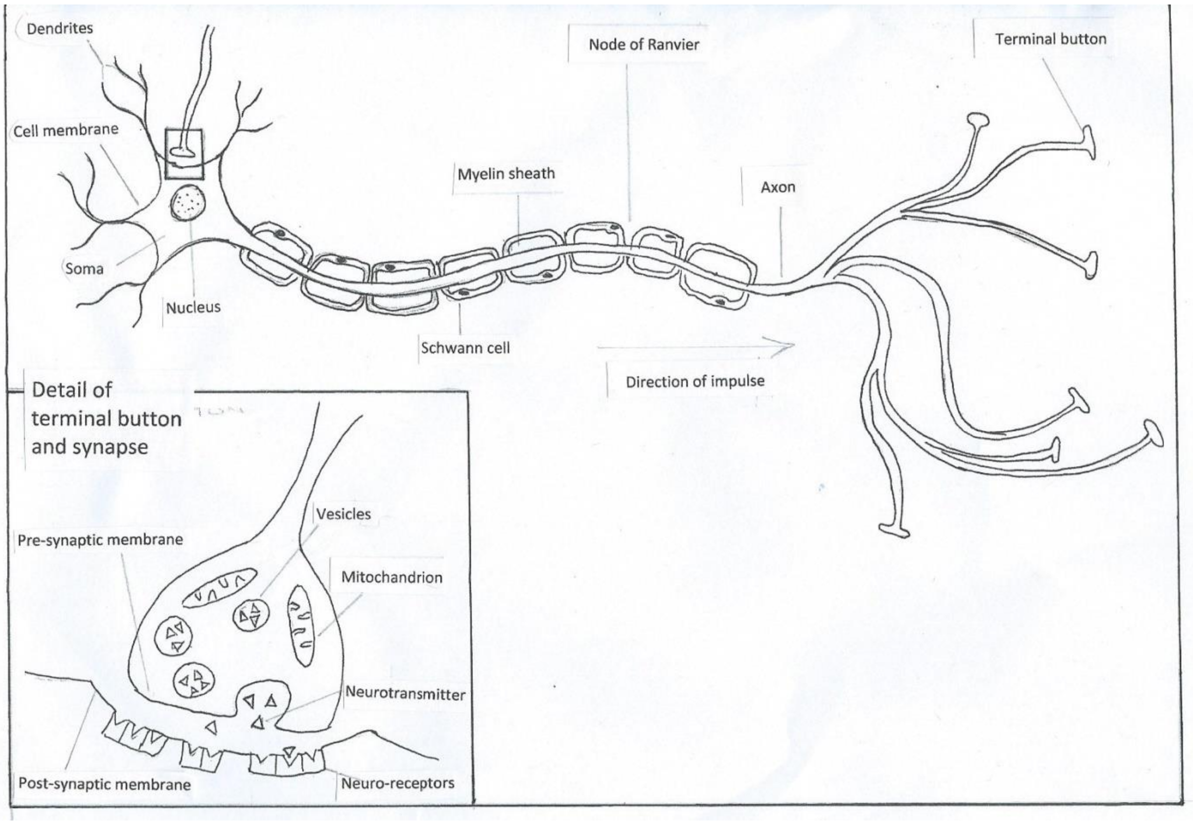


Fig. 1 Diagram of a neuron showing detail of the synapse

Neurons communicate via electro-chemical systems. In brief, within the terminal buttons of each neuron are a series of small structures known as synaptic vesicles which are filled with neurotransmitters. When an electrical impulse from the axon reaches the terminal button, the synaptic vesicles are stimulated to release the neurotransmitters into the synaptic gap between the terminal button and the soma of the neighbouring neuron. When neuro-receptors on the neighbouring neuron receive the neurotransmitters, the cell is stimulated to send an electrical impulse down its length to its own terminal buttons.

Glial cells play a supporting role within the nervous system. Initially they were thought to simply fill in the gaps between neurons and provide the 'glue' that held them in situ, hence the name *glia* (from the Greek meaning glue). While glia are unable to transmit information across the nervous system it has become understood that they play a vital role providing supporting, nutritional and scavenger functions. There are three major types of glial cell: astrocytes, ogliodendrocytes and microglial cells. The astrocytes are vital in maintaining the correct biochemical milieu for effective transmission of information across the nervous system; ogliodendrocytes manufacture the fatty myelin sheath that surrounds many of the axons in the central nervous system and the microglia act as macrophages consuming the detritus caused by injury and cell death (Purves, Augustine, Fitzpatrick et al, 2001). In recent years it has become increasingly apparent that glia play a central role in other mechanisms within brain function e.g. in learning and memory (Gross, 2005) and in the pathophysiology of chronic pain (Loggia et al, 2015); crucially they have been identified as playing a significant role in the processes that are triggered when traumatic brain injury occurs (Nedergaard, 2016).

Appendix 2

Defining Sexuality

An understanding of the breadth of terminology related to sexuality can be gained from the following document from the World Health Organisation:

“Working definitions

These working definitions were elaborated as a result of a WHO-convened international technical consultation on sexual health in January 2002, and subsequently revised by a group of experts from different parts of the world.

They are presented here as a contribution to on-going discussions about sexual health, but **do not represent an official WHO position, and should not be used or quoted as WHO definitions.**

Sex

Sex refers to the biological characteristics that define humans as female or male. While these sets of biological characteristics are not mutually exclusive, as there are individuals who possess both, they tend to differentiate humans as males and females. In general use in many languages, the term sex is often used to mean “sexual activity”, but for technical purposes in the context of sexuality and sexual health discussions, the above definition is preferred.

Sexuality

Sexuality is a central aspect of being human throughout life and encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, ethical, legal, historical, religious and spiritual factors.

Sexual health

Sexual health is a state of physical, emotional, mental and social well-being in relation to sexuality; it is not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence. For sexual health to be attained and maintained, the sexual rights of all persons must be respected, protected and fulfilled.

Sexual rights

Sexual rights embrace human rights that are already recognized in national laws, international human rights documents and other consensus statements. They include the right of all persons, free of coercion, discrimination and violence, to:

- the highest attainable standard of sexual health, including access to sexual and reproductive health care services;
- seek, receive and impart information related to sexuality;
- sexuality education;
- respect for bodily integrity;
- choose their partner;
- decide to be sexually active or not;
- consensual sexual relations;
- consensual marriage;
- decide whether or not, and when, to have children; and
- pursue a satisfying, safe and pleasurable sexual life.

The responsible exercise of human rights requires that all persons respect the rights of others.

These definitions do not represent an official WHO position, and should not be used or quoted as WHO definitions."

Appendix 3

Sample Memos

The sample memos presented here are drawn from across the 5 years I have been working on the research, from the first memo I wrote through the initial frustration of grappling with epistemology and methodological issues to the final days of analysis. I hope they give a flavour of the journey I have made.

Memo 1 - 18 September 2012

Article – The counselling Psychologist Researcher by Elaine Kasket

In Counselling Psychology Review 27 (2), 64-73

First of all reading this article made me feel that I was on the road again with my research – a tick on my getting going again list. However, it is also a very clearly written paper giving some very clear guidelines in relation to writing a thesis for a professional doctorate and I think summarising it here will help me to reflect on some of her arguments more fully.

The first thing Kasket does is to define what a professional doctorate is and what it demands. Although this has been outlined to me before for some reason there was a 'light bulb' moment when reading this paper. Kasket highlights the need for a professional doctorate to answer "*a need in the field* by producing knowledge that practitioners *can readily use*, and that knowledge may arise from the practice setting itself" in the way a PhD does not. She sets 3 questions for the would-be researcher to help focus the mind on the relationship between the research and the professional discipline.

She asks trainees to reflect on what it means to be a counselling psychology researcher and suggests that this is key question to be addressed by anyone undertaking the doctorate that is frequently not adequately addressed in the thesis write up – including the line that the research is 'in line with counselling psychology values' is not enough! Her paper led me to Coopers (2009) paper "Welcoming the Other: Actualising the humanistic ethic at the core of counselling psychology practice". Kasket names the essential values outlined by both Cooper and by Orlans & Van Scoyoc i.e.

- Prioritisation of the client's subjective and intersubjective experiencing.
- Focus on facilitating growth and actualisation potential.
- Orientation towards empowering clients.
- Commitment towards democratic, non-hierarchical relationship.
- Appreciation of the client as unique

Interestingly Kasket does not mention the final value identified in Cooper's article:

- An understanding of the client as a socially- and relationally-embedded being, including an awareness that the client may be experiencing discrimination and prejudice (versus a wholly intrapsychic focus).

This strikes me as being an important point to acknowledge in relation to the participants within our research.

Kasket also highlights the pluralistic nature of counselling psychology and argues that this stance is valid in counselling psychology research – recognising that there are many valid ways of conducting research and this pluralistic attitude facilitates curiosity in the research process and an openness to the multitude of ‘paradoxes, divergences and … perspectives" within the process.

Kasket suggests seven sins in counselling psychology research which should be avoided. These are the sins of:

- Insufficiently reflexive reflexivity
- The pre-established research question
- The boring introduction
- The uncritical literature review
- The mindless critique
- The applicability void
- Poor packaging

Final she highlights the importance of dissemination.

This is an article that I feel I should return to repeatedly throughout the research process; it is clear and succinct and will hopefully keep me on track and guard against some of the most common pitfalls.

Memo 2 - Oct 2012

What do I want my research to be?

This is a question that is beginning to assert itself in my mind as start to read more widely. I still feel as if I am doing nothing; I somehow have to get over this idea that unless I am writing something down I am not being productive.

At the end of last week and today I have been starting to look at ideas that feel as if they run counter to mainstream psychology. I have come across Kim Etherington’s book “Becoming a Reflexive Researcher” which looks at the use of self in the research process. I read the few pages available on amazon and was very taken with the idea of creating narrative as part of the research process. Etherington talks about people living rich and storied lives, which links with my experience of using narrative approaches within my work. I was aware as I was reading her work that I will be asking my participants to talk about their stories and again, as so often before, I was aware of the need to ensure that somehow we together find the positive aspects or ‘unique outcomes’ in their stories so that they are not left with a feeling of helplessness or being a victim. I realise that I need to visit the disability literature to help me with this and I need to hold in mind the requests for me to ‘set up a dating agency’ or ‘find me a girlfriend’.

Somehow I have also found my way to the critical psychology literature and the ideas that ethics and psychology for that matter are culturally and historically constructed. Fox talks about how psychology is both a product of these contexts and supports the traditional norms that reinforce the status quo. This is very close to my heart in terms of my research. Do I want to simply ‘measure, categorize, manipulate and control?’ with my research or am I trying to do something else? Perhaps the first step is to really listen to the stories I am told and to be sensitive for those unique outcomes, the surprises etc. that Carla talked about but then something has to be done with those so that I don’t betray those who have shared their stories with me.

Memo 3 – July 2014

Memo – Feeling confused and Pissed off

Today has been somewhat difficult and I didn’t realise it was so until Adam rang. I have been rereading my research proposal and I guess it all seemed so very clear cut at that point; my aim that I wanted to construct participative research, really involving the participants. Reading about how interviews would be transcribed and analysed as part of an ongoing process, learning from each one; adapting and adjusting the interview in response to the participants; recruiting new participants in response to themes emerging from the data. It’s just depressing now. I didn’t manage to recruit people for a focus group to help me develop the interview and I eventually became so utterly desperate for participants that I would have taken 8 people who had all had their accident in the same minibus and been treated together by the same people. There is absolutely nothing theoretical about any of this, I am just lucky that the participants represent a broad age range, that the cohort includes someone who is married and a couple of people who have visited prostitutes. How can I justify this group within the framework of grounded theory method?

Ultimately I have been constrained by any number of extraneous factors. The fact that while I was collecting most of the data it simply wasn’t my first priority, the fact that my father was very ill and I thought he might be dying was. I couldn’t recruit participants and when I did eventually manage to find 8 who were willing to volunteer they were based over 150 miles away necessitating expensive train travel and overnight stays which resulted in the interviews being carried out in two blocks with little time in between to transcribe or analyse. Yes, I should have listened to them at the time but I was also working and caring for my father, which in itself was a huge emotional thing. It threw into sharp focus that I was suddenly caring for him by default when he had never cared for us – he left when I was 5 and had little contact with us – and I was/am unable to care for my mother, who although incredibly difficult at times, did care for us and bring us up. Frankly I didn’t care. I was so relieved to have ANY participants I just wanted to capture the data because at least then I would have a chance to finish my degree. If I had the data I could deal with it at a later stage. Now I am trying to come back to it and I find that all my perfect, well planned ideas are in shreds. I had a well thought through plan, including a time-table that allowed me to finish by Sept last year with a couple of months in hand. I feel really angry and disappointed.

And that's another thing GTM, what is the point of it? That article by Pratt made me think, made me wonder if there really was anything new or different in what Glaser & Strauss proposed. What is the utility of it? I wrote something about this the other day and I can't answer the question. What is the point of an ever increasing number of people coming up with an ever increasing number of theories that are never tested? And further, what is the point, what is the utility of this in clinical practice if we really do recognise subjectivity and assert that every researcher has the potential to elicit different information from the clients and even if presented with the same data, may well 'find' different categories and themes because of the influence of self. As a counselling psychologist, of course I can see the usefulness of exploring individual experience, but as a clinical practitioner I have to wonder about its utility. If there is no such thing as a truth to emerge, if truth and meaning are co-constructed between the protagonists the logical conclusion is that any so called 'theory' or findings that I produce are simply the product of that particular conversation, at that particular time, between those particular people and how can that elucidate everyone else's clinical practice?

Maybe I am too caught up in my training in quantitative methods, still wanting a representative sample, wanting to find a simple 'truth' that can be applied across the board. But the problem is I don't know where to take all this and I don't know how to get on with my very imperfect study using terrible non-theoretically sampled participants.

And I feel guilty about taking so long, about all the time and money we have spent for me to do this bloody course and about Adam having to bear the brunt of my misery.

Maybe I need to get back to my participants – interesting that I nearly typed clients. Just listen to their stories. I so desperately want to do them justice; I so desperately want to do my family and especially Adam and Katie justice

Memo 4 - 2 days later

Beginning of Epistemological Reflexivity

Since my mini meltdown on Wednesday I have done some thinking and reading. Perhaps it was a good thing to happen because it is really making me think about my epistemological position and about the value of the work that I'm currently doing. I have read part of an article by Ruth Fassinger (2005) in which she states quite clearly that in spite of her commitment to qualitative methodology and grounded theory in particular, she still finds herself struggling and falling into the trap of trying to justify her work using the rhetoric of the quantitative paradigm, which is antithetical to her aims. I have also gone back to Willig and began to try to really understand the different epistemological positions. Having read the Pratt paper think this can only be a good thing as it will help me to be critical in my thinking in relation to my position with regards paradigms and methodologies. This 'crisis 'has also let me to begin to look at some literature on the way we judge the quality of research. So far I've read article by Salmon in The Psychologist (2003) but it is my intention to read the more around this, as I think it is crucial to a positive outcome. One of the things that Salmon talks about is the need for research to be a creative endeavour rather than something whereby one slavishly adheres to the rules of others. I think this helpful when thinking about the issue over my sampling not being theoretical. I I talked about John about this last night and have decided that I need to acknowledge the practical difficulties in my research and that the sample is effectively the sample that I have to start off with. I need to also include information about where I would go from here. This piece of research is not going to be the final answer, it never can be, it is only a start.   If I was taking the research forward and acknowledge that what I have done is little and a start. Whilst I did want to produce a theory grounded in data as my outcome, perhaps I now need to begin to acknowledge that what is possible is an initial exploration of an important topic and that if the topic is going to be treated with the respect it deserves it is inevitable that further work needs to be done.

I'm currently reading loves executioner by Irvin Yalom and one of the things that has struck me, really moved me, is his honesty in admitting the times when things gone wrong and what he has learnt from it. There is a humility and authenticity about his work, which is something that I would like to bring to my work. I have been very aware that everything that is written for the course is written with a positive start and to ensure par for my research I really do want authenticity.

Carla gave the number of questions when she was teaching us the research methods unit and I wonder if it is time for me to revisit them and review my motivation.

This feels like the beginnings of epistemological reflexivity!

Coding Memos

Memo 5 - 15/09/2014

The aloneness of TBI (Page 9/10 interview amcR10.03 part 2)

He chose a picture that I thought looked like a man relaxing in a pool to represent the challenges in relation to sexuality and intimate relationships after TBI. He saw the rock walls around the man and talked about it being like a wall and wanting to be on his own. About how even with his wife next to him when he feels turned on he will turn over and go to sleep because he felt like being on his own.

And I am left wondering about the aloneness of TBI. About young men needing to focus on themselves to get through rehab. About people simply not understanding the challenges and the changes they have been through. About the isolating power of the hidden disability – as he said earlier in the interview of not fitting in with the ones with major disabilities and not fitting in at work either. Where do you fit in when such a fundamental change has taken place in your power to be, to remember, to solve problems, to learn, to move etc., etc. Where do you fit in when you find that you can no longer observe the social niceties and meet social expectations. How isolating and alone are you when you are slotted in to rehab groups and charities with people you may not have chosen to spend time with before the brain injury?

There seems to be something very powerful in this idea of the aloneness of TBI.

Memo 7

Being a lab rat (R03/06 P54)

Throughout the struggle with the extremely compromised speech, his intellect shows through; whether it's making a play on words – "I'm not a lab brat" or his incisive and insightful comments.

Describing the health care professionals as being very knowledgeable but still feeling like a lab rat (p54). Having that feeling of exploring something unknown. This is new territory for him and the uniqueness of each individual and each brain injury, in reality make it unknown territory for the HCP's as well. This links with his comments about having to be ok with your inner self in order to overcome the difficulties or find ways of compensating. He tells me that "obviously you're not going to be the same guy as before your accident". This calls to mind some of the other comments from other participants about changing, being different.

Is there something about having to get to know this new self thoroughly before you can get to know someone else? How can you have a relationship with someone else when your whole relationship with self has fundamentally changed? If you no longer recognise or know yourself; if you no longer have a stable sense of self, what does this do to the possibility of knowing another?

Something else that comes to mind is that those around you, family and friends, are also used to the old you. Are you somehow preoccupied with trying to be who you were in order to fulfil some need in them? And possibly yourself? I wonder how developing a relationship fits with this? It seems like it would be a huge task to try to explore the new and find the old, let alone then develop new relationships with someone else. How can you be intimate with another if you no longer know yourself well enough to be intimate with yourself?

Would a relationship with a counsellor help this process? Having a space to be whoever you are and to try out new ways of being?

Memo 8

Memo – Time - `Standing on the Shoulders of Giants 27/10/2016

I've just been reading Cathy Charmaz's chapter on memo-writing and reading a couple of her examples has jolted me into realising that these are things that may be present in my own data.

The ideas that she talks about relate to the concept of time. On p163 she writes about Teresa who was an opera singer who developed cancer and as a result lost the ability to sing. She talks about how "meanings of time permeate Teresa's narrative" and her thyroid cancer as a defining event separating past and present. She also talks about how for Teresa voice and self seem merged, with the loss of the former leading to a sense of a loss of the latter. Teresa saw herself as defined by her voice.

The second idea looks at treating the *In Vivo* code "living one day at a time" as a category. This code arose in her work with people living with long term chronic conditions. A similar code arose in my interviews, with Charlie saying "I wakes up every morning and takes every day as it comes"

I realise that both of these ideas dovetail with some of the things I have been grappling with over the last few days in terms of thinking about everything changes but the striving to assert that there are also parts of themselves that haven't changed. I have also been testing out ideas linked to hope for the future and yet not planning for the future, a sense of uncertainty, a sense that you never quite know what is going to happen in the future and so plans are to some extent futile. I realise that the brain injury is a pivotal point in time, like Teresa's cancer. I wouldn't say "separating" past and present in the way that Charmaz has. To me there is something far stronger, more dramatic than separation. Something that fits with the things that I wrote about previously around a catastrophic event. Perhaps severing? It feels like a bolt of lightning….rending… yes perhaps rending past and present asunder. This sounds like biblical language but it feels more fitting, less civilised than separating or severing.

In the second memo Charmaz talks about an alteration in participants' time perspective, that "living one day at a time pulls the person into the present and pushes back past futures…. so that they recede without mourning [their loss]. I love the idea of past futures which are possible futures that existed in the past but no longer do, in the case of my work due to the brain injury. The loss of past futures fits with my thinking in relation to Conway's work on memory and the self and also to Boss's theory of ambiguous loss.

Memo 9 – A Personal Reflection 31/10/2016

Over the course of time the analysis has developed and metamorphosed. It has grown. It has been all consuming, like the rehabilitation these young men have undertaken. I have been away on my own and struggled with it, missing my husband, family and friends. I have been coming to terms with my own life changing diagnosis. Walking the orchards of Kent allowing thoughts to come and go. Being in the present, praying and searching. And finally this morning, with way too many words in my analysis, I think I have found a way to structure it. And somehow I am afraid and don't know what to do.

Memo 10 - 16.11.2016 Thoughts on Properties for Growing GT

Just reading Stern's chapter 'On solid ground' in the Sage handbook. A couple of thigs that have made me feel better.

She references Stebbins paper 'Concatenated Exploration (2006) in her section which asks 'when is enough enough?'. I read his paper and it is very interesting because he adds to the debate about the place of prior knowledge almost without referring to it. He advocates that research projects should be like a chain with one project leading into another which builds on all the previous projects. Suggesting that smaller projects building on each other might have more utility than one big project. This is really salient in respect of the kind of 'grounded theory light' that we have to do in the face of the constraints of the professional doctorate but it also fits with how I feel about my own research, that it is a beginning and not an end in and of itself. There seem to be so many directions that could be taken to develop what I have done and it would be good to see some of them come to fruition.

In the section entitled 'worrisome accuracy' Stern states that she doesn't bother with line by line coding because there is too much filler to skip. I disagree with this approach. I have found the line by line coding process helpful as a beginner researcher. It brings you back to the data and helps you to focus on it, however, Stern is also making the point that students are not comfortable with trusting their own memories and "allowing the cream to rise to the top (p118).   She is making a point about over-reliance on tape recorders and verbatim transcripts the danger in which is producing a detailed description rather than theoretical description of what is happening in the context of interest.

I love the idea of allowing the cream to rise to the top. It resonates with what we are told when we first start working in the counselling setting. Don't take notes; don't try to record everything the client says. That which is important will rise to the surface and if you miss it this time, it will resurface another time. It is interesting because when I was completing the analysis I was convinced that 'Losing my normal look' was a direct quote from one of the participants. In fact it wasn't, it was something that I had written but it seemed to me to reflect perfectly what was being said, or not said.

Appendix 4

Recruitment Pack

Including:

- Introduction Letter
- Who Can Participate Sheet
- Information Sheet
- List of organisations contacted
- Recruitment Poster

Dear …………………………

My name is Alison Clark. I am a trainee counselling psychologist and I am writing to ask if you would consider participating in my research project.

I am doing a piece of research for my doctorate which looks at the experience of sexuality and intimate relationships in young men who have had a traumatic brain injury. I have worked in neuro-rehabilitation services and found that this was something that was rarely mentioned. I want to find out if it was just the services I worked in or if it is something more general. I also want to ask young men how they think services could be made better in relation to sexuality and intimate relationships. The research has been through the City University Ethics procedure and passed.

To help me get in touch with young people Headway have kindly posted this information pack to members of the Younger People's Network. They have not given me your contact details and I will not know who you are unless you contact me.

I do realise that talking about sex can be a bit embarrassing but I think that it is an important subject to think about in relation to disability. As a trainee counselling psychologist I am used to helping people to talk and think about sometimes difficult and embarrassing subjects. People often find that when they start talking about these things they have quite a lot to say!

If you are interested in taking part in the research please read the checklist about who can take part. If you can be included in the research, read the information sheet to find out more and talk it over with family, a friend or a professional you trust. If you have any questions please feel free to contact me. If you still want to take part get in touch and we can talk further and make an appointment.

Thank you for taking the time to read this.

Best Wishes

Alison M Clark

Who Can Take Part in this Research?

This research is about the experience of sexuality and intimate relationships of young men who have had a traumatic brain injury.

This is quite a small research project so unfortunately it will be necessary to limit the types of people who take part, even though they may have very interesting things to say about sexuality and brain injury. If you are interested in taking part please answer these questions:

<u>Part 1</u>

Are you male? Yes
No

Are you between the ages of 18 – 25 (inclusive)? Yes No

Have you had a <u>traumatic</u> brain injury between the ages of 16-25?

(A traumatic brain injury (TBI) is an injury to the brain caused
by a blow or jolt to the head. Some of the ways a TBI is caused Yes
No
include accidents, falls or assaults.)

<u>Part 2</u>

Did you have mental health problems before you had a brain injury?

Yes
No

Did you have a learning disability before you had a brain injury?
(not including specific learning disabilities like dyslexia/dyscalculia)
Yes
No

Do you have any other obvious physical disability? Yes No

If you have answered 'yes' to the questions in Part 1 and 'no' to the questions in part 2 you may be able to take part in the research if you would like to. Please contact the researcher, Alison Clark, for more information at [redacted] . Thank you.

Information About The Research

I am training to be a counselling psychologist. As part of my training I have to do a piece of research. I have worked with people who have had a brain injury and I am interested in trying to find out more about what sexuality and intimate relationships are like for young men who have had a brain injury. To do this I am doing a project called:

A study of sexuality and intimate relationships in the rehabilitation of men who have experienced a traumatic brain injury (TBI) between the ages of 16-25.

I would like to invite you to take part in this study. This sheet tells you about the research. Before you decide if you would like to take part, please read this sheet carefully and talk to others about it if you think it might be helpful. If you have any questions please contact me, my details are at the bottom of the sheet.

Why are you doing this?

When I worked with people who had had a brain injury I noticed that sex and relationships were not mentioned very often. I want to find out if other people have noticed this or if it was just where I was working. I also want to find out if it is a subject that the young men who have had a brain injury want to talk about. Finally, I want to find out how we can help young men better after they have had a brain injury.

Why Have I Been Asked?

I am asking men who had a traumatic brain injury between the ages of 16-25 if they would be willing to talk to me about their experience of intimate relationships and sexuality since their brain injury.

Do I have to take part?

No. Taking part is voluntary; it is up to you to decide. If you decide to take part I will ask you to sign a consent form to show that you have agreed to take part in this research. If you change your mind later on, that is fine, you can withdraw at any time up to a month after the interview. You don't have to give a reason for withdrawing.

Will it affect my treatment if I do not take part?

No, not at all. This study is completely separate from your treatment and from the things you do with Headway.

What will happen to me if I take part?

I will contact you and talk to you a little bit more about the study. I will check that you are still happy to take part. After this I will arrange to meet you and interview you. I will ask you what it has been like for you since your brain injury. I particularly want to ask you about intimate relationships and your sexuality. The interview will last about 1-1½ and no more than 2 hours. If you get tired or can't concentrate we can take a break or stop altogether and meet some other time. I will record the interview. I may need to contact you again after the interview to check some things out or talk to you briefly again.

Disadvantages of taking part

You will be giving up a couple of hours to talk to me. It is also possible that you might get a bit upset because you are talking about how things have been since you had your brain injury. If this happens we will stop talking about it until you feel more settled. If you don't want to carry on talking to me that is fine, we can stop completely. I am training to be a counselling psychologist so I am used to working with people who might get upset.

Benefits of taking part

I cannot promise that taking part in the research will be helpful to you but lots of people do find it helpful to talk about their experience, even if it makes them feel a bit upset at the time. After they have talked about things they often find that they feel better. If you mention any problems or difficulties the researcher may be able to give you some advice about services that can help. The information I get from this study will help professionals to understand how they can help young men who have had a traumatic brain injury better.

Will my taking part in the study be kept confidential?

Yes. I will follow legal and ethical guidelines including the British Psychological Society Guidelines. All your information will be kept strictly confidential. If you would like more information please contact me.

What will happen to the results of the research?

I will write about what I find out and this will be assessed as part of my doctoral course. I might send an article to a professional journal for publication and I might make a poster to display at professional events. I will write a summary to send to those who have taken part. I will not write your name or details on any of the information I publish; that will be kept confidential. Once this happened I will destroy the recordings.

Who is organising and funding the study?

I am a doctoral level student who is training to be a counselling psychologist. I am organising and funding the research myself. The study has been reviewed by City University Ethics Committee and is supervised by a qualified psychologist. This is to protect the safety, rights, well-being and dignity of those taking part in the research.

Thank you for reading this sheet. If you are interested in taking part in this research or if you have any questions you want to ask, please contact me, Alison Clark by email at:

[redacted] or

Mobile: [redacted]

Website: www.tbi-relationships.co.uk

Organisations Contacted

Aftermath Support – Don’t do anything related to sex!

ASB Aspire

Avenues Group – social care organisation no reply

Basic – Advertised via social media

BrainBox – Support group in Newcastle

Eastern Region Brian Injury Forum – taking to June meeting

Headfirst – Charity that supports research, lovely lady but can’t help

Headway – National – advertised via social media

Headway Cardiff

Headway East London

Headway Oxfordshire – spoke to woman who will present it to CEO

Independent Neurorehab Providers Alliance – INPA

Kent Acquired Brain Injury Forum

Lincolnshire Neurological Alliance – no reply

Neurosupport.org.uk – advertising

Nerual.org.uk – Neurological Alliance

Northern Brain Injury Forum – Secretary Kate Mcmullen very, very helpful.

Rehab Without Walls

Sussex ABIF

TBI Families – sent out on their email list

UKABIF

West Berkshire Neurological Alliance – John Holt – wants copy of report.

Gay, Straight, Bi?

Are You Interested In Sex?

How do you cope after TBI?

Worried about relationships?

No worries – Everything's fine?

Do you think it's an important issue for young men with a traumatic brain injury? Has anyone offered you any support about intimate relationships and sex since your injury? Would you like the chance to talk about your experiences and concerns?

I am researching the experience of young men who have had a traumatic brain injury. If you are a male between the ages of 18 – 25 who had a TBI between the ages of 16 – 25, I would be interested in talking to you.

To find out more visit my website at: www.tbi-relationships.co.uk

Or contact me. Alison Clark at: [redacted]

Phone/text: [redacted]

I am doing my doctorate in Counselling Psychology at City University. My research project has been cleared by the university ethics committee. If you send me your phone number I am happy to call you to talk about the project. My thanks to Headway for their support in conducting this research.

Appendix 5

Confirmation of University Ethics Approval

Consent Form

Application for Ethics Amendment

Confirmation of ethics approval for the research study

Jones Nielsen, Jessica

Reply all |

Wed 10/04/2013, 15:08

Clark, Alison;

Filippopoulos, Pavlos;

[redacted]

> Dear Alison,
>
> After careful review and consideration, we have APPROVED your amendments to your ethics and research protocol. Please include your revised ethics form and research protocol to your final document.
>
> With best regards,
>
> Jessica
>
> ---
> Jessica D. Jones Nielsen, PhD
> Deputy Programme Director
> Research Coordinator
> Counselling Psychology
>
> City University London
> Northampton Square
> London EC1V 0HB
>
> [redacted]

Consent Form

Title of Project: A study of sexuality and intimate relationships in the rehabilitation of who have experienced a traumatic brain injury (TBI) between the ages of 16-25.

Name of researcher: Alison M Clark

Name of Supervisor: Dr Karen Ciclitira

- I have read and understood the information sheet about the research and have had the chance to ask questions about it.
- I understand that I am a volunteer and I have the right to withdraw from the research study at any time up to a month after the interview without giving a reason.
- I understand that the researcher is not part of Headway and that by taking part in the research or deciding to withdraw later, my treatment or involvement with Headway will not be affected in any way.
- I understand that audio recordings of the interviews will be made and that these will be kept until after the research has been published. After this time they will be destroyed.
- I understand that all my data will be kept securely in line with relevant guidelines.
- I understand that although the findings of the research will be published, including anonymous quotes, my identity will remain confidential.
- I agree to take part in this research study.

Name of Participant ……………………………………………………………………………………

Signature ……………………………………………………………………Date ………………………………

Name of Researcher …………Alison M Clark…………………………………………………………

Signature ……………………………………………………………………Date …………………………………

Application for Ethics Amendment 1

5 November 2012

I am writing to request that the ethics committee give consideration to the following issues:

1. In order to stimulate thought during the semi-structured interviews, in addition to verbal questions I would like to offer participants a range of pictures to choose from which might represent the way they feel or think about their rehabilitation in relation to sexuality and intimate relationships. It is proposed that a wide selection of pictures will be offered, the majority of which will not be directly related to the topic being examined e.g. animals, different environments, buildings etc. Care will be taken when selecting the pictures to ensure that a range of backgrounds, ethnicities and sexualities will be represented as appropriate. The idea is to help participants think 'outside the box' about the topic in question.

2. I have been offered the opportunity to extend recruitment of participants from individual local branches of Headway to the national network by using their Face Book and Twitter pages. Given that the target group is young men aged 18-25 this seems to be a far more appropriate and efficient way of recruiting than sending out flyers via the local groups. I would appreciate approval of this extension.

3. A young man with whom I have worked briefly in the past has offered to participate in my research. He was a resident in the inpatient unit I worked in some 5 years ago, at which time I did not work directly with him, then approximately 3 years ago I conducted a risk assessment with him on behalf of the community neuro-rehab service I worked for as an assistant psychologist. Although my initial response was that I should not accept his offer, this has increasingly come to feel like denying him the opportunity to have a voice and a chance to explore some of the issues this research raises; this seems to directly contradict the ethical foundation of qualitative research which Parker (2005) argues that offers the opportunity "to do something radically different". I have reflected on this issue extensively and although John[7] does not fit within the inclusion criteria for my study due to his age now[8], I think that I have a duty to let him speak and explore these issues if he so chooses. I would like to invite him to help shape my research by having a conversation with me about what he thinks are the important issues and by seeking his permission to do a practice interview with him so that he can explore some of the issues himself and contribute to making the research more relevant to young men who have experienced brain injury. This fits with the participative research paradigm (Robson, 2002) I hope my research will follow.

---

[7] Name changed to protect the client's identity.

[8] This was prior to seeking and obtaining an ethics amendment to change the age criterion from young men between 16-25 to men who had sustained their injury between the ages of 16-25

Appendix 6

Interview Schedule

Date of Interview…………………

Interview Schedule

Part I

1. Participant Reference ……………………………..

2. Age at interview ………………………… **3**. Age brain injury …………………………

4. Length of time since brain injury ……………………………..

About the Brain Injury

5. Loss of consciousness Yes/No Length of time ………………………………….

6. Were you taken to a specialist brain injury unit? Yes/No

7. How long were you in hospital?..................................

8. Can you tell me about your brain injury? Which part of your brain was injured? Did you have any memory loss? How do you think your brain injury affects you? What has changed? What has stayed the same?

9. Did you go to an inpatient rehabilitation centre? Yes/No

10. Did you receive community rehabilitation? Yes/No

11. Did you see any of the following professionals:

Professional	**Seen** (Please tick)	**Roughly how many times**	**Did they ever mention sex or intimate relationships?**
Neurologist			
Other doctors			
Nurses			
Physiotherapist			
Occupational Therapist			
Psychologist			
Counsellor/Psychotherapist			
Chaplain/Faith Leader			
Speech & Language therapist			
Pharmacist			
Dietician			
Social Worker			

12. Did you have any other injuries? Yes/No

If yes, please tell me about them.

Your Life Now

13. Are you still receiving rehabilitation? Yes/No

If yes, what?

14. What services do you receive from Headway?

15. Do you receive services from any other organisations? Yes/No

If yes, what?

16. What was your highest level of education before you had your injury?

GCSE A Level Diploma Bachelor's degree Postgrad Certificate

Master's Degree Doctorate

17. Are you in education at the moment Yes/No

If yes, what are you studying (subjects)

At what level?

18. Are you currently employed?

If yes, what work do you do?

How long have you been working there?

Semi Structured Interview Questions – Part II

Prior to the TBI & Now?

What was your experience of intimate relationships? - e.g. Had you had a girl/boyfriend prior to the TBI?

How did you experience relationships? What did you find easy/difficult?

Did you have a sense of your own sexuality before the TBI? What was your experience of it? Did you engage in sexual behaviour – same sex, opposite sex, masturbation?

What do you perceive as being the main barriers to developing intimate relationships?

Have these changed since your TBI?

What steps, if any, have you taken to overcome these difficulties/barriers?

In what ways has your relationship with your body changed since your brain injury? How do you think this has impacted on your ability to have sexual/intimate relationships?

What are your ideas about feeling masculine and being a man? What things did you do before in this role that you don't do now?

In what ways do you think these might have changed since your accident?

The process of rehabilitation

Reflecting on the rehabilitation process what was your experience of issues relating to sex and intimate relationships?

e.g. Did anyone mention sex or intimate relationships to you during rehab? Profs, carers, relatives?

Did you feel it was something you wanted to ask about?

Was it ever a priority for you?

(Did you ever ask anyone about sexuality or intimate relationships? What sort of response did you get?)

What was your understanding of the aim of rehabilitation? What were your priorities for rehab? How do you see issues relating to your sexuality and intimate relationships fitting into rehab?

What were the people like that you found it most helpful to work with in rehab? (Ask re their characteristics if necessary)

What do you think would help you talk to a health professional about sexuality and intimate relationships? (What would you want from a person you chose to open up to?)

What would rehab look like if health professionals dealt with issues relating to sexuality and intimate relationships well?

What are the important aspects of sexuality and intimate relationships that you would like to have been addressed during rehab, if any?

What do you think would have been most helpful for you in relation to sexuality and intimate relationships during rehab?/What would be the best/most comfortable way to address them?

Is there anything which you feel could help you with making intimate relationships?

If you were a health care professional how would you bring up/deal with these issues with young men who'd had a TBI?

Why do you think it isn't mentioned?

From your experience, what would you want to say to a young man with a brain injury who was concerned about sexuality or having intimate relationships after TBI?

What do you think are the best ways to help them build positive intimate relationships?

*Choose a picture that reflects how rehab felt to you and one that reflects how you would have liked it to have been.

*Choose a picture that represents the challenges you have faced in terms of sexuality and intimate relationships? (How has this changed since your injury?)

*Choose a picture that represents your hopes for the future. What are the strengths that you carry forward with you to create that future?

Ending Questions

There has recently been an article in the papers about a care home that assisted people with neurological conditions to see sex workers; what do you think about this?

Who/what has been most helpful to you in relation to this aspect of your life? How have they been helpful?

Is there any question about the issue of sexuality and intimate relationships after TBI that you would like me to ask?

Is there anything else that you would like to tell me which may help me to understand your experiences?

Has being a part of this study made you think about anything new or differently?

Is there any question I haven't asked that you would have liked me to ask?
What is the one thing that you would like (to say to) professionals to take away.

Appendix 7

Picture Choices Offered in the Interview

The individual photographs were placed as a random array on the floor or table. Participants were invited to look at them and select one or more photographs in response to a given question. Picture questions were:

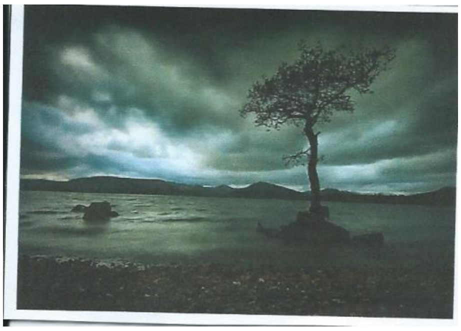
1. Choose a picture that reflects how rehab felt to you and one that reflects how you would have liked it to have been.

2. Choose a picture that represents the challenges you have faced in terms of sexuality and intimate relationships? (How has this changed since your injury?)

3. Choose a picture that represents your hopes for the future. What are the strengths that you carry forward with you to create that future?

1.

2.



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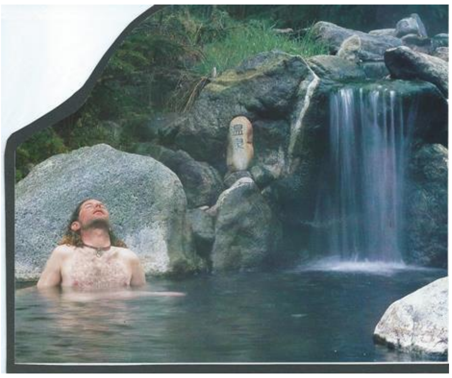

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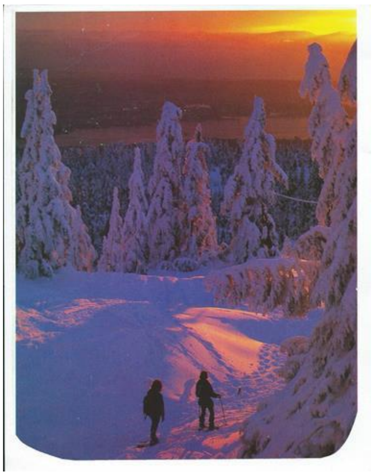
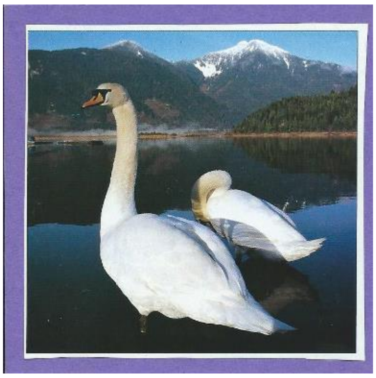
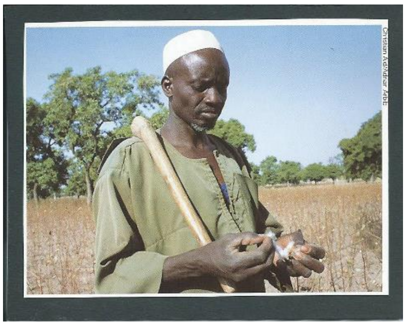


5. 

6. 

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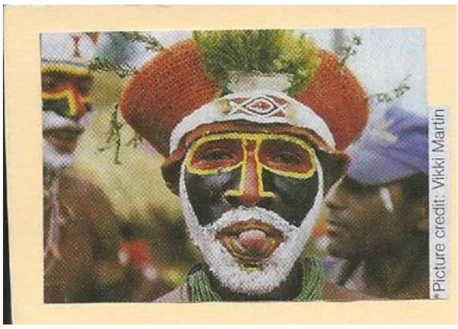
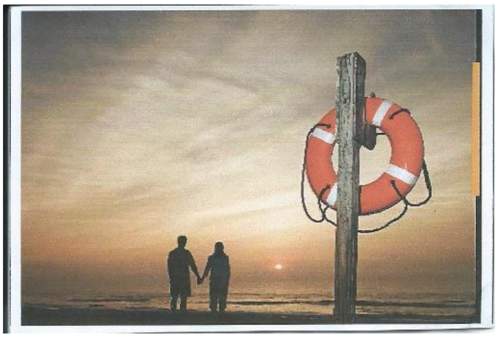
8. 

9. 

10. 

11. 

12. 

13. 

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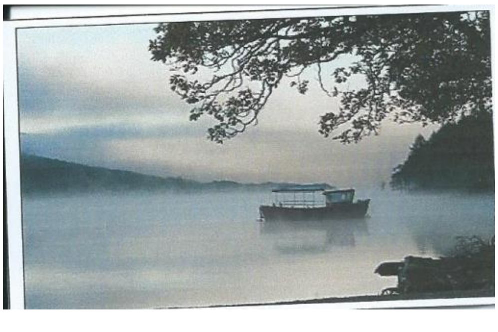
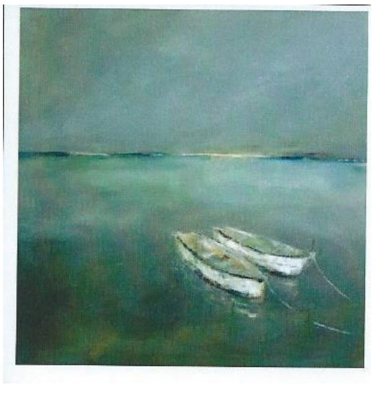
15. 

16. 

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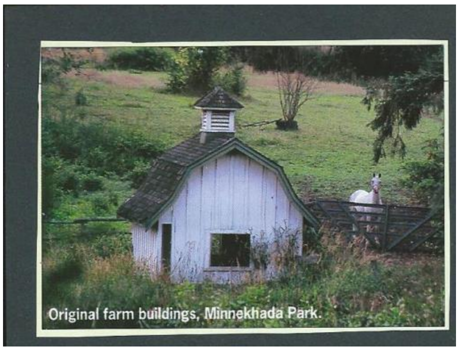

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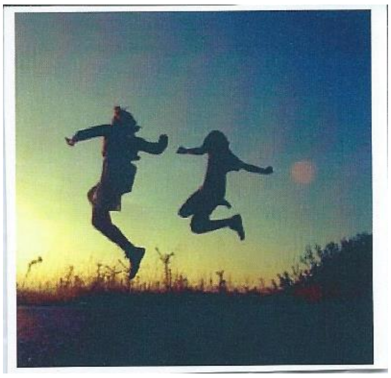

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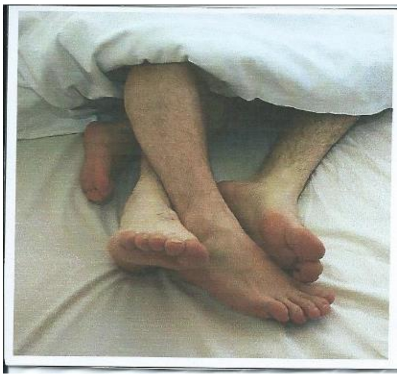

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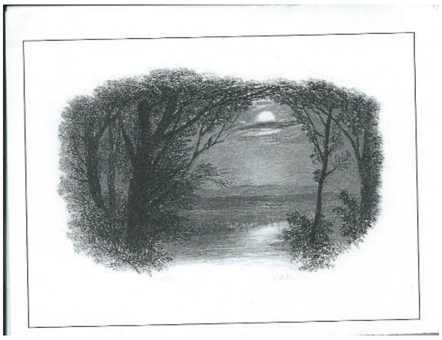

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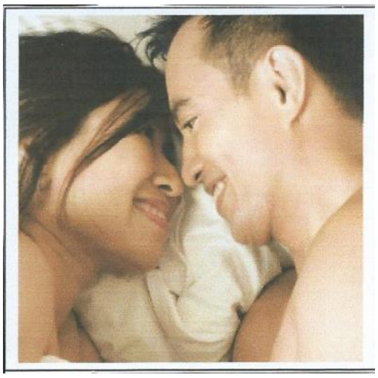

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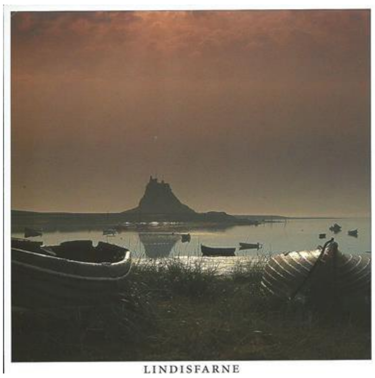

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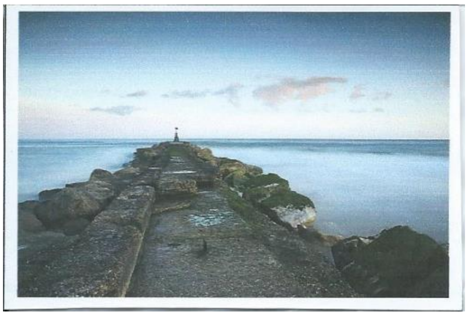

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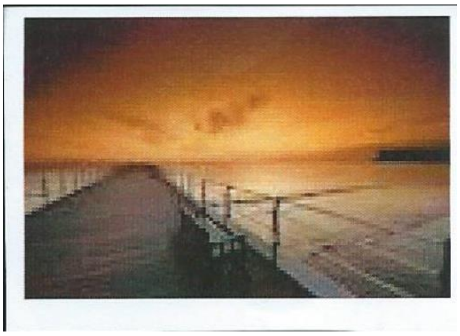

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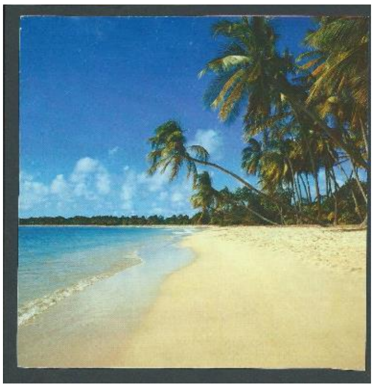

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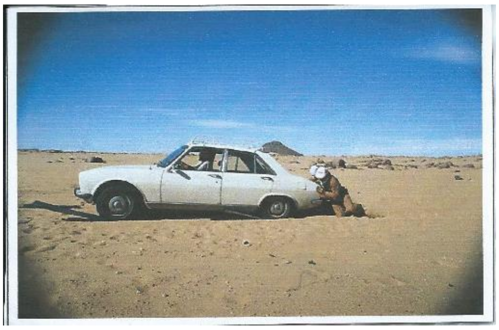
35. 

36. 

37. 

Note:

The pictures were collected over many years from a variety of sources e.g. magazines, cards, charity advertising. They were originally collected as inspiration material for creative writing when working in the field of adult literacy. Unfortunately this means it has not been possible to attribute any of the photographs as the individual sources are long forgotten. However, if you recognise any of the pictures please do contact the author who will be happy to make appropriate attributions in future publications.

Appendix 8

Sources of Help and Support

If participating in this research has made you think about issues relating to sexuality and intimate relationships differently or you feel that you would like to think or talk more about it the following suggestions may be helpful:

Your G.P. is available for you to talk to about any sexual difficulties you may be having and any other concerns you may have about your brain injury and other injuries you may have. He/she is in the best position to refer you to local specialist services.

Every area has a sexual health service where free contraception and advice are available. Google "sexual health" and the name of your area or ask at your GP surgery.

Brook is an organisation that provides free confidential information to under 25's. You can contact them at www.brook.org.uk or call Ask Brook on 0808 802 1234. The drop down menu under the tab My Rights on their website has a page about Sex and Disability.

In Touch is a website for young disabled people about sex, sexual health and relationships. You can find it at www.lcdisability.org/?lid=11901

www.thesite.org is another website for young people. Go to the 'sex and relationships' tab and under 'Having Sex' you will find a link to information about sex and disability.

Outsiders is a club for people with physical and social disabilities who want to make the most of their lives. It runs a general helpline and a helpline focussed on sexuality and disability. They are passionate about combating the isolation felt by many disabled people and campaigning for acceptance of disabled people as sexual partners. Their website is at www.outsiders.org.uk

Headway provide help and advice for people who have an acquired brain injury. Their helpline number is 0808 800 2244 website is www.headway.org.uk

General information about brain and spinal injuries is available at www.brainandspine.org.uk Their helpline number is 0808 808 1000

If you feel desperate or just feel the need to talk to someone you can call The Samaritans either at the central London branch on 0207 734 2800 or on the national number 08457 90 90 90.

If you would like to find a psychologist who specialises in neurological problems or sexual difficulties go to the British Psychological Society Website at **www.bps.org.uk** and click on the 'Find A Psychologist' link.

You could also try the COSRT (College of Sexual & Relationship Therapy) website at www.cosrt.org.uk/ . They also have information about common problems and tips for sexual well-being.

Appendix 9

Sample of transcript and coding

Checking | Clarifying	**Int:** Was that? You were quiet,	
Repeating - Having been quiet	**Par:** I was quite quiet person	Being quiet
Asking if he was shy	**Int:** I was gonna say was that because you were a bit shy or?	
Not standing out, because of lack of height	**Par:** I didn't, you know I didn't, you don't really stand out like being five foot five. [both laugh] so	Not standing out. Being short impacting on ?
Asking re sexual rel'ps	**Int:** Okay. So, had you had a sexual relationship that point. By then?	
Having had sexual relps	**Par:** Yeah	
	Int: You had	
	Par: Okay	
Asking re experience of relps. Wondering re impact of shyness + if difficult to begin them. + Way of being = someone	**Int:** and how did you experience relations, you said that you were shy (mmm) so it sounds like mebbe it was difficult for you to start relationships (yeah). How, how, how did you experience relationships? Did you find it quite easy to, kind of, be with someone else or did you, whether things you found difficult or?	
Differed with each rel'p. Always wanting someone he could talk to + get on with. Not going for looks. Enjoying company more important.	**Par:** Well, I was different, depends on the person really. I was, I've never really (2) gone for, it was always like if I could talk to the person I you know, like to you know if I can talk to the person, I can get on with them, and that sort of what I look for (yeah) It's not really about like, you know you get people going for looks, that, it's not really about that for me. I'm thinking, well, could I go out with that person, could I (1) spent time with the person and stuff like that, it's more important to me really	Personality more important than looks. Wanting to be with someone he could talk to/get on with.
Summarising that he prefers someone he can get on with.	**Int:** yeah, okay. So you were looking for someone that you could, kind of get on with (yeah) and enjoy being with	
Confirming	**Par:** Yeah, that's more important really [starts to laugh, interviewer joins in]	
Agreeing that its important for a long term relationship	**Int:** well I think if you're going to be with someone for a considerable amount of time,	

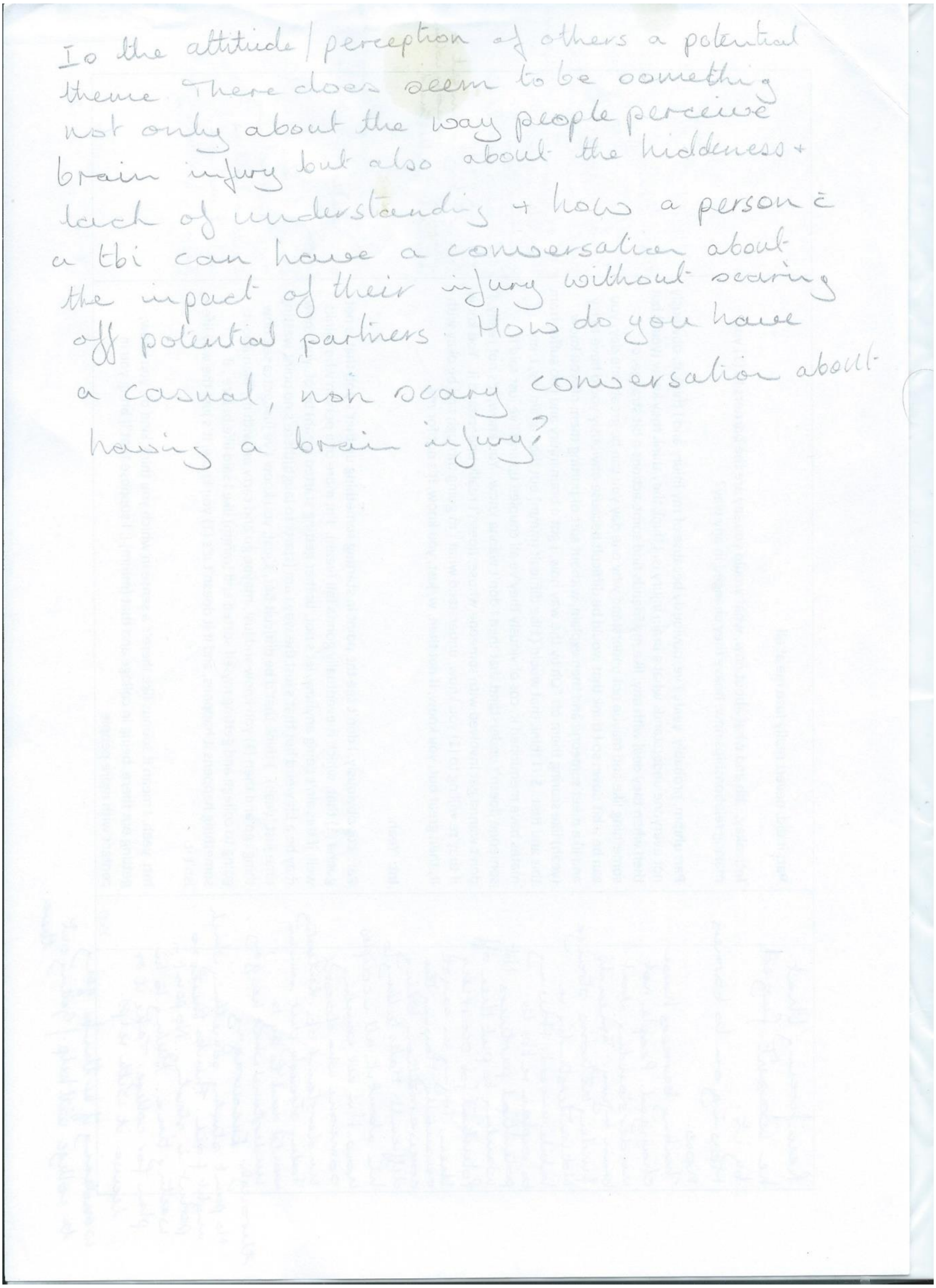
Joking to develop rel'p.		you've got to be able to put up with them haven't you [both still laughing]	
		Par: Yeah	
Affirming what has been said		**Int:** ..hh Okay, so it sounds like you, you had a sense of your in sexuality (mm) before the, before you had the brain injury	
agreeing		**Par:** ahh yeah, mmm	
Asking for further info		**Int:** and I just, I suppose I'm wondering what, what your experience of that was for? So did you engage in sexual behaviour, same sex, opposite sex, masturbation, (mm) those	
Answering via the negative.		**Par:** same, not same	* PTO
Repeating		**Int:** not same sex	
Confirming		**Par:** No	
Making the jump to what he did do + then asking re barriers		**Int:** Okay so heterosexual relationships (mmm) okay. [sniffs] Uhmm and what, what did, you (1) perceive (2) at that point to be the main barriers to, to forming relationships? Sounds like your, your quietness	
Problem = quietness Being labelled as "too quiet" needing to be more confident. Not worrying about it. Thinking he'd "get there eventually but not a priority. Priority to get himself in a good place, get a Job etc		**Par:** Yeah, I think that's in the way, x always used to say "oh you're too quiet" and "be more confident" or stuff like that (yeah)but that's just the way I was. I couldn't really help it but. It was, wasn't something that worried me too much 'cos I always thought I, I'd eventually get there. It wasn't something I was sort~~ed~~ of I have to do this, I have to do that because I was, I dunno, I was sort of more (1) interesting getting myself in a good place, with jobs and stuff like that. The thing is if I get a goal like that I just stick to that	Labels/perceptions of others but not being bothered himself Aiming at getting self in a good place Single minded
		Int: Okay	
Summarising what he said. If he met someone great, if not, not that bothered.		**Par:** So, you know, if I'd met someone and something happened then great (yeah) but if it didn't	Not being bothered
		Int: you weren't too bothered about it=	

My sense of him was of someone embarrassed + perhaps inexperienced in/by relationships. His answer here seems to affirm that; he tells me what he didn't do rather than what he did do.

Interestingly there is a contrast between the way others perceive him as "too quiet" + "needing to be more confident" + his own view that he wanted to get himself sorted out first. My memory of the interview is that this is something that hasn't changed; he still wants to get himself sorted out before he turns his attention to rel'ps.

He seemed shy + perhaps his height has contributed to that. Perhaps getting himself in a good place will give him some stature.

Reinforcing that he wasn't fazed by it. Moving on to barriers now. Thinking barriers have changed. People not understanding about brain injury. Friends finding actions strange Not understanding re labile mood. Having to explain re tbi to potential partners. Not wanting to put them off Potential for scaring them. Trying to say it casually. Having the conversation being difficult. Mates talking to him about it, all in couples now. Him not wanting someone who doesn't understand tbi. Reiterating Feeling strongly that someone would need to try to understand what he's going through. Encouraging No point starting something which might fail. Thinks there's no point in starting. No point in wasting time. Sticking to his plan for college. Take it or leave it with relps. wondering if he thinks going to college will help. / Getting out there.	29.37	**Par:** it did, nevert really faze me at all **Int:** okay. ..hh and what about now, what would you say are the barriers to (1) you making relationships now, hoave they changed in any way? **Par:** uhmm, probably, yeah, I've, obviously because of my injury and I think it, obviously not everyone understands what a brain injury is. I think they think they know (yeah) but then when they deal with any, like my friends find some actions a bit strange, or something like and maybe not understand why one day you can be great, one day, you can be a bit down so I think that would be difficult because obviously you'd have to try and like meet someone and then explain, without sort of putting them off you know (yeah) like scaring them off "Oh by the way now, I got a brain injury and I do suffer from this and that. So I think that would (1)be difficult (mmm) but then again it's, I, my mates have mentioned it, cos obviously they've all coupled up and I've just said if someone doesn't understand that then I don't wanna know. You know, it's not really, I don't wanna get involved with someone whose, doesn't really understand it. You know, if they're willing to (1) you know, understand what I'm going through and be okay with it, then great but, you know, if not then, w, just, you know, it's not for me. **Int:** Yeah. **Par:** cos obviously, I don't see the point in starting something up that's not, that is not gonna (1) that, which is eventually gonna fail (yeah). I'm more of a person who thinks well, if this ain't going anyhow, let's not, bother getting started (yeah) bit of, you know, may be a bit weird but that's just the way I am [starts to laugh]there's no point wasting time just (yeah). I think that'd be difficult but, s'just, you know I've just gotta see how things go and then (1) you know and just, maybe go and carry on with my plan about going to college and getting myself sorted and (mmm) like I said like before , if something happens it happens, and if it doesn't it's (1),you know, it's just the way life is. Isn't it. **Int:** yeah, I mean it sounds like there's a sense in which you think kind of, you know, getting out there, being in college and that (mmm) I, I suppose that'll bring you in contact with more people	?Hard work People lacking understanding re brain injury. Not understanding hidden consequences eg labile mood Diffy telling people c̄ out scaring them off. Mates now in couples - Moving on. Not wanting to invest in something c̄ someone who doesn't understand. Rather not start then fail. Not wanting to waste time. Single focus of college ?No distractions? Ambivalent re relationship - Aiming for his goal.



Is the attitude/perception of others a potential theme. There does seem to be something not only about the way people perceive brain injury but also about the hiddeness + lack of understanding + how a person c̄ a tbi can have a conversation about the impact of their injury without scaring off potential partners. How do you have a casual, non scary conversation about having a brain injury?

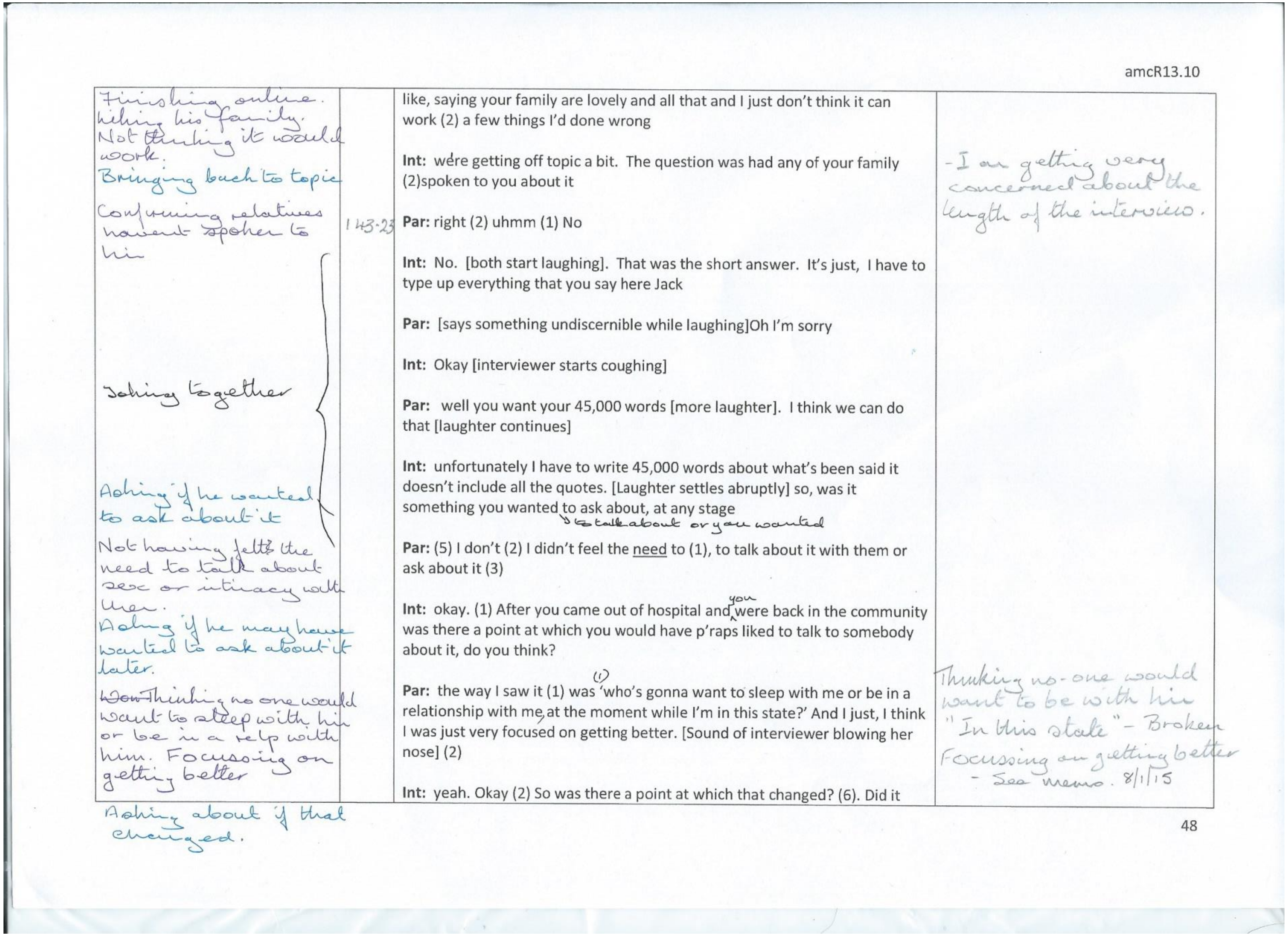
College giving increased contact with people. With extended contact people will get to know him. Might get to understand his tbi. More able to talk about it. Too much to convey in a night out	**Par:** Yeah, there'll be more contact and you get on with various people, you know, you meet more people and they, they'll sort of get a chance to see, like different, like who I am basically, rather than me, just going out, and talking to someone for one night, you know, you don't really get, to know who the person is whereas if you're out all the time and they see you a couple of days, it's sort of well (1) it may be then, maybe they understand it, and talking about my brain injury , maybe that would be a bit easier, maybe they'll be a bit more, aware (yeah) where is if you go on a night out you can't really get all that across (yeah) so there's, you know, it's a bit strange but it's just, just	Prolonged contact enabling people to get to know him + his tbi Get to know about it more naturally. Too much info to convey in a night out.
Affirming his perception Moving on to ask re overcoming barriers. Noting going to ~~hospital~~ college may help.	**Int:** Well I don't think it does sound strange, actually, I think it sounds quite sensible really (mmm)[both laugh]so. Okay, so I mean my next question is what, what steps, if any, have you taken to overcome these, these barriers, or these difficulties? (mm) but it sounds like your, kind of, your plan to be in college (yeah) and things is all a part of that (mm)really and uhmm	
His friends having tried to help	**Par:** Yeah, uh,I mean my mates have tried, they tried	
checking if he means fixing him up.	**Int:** what try to fix you up with somebody and?	
Going out with friends being introduced. Barrier of lack of understanding re brain injury. Difficulty of even simple conversation about work. Having to tell people re brain injury Seeing a change in their eyes	**Par:** Yeah [both laugh] yeah we'd go out in the. You know "oh these are my friends and all that sort of thing (yeah) but you know, you get talking to them and it's like that barrier of not really understanding the brain injury. Like they sort of say "Oh so where do you work" and "awh well I don't work", and they think, well you're in your, at the time late twenties, "why don't work?" (yeah)and I say "Oh I suffered an injury, a head injury" and they're like "wha, what's 'appened to you then?" Got a brain injury and you just seen their eyes it's naa 'cos	Complexity of simple conversations Having to tell pple re brain injury Seeing a change in their eyes.
Encouraging to say more.	**Int:** wha, what does that mean?	
Perceptions of brain injury Fear of public - nasty, crazy. Being uncomfortable Him not wanting to be talking about ins + outs of tbi in Social situations	**Par:** Yeah. Brain injury is like, is this guy gonna, you know, gonna be nasty is he crazy or stuff like that? (yeah) but you can just see in their eyes they're not really comfortable and I thinking well, I don't really want to be sitting here talking about (1) you know, the ins and outs of brain injury sort of thing. If they don't really understand it, then I don't really wanna ..hh you know sit in the pub sort of talking about brain injuries for three	Having to educate people Facing people's perceptions + discomfort / Stereotypes Not wanting to focus on it. PTO

Someone will either understand & get to know him or he's not bothered by them		hours. It's, you know, either they understand and like ~~we'll~~ will get to know me for who I am (yeah) or not this (3)	Wanting someone who will understand re tbi but get to know him.
Noting the importance of wanting to be known for who he is		**Int:** it sounds really important to you that somebody would want know you (mm) for who you are	Getting to know the person (beyond tbi)
Agreeing		**Par:** Yeah	
Noticing that this hasn't changed		**Int:** and that sounds like something that ~~has~~ hasn't changed actually (no) from, from before	
Agreeing. Contrasting ē friends who have short term relp's. Not being motivated for that.		**Par:** no, I've always been like that, I've just you know, I got mates, they like pick up the girls , and they're there with them for like 2, 3 weeks that sort of thing. But I just can't be(you) bothered	
Affirming		**Int:** Yeah. It's not your style	
Knowing his own personality. Not wanting a relp for the sake of it. Not wanting someone who doesn't get on with. Wanting to be happy. That might mean being on own.		**Par:** It's not me. I, I just, this is the way I am if I don't see any, you know I'm not gonna go out with someone who, who just annoys me. I'm thinking you know if, we're not gonna get on then what's the point (yeah). I'd rather be happy and if happy means I'm on my own, doing what I want to do, enjoying myself (1) then that's what life's about isn't it. [laughs]	Wanting to be in the right relp ē the right person. Being happy is most important. Enjoying himself is what life's about
Agreeing then moving interview on		**Int:** I think so [joins laughter]. Would you say that your relationship with your body's changed since you had your brain injury	
		Par: uhmm, phrw	
Giving examples		**Int:** I mean for example, some people are very much into fitness and exercise beforehand and then they find that it's, it's kind of much more difficult (mm) or their body doesn't quite do what, what they want it (yeah) to do or, you know, they were sort of used to, kind of being very lively (mm) and	
Being more serious about exercise		**Par:** I think of become more serious about fitness and stuff like that	Being more serious re exercise
Encouraging elaboration		**Int:** You've become more serious about it?	

Having done exercise before. Being ē mates; Having a laugh; having fun Commenting on social nature. Agreeing it was social not fitness focus. Focus having changed. Fitness Job to do. More serious Doing it to get better. Referring to physical symptoms Asking re impact. Weakness affecting him when tired. L side switching off becoming v weak. Asking re consequences Initially finding it frustrating. Being a drastic change. Not understanding it. Being aware now. Becoming attuned. Knowing what to do/how to manage it. Having to rest etc Noticing current attunement. Wondering if thats changed		**Par:** Yeah. I used to go to like err boxercise classes stuff like that with my mates but it was more for (1) , having a laugh (right) it was like awhh it was a bit of fun **Int:** so a social thing **Par:** Yeah social thing rather than a fitness thing but now it sort of, you know, I go to a gym and I'm (1) focused on getting myself fit, rather than going there and chatting around to different people, you know I'm there to do a job sort of thing and that's. So I've become more serious that way but I feel like I've got to do that to get better (mhmm) **Int:** you said that you've got left-sided weakness **Par:** Yeah **Int:** does that have a big impact? **Par:** err now and again if I get very tired (yeah) it's sort of, that side'll sort of switch off, completely and I'm just weak basically, really weak on that one side **Int:** So (1) is (1) how does that affect you? I mean for example, do you get frustrated with it, or I just able to accept that that's how I am and (uhmm) that's **Par:** I was frustrated err like the very 1st, when I came out of hospital and I just didn't really get it, cos it was just a drastic change, but now it's sort of (1) I dunno, I just sort of fully aware of it. I know when it happens and, some days I can, I can feel I know when it's gonna happen uhmm before it actually happens (right). Cos I'm sort of, over the years, I've just sort of got used to what I'm doing (right) and if I, you know usually I can feel when my hands getting a bit tired Okay in about half an hour that's gonna pack in. So I know then if ~~I'm an~~ I'm out with my mates sort of thing, I'm just gonna, I just have to sit down for 5 minutes (yeah) you know and have drink of water, get up, and then carry on. I'm okay then (3) x **Int:** it sounds like your kind of attuned to, to the signals that (yeah)that. Would you say that, that's something (1) you're more attuned your body now than you were before?	Gym etc changing from social + fun to serious + work – Rehab as a job? Having to do it to get better. Impact of tiredness Being unable to control body. Hidden disability Frustrating at first Learning to manage + live with 'new' body. Getting used to it. Becoming more attuned to it. Way body works Changing

and you it more .

Giving an alternative		Or (yeah) is it just that it, it's a pain ~~in new~~ kind of notice?	
Needing to think about his body more. Before injury having done what he wanted wout thinking. Always being alert now for signs that his body is tiring.		**Par:** Yeah, I, I sort of think about things a bit more (mmm) sort of thing, like years ago I didn't have any serious injuries then so I didn't really think, I'd just go out and, whatever, like normal but I do now, if I go out and I do think, I do ~~is~~ always have in the back of my head about keeping an eye on (1) ..hh you know, stuff like (1)even if my vision starts going, cos obviously my eyes, played up since the injury as well (yeah) so I just, you know, it doesn't really affect me. I just sort of naturally now, whereas I just	Taking things for granted before tbi. Now being alert/watching for signs he's tiring. Doing this is 2nd nature now.
Wondering if he is now 'managing' his body.		**Int:** sounds like there's a sense in which you kind of managing your body a bit	
		Par: Yeah	
Noticing his need for awareness of his body eg when driving.		**Int:** and, and you're just kind of aware that (yeah). I guess, particularly if you go out somewhere and you've got to drive home (mm)you've got to make sure you're	
Not overdoing it. Knowing his limits - sensing when he can't do things. Managing his day; managing fatigue.		**Par:** yeah I don't overdo it and I know, and I know when, I know like the sort of limits where I feel like I can't drive, sort of feel like I can drive and I know if I'm out I'm thinking well, you know, if I've had a long day and I need to get back, I'm thinking, well , I don't want to be staying out until 10 o'clock at night, then driving back (yeah) so it's, it's just sort of, I've managed it over the years an' (2)	Not overdoing it. Knowing the limits Balancing demands & Managing fatigue
Asking if ~~there~~ he is anticipating impact on		**Int:** Do you think, that, that relationship with your body as it is now (2) does or will impact on your ability to have a sexual relationship or an intimate relationship?	
Not anticipating impact. Usually being aware/ anticipating problems. Having some sudden bad periods but more rare now. Keeping aware of body. Watching for early signs.		**Par:** errm, phhww, I don't think so, no (no) because I' (2) you know, I'm, obviously, sort of, just, aware of (1) like, if I'm out gonna have a problem sort fo thing. I still have my bad days where it hits me sort of like that [snaps fingers] (yeah)but it's getting rare now because I like, I just keep, I'm sort of always try to keep fully aware of what my body's like an' like what my leg is like, and my arm is like, and if I'm feeling tired and stuff like that (yeah) so it's like sort of, I know, the early signs like the warning signs sort of thing (yeah). So I don't think anything like=	Would use monitoring i intimate relps Keeping aware of body. Watching for signs of low mood & tiredness.
Acknowledging that he thinks he would manage		**Int:** so again you would be able to kind of manage (yeah) how that was, in terms of intimacy and (yeah)[interviewer blows her nose] I'm so sorry	



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Finishing online. Liking his family. Not thinking it would work.		like, saying your family are lovely and all that and I just don't think it can work (2) a few things I'd done wrong	
Bringing back to topic		**Int:** we're getting off topic a bit. The question was had any of your family (2)spoken to you about it	- I am getting very concerned about the length of the interview.
Confirming relatives haven't spoken to him	1 43.23	**Par:** right (2) uhmm (1) No	
Joking together		**Int:** No. [both start laughing]. That was the short answer. It's just, I have to type up everything that you say here Jack	
		Par: [says something undiscernible while laughing]Oh I'm sorry	
		Int: Okay [interviewer starts coughing]	
		Par: well you want your 45,000 words [more laughter]. I think we can do that [laughter continues]	
Asking if he wanted to ask about it		**Int:** unfortunately I have to write 45,000 words about what's been said it doesn't include all the quotes. [Laughter settles abruptly] so, was it something you wanted to ask about, at any stage to talk about or you wanted	
Not having felt~~s~~ the need to talk about sex or intimacy with them.		**Par:** (5) I don't (2) I didn't feel the <u>need</u> to (1), to talk about it with them or ask about it (3)	
Asking if he may have wanted to ask about it later.		**Int:** okay. (1) After you came out of hospital and you were back in the community was there a point at which you would have p'raps liked to talk to somebody about it, do you think?	
~~Won~~ Thinking no one would want to sleep with him or be in a relp with him. Focussing on getting better		**Par:** the way I saw it (1) was (!) 'who's gonna want to sleep with me or be in a relationship with me, at the moment while I'm in this state?' And I just, I think I was just very focused on getting better. [Sound of interviewer blowing her nose] (2)	Thinking no-one would want to be with him "In this state" - Broken Focussing on getting better - See memo. 8/1/15
Asking about if that changed.		**Int:** yeah. Okay (2) So was there a point at which that changed? (6). Did it	

48

Appendix 10

Themes from Pictures

Possible Themes in Pictures

Participant **R07.13 Mike**	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My Reflections**
How rehab felt	1	A wrecked ship, possibly locked in ice, lying on it's side, utterly helpless.	I was just gonna say cos like my life was just a re, in a mess like it felt like a wreck, wreckage.	16a	Powerful image of brokenness, wrecked ship; wrecked life
Gets rid of first picture and chooses another	2	Single tree in a lake	Although there was lots of staff to help you get through it and that, it just felt really lonely.	16b	Experiencing intense loneliness amidst all the staff. Being alone and separate – what are the implications for relationships? How long does it persist? Do they continue being isolated?
				17	Being lonely, being in the wrong place, being different
				17	Feeling that life was dull and gloomy. Sense of darkness. Not making/noticing progress at first
				17	being given a poor prognosis
How would you like rehab to be	3	Man in a natural pool with waterfall	Looks like he's not got a care in the world. Obviously he don't care what people think of him with hair like that. Yeah that's how I'd want it to be like, relaxed, chilled, very chilled, no stress.	19 & 20	Wanting to be relaxed. Wanting not to care about others opinions

Challenges faced in terms of sexuality and intimate relationships	4	2 people walking in snow in the mountains	I just think I have trouble walking on flat ground like errm I'd never be able to or I don't think that any time soon I'd be able to go walking **....** I just think that that's, that's gone for me at the minute.	20	Recognising loss and stressing his limitations
Hope for the future	5	Pair of swans	They mate for life don't they? that's that's that be me hopefully one day that male swan (mm). I'm looking for someone who's gonna be serious and someone who'll wanna get involved and wanna stick around	21	Desire for a long term relationship. Changing priorities and desires in terms of rel'ps
Participant R05.14 Nathan					
How rehab felt	9	Dark grey image of a ferris wheel against a stormy sky	Slow jes' (makes a gesture of a circle with his hand). It's dark also	25	Felt he was going round in circles, doing the same thing repeatedly. A dark time when he didn't feel he was getting anywhere. Perhaps the darkness is indicative of so many unknowns following TBI? You don't know where you are going or how you will get there.

How would you like rehab to be	30	Holiday hotel with swimming pool & bright sunshine	Bright & happy	26	Wanting it to be a lighter, happier experience. Perhaps more freedom? Trying to find a sense of happiness that he now feels he's found by having a place of his own.
Challenges faced in terms of sexuality and intimate relationships	35	A desert scene with a broken down car that two people are trying to push. The back wheels seem to be embedding in the sand.	alone. They are trying to help but what's the point? There's nothing everywhere. Agrees that he sees himself as the car.	27	I wonder about the link with his first picture relating to rehab. The idea that “there's nothing everywhere” is a very strong one. Even if people (profs) help, if people only notice his wheelchair (or pt 1s waddle or 11.04s lack of social skills) then there is no one to share intimacy with.
Hope for the future	2	Single tree in a lake	Dark. Don't think I have much of one (future). (will be) alone. Wanting to be in an intimate relationship.	28 & 29	Wanting to be in an intimate relationship but thinking he will be alone. Does this desire make it all the more lonely? It feels over whelming

Participant R11.04 Dylan	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	None	Rehab feeling good. They were helping him reach his goal. Not caring what happened in rehab	I knew it's all good in the long run	42	Focussing on his goal. Regarding staff as helping him get there. Going through anything to get there

How would you like rehab to be	None	Question not really answered. Continues with themes from previous question	I, like , carry on on my own. On like, how can I, it was like err, a mission. You've got to do it yourself. I'm number one	42	Idea of a mission – single minded focussing on goal, putting self/goal first. Clearly stating needing to take responsibility, no-one else can do it for you
Challenges faced in terms of sexuality and intimate relationships	6	An African farmer. Land and crop look dry. He is examining a bol of cotton & looking worried	One man on his own. Far as I'm concerned it's just me and whoever else comes comes like, but. Don't wanna like (2) oahh get told what to do by no one else	43	I wonder if it raises feelings about being unproductive/barren in terms of rel'ps. The man is alone in the picture and I have the feeling or him being at the mercy of powers beyond his control.
Hope for the future	33	Tropical beach with golden sands and palm tree. Beach is empty & sea is calm.	It's beautiful. The number one place to go. I wanna be the number one person. It just sort of like sticks out. That's sort of like my dream. I know it's not gonna look like that because this is Britain (acknowledging the impossibility of his dream?)	44	It's a calm, quiet, lovely looking place, maybe this is what he strives for. Not wanting to travel – hating it, wanting it in his back garden. I have noted "and yet he is a traveller, having metaphorically travelled a great distance".

Participant R10.03 Charlie	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	18	Shows a man's head bowed against clasped hands. Looking pensive/praying. Looking sad. Black & white not colour	I wanted to be in work. I wanted my old life back. Disappointed. Didn't wanna be there. I honestly thought I never had a brain injury - so not feeling he fit in with the groups etc. People worse than him. "I was just taking up a space which I didn't really need.	8 part 2	Difficulty adjusting; wanting what was lost; feeling guilty about being better than others; rejecting/denying what had happened. Specific problem with fitting in due to hidden nature of the disability
How would you like rehab to be	33	Long tropical beach with palm trees	Now that just seems happy and it ust looks like loads of fun	9	Theme of wanting rehab to be more fun, feel more like a holiday while not wanting to appear critical to the staff.
Challenges faced in terms of sexuality and intimate relationships	3	Man on his own in a natural pool surrounded by rocks	It's just like a wall; I just want to be on my own. Even when my X is here next to me and like I said I felt horny and randy 'sjust like I said rolled over went to sleep. Felt like being on my own.	p9 - 10	The wall is very present for him. Describing conflicting feelings but brings me to the loneliness or is it the aloneness of TBI
Hope for the future	No picture chosen		Enjoying life. Don't look back. I don't even look to the future really. I wakes up in the morning and takes every day as it comes like you never know what's gonna happen		clearly rejecting baby picture not wanting more children. Enjoying every day. Sense of the unpredictability of life and the future. Is this even more so after TBI?

Participant R03.06 Frankie	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	6	An African farmer. Land and crop look dry. He is examining a bol of cotton in his hand & looking worried	"I have the feeling that more and more that he's a knowledgeable man"; Obviously by his way of dressing he's not, but he's an exploring man; Although the people I worked with were very knowledgeable, I still felt like a kind of lab rat. You have to be fine with you inner self in order to overcome the difficulties you have because obviously you're not going to be the same guy as before your accident and you have to find different ways either to overcome those difficulties, either to compensate.	53-55	Perhaps he feels like the cotton bol being examined. The man is a farmer and knowledgeable yet he still looks as if he perhaps doesn't know what is wrong with the cotton bol. Ppt is articulating something about each brain injury being somehow unique - HCPs are generally knowledgeable about brain injury but there is something unknown about each case and therefore it is an experiment.
How would you like rehab to be	28	Picture of a couple in bed gazing at each other	I would like to have someone to go to. A partner	55-56	

Challenges faced in terms of sexuality and intimate relationships	12	A girl throwing a bunch of leaves into the air in the sunlight	this picture sh shows the freedom looks like. {then changes approach when the question is repeated}Every leaf on this picture is a challenge. Think of the floor…picking them up afterwards. It's very easy to chuck them but getting them (2) like my brain it is very easy to damage ....it’s a completely different matter to put all the pieces back together.	56-57	It is an attractive picture and his first response about freedom is important - the freedom he feels he has lost perhaps. It is a joyous picture of a physical freedom he no longer has. The alternative interpretation he uses is also very moving - throwing the leaves is easy but putting everything back together is very difficult. If each one is a challenge there are so many challenges
Hope for the future	30	Picture of the Holiday Inn with swimming pool	I…I don't know … because I've decided it's pointless to make plans for far ahead …..because they might change {I suggest he might like a bit of the good life} well you have to mainly….you only get one shot in life although this is kind of my 2nd shot because I died for about 20 seconds....and I want to spoil myself in every way that I can	59-60	How can you plan for anything after TBI, when something unforeseen and unexpected comes out of the blue creating a fundamental shift in your life and experience of life? Can life ever feel safe enough (predictable enough) again to make you feel you have any control over it. Thinking about it perhaps this is the root of the rigidity and inflexibility, perhaps control and organisation are what are required in order to create enough safety and the illusion of predictability to make life liveable again.

Participant R10.04 Dave	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	35	A desert scene with a broken down car that two people are trying to push. The back wheels seem to be embedding in the sand.	“cos it looks like a bit of a struggle, but, they will get there eventually”, “trying to push the car”, “struggle to begin with, but you will eventually sort of get there”	39	Very much reflecting the narrative he has given over the course of the interview.
How would you like rehab to be	30	Picture of the Holiday Inn with swimming pool	Rehab being hard work. “ it's worth it in the end because you, you know your. The harder you work the better you feel”. Wanting a bit more sunshine	40	Sense of achievement through the hard work
Challenges faced in terms of sexuality and intimate relationships	12	A girl throwing a bunch of leaves into the air in the sunlight	“it's got a lot of leaves isn't it?” “trying to maybe look for a particular type. There's so many things in the way”, “ if you're looking for that certain type of person and you've got all these around sort of maybe a bit difficult to sort of find”. Not quotes – fighting way through to try to talk to someone. Lots of leaves in the way, looking for one small leaf, more difficult when you've got a lot going on “it's like you sort of got all this going on and then trying to find that one small leaf”	40 41	He says the leaves represent people – all the girls you have to encounter when trying to find the right one “that one small leaf”. And yet as he continues talking on p41 there is also a sense of the leaves being so many things to cope with after TBI. Relationships are just that one small leaf and maybe the other bigger leaves demand more attention. How is it possible to focus on the one small leave when there is so much else to attend to?

Hope for the future	13	Initially tempted by 30 again then chose this: a couple walking hand in hand along a beach at sunset, in the foreground a very prominent life ring hooked on a post.	"it looks sort of normal. You know it's nothing too over the top". After being asked about the life ring:- "well it's safe init....you know you're safe", "I like to be sort of like comfortable"	43	Stressing the normality of the scene – just people going to the beach. The hotel picture wouldn't happen unless you won the lottery. This is normal and achievable but it is also safe and that is what he craves, normality and safety. Not having to try or pretend to be something he's not, just being comfortable.

Participant R16.12 Luke	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	8	A picture of a fox looking alert, standing in deep snow	"he's tryin' a live which is what I was trying' a do at that point. I was tryin' a get better, tryin' a walk tryin' a get myself back fit ….I was in a wheelchair over 2 years." "Yeah he's in the snow but it's like an hunting..... he's fighting for his life in' he really	51	Speaking to him of survival. Hunting. Struggling and simply trying to live again, to get back to normal. To get his life back - ? To get himself back? Fighting for his life.

How would you like rehab to be	28	Head and shoulders of a couple lying in bed together, intimate, looking into each other's eyes. Smiling looking happy.	“Physio said making love is good exercise for the pelvis. It's good for your transverse abdominals”. It wasn't a pleasant experience tryin' a walk again. Being physically fit and strong had always been important to me.... and then it was all taken away”. Heartbreaking	51	Laughing over what the physio said then I wonder if he chose the picture because he would have liked rehab to be more pleasant. He makes the shocking contrast between what was and is. The word 'heartbreaking' is potent enough “and still is” - this is something that is so hard to 'get over'. Rehab is supposed to open up normality again and yet horizons seem to be forever narrowed by TBI.
Chooses his own picture of his life now	1	A wrecked ship, possibly locked in ice, lying on its side, utterly helpless.	“it's just all wrecked and ruined”. “perhaps I would have got married and had children and had a normal life really. Been a respected member of society instead of like being on the fringes of …. society as I am now”. “I haven't got no friends. I haven't got no social life. Only social life I have is the charity shop and that's it. Once I leave there I have none. Ahh, ah, only people I see then is my parents”	52	With his old life there being the possibility of a normality he now doesn't expect. Feeling he has no place in society. Being on the fringes, stuck in his small village, his horizons narrowed by TBI. His loneliness is palpable

Challenges faced in terms of sexuality and intimate relationships	27	A lighthouse being pounded by waves.	“It's havin' a beatin' really. It's strugglin' init? Although it's standing there quite strong and quite.... a powerful thing but it's, it's, it's (1) it's havin' a hard time you know with the sea beating the side of it like.” “This is the thing isn't it, you shown to people? No-one cares, everyone says 'alright James?, You say 'yeah great, sound' but there's no point saying no, no-one wants to know. No-one cares.” “No I'm struggling” “You know I think every person is like that anyway; we're all tryin' a stand up strong and be strong while perhaps things are not going well for us like.”	53	He chooses a picture of a lighthouse being pounded by waves and says very clearly that this is the picture of strength that he puts over, telling everyone he is fine because he thinks that is all they want to hear. He says that he is struggling, he too is being beaten by forces outside himself over which he has no control but he also acknowledges that this is what he thinks everyone does to some extent.
Hope for the future	7	A baby in pink sucking it's thumb	Had been hoping to meet the girl who had been his girlfriend's friend “perhaps fall in love, have a child, p'raps get a part time job.” “As I get older I can't really look after myself so I feel that I wouldn't, I wouldn't be a good parent, or a good role model	54	He is acknowledging that his hopes are changing as he gets older. He had hoped for a normal family but as he ages this feels further from his grasp.

13	A couple walking hand in hand along a beach at sunset, in the foreground a very prominent life ring hooked on a post.	“Long life and good health is what I hope really. As long, you know, as good, as long and as happy a life as I can.” …. “Here is like a man and a woman in love and, p'raps they've got that, that safety. A life buoy is something that they working on together like, in stayin' healthy and livin' a healthy life and stayin' well, lookin' after yourself, not drinkin' and not doin' drugs	55	Still hoping for some kind of long term relationship. Wanting some kind of safety/security within that relationship or perhaps for the relationship. Also considering the idea of working on something together (not one being cared for ?)
35	A desert scene with a broken down car that two people are trying to push. The back wheels seem to be embedding in the sand.	“represents my motability car which is my lifeline to the world and community. 'Cos without the car I wouldn't have been able to come here this morning. …. I wouldn't be able to go to the charity shops in the week, I wouldn't be able to access anything, I'd be, I'd be completely housebound really.”	54	Highlighting the importance of his car as a means of remaining part of the community. Interesting that the picture is of a broken down car – is this his fear?

Participant **R13.10 Jack**	**Picture Chosen**	**Description**	**Quotes**	**Page No**	**My interpretation**
How rehab felt	19	A picture of people seemingly paddling in the sea. In the foreground a yellow sign reading "Danger sinking mud"	Rehab was hard, struggle …. I felt like I was sinking at times	60 – 61	My reading of the picture is that those who are paddling look quite safe. They are some way from the sign. It seems to be a place where the beach is very flat and the tide comes in quickly making the sand/mud unstable and dangerous. I can't see it without thinking of the Morecambe Bay Cockling disaster

1	A wrecked ship, possibly locked in ice, lying on its side, utterly helpless.	I never felt balanced....I thought (I) was a submarine coming up out of the water and latterly, when I achieved something I'm breaking through the waves	60 – 61	Never feeling balanced – feeling unbalanced/out of kilter – knocked on one side. This seems to fit with his Left sided TBI producing right sided weakness. Sense of being a submarine speaks to me of being in a foreign environment. TBI changes everything your physical boundaries, cognitive boundaries, your future, your context. Is the breaking through about coming back up into the air? Into a more familiar environment. Are the waves representative of a barrier? You can swim around beneath the waves in your sub, you can be safe on the surface but there is something tempestuous about the pint at which you break through the waves.
18	Shows a man's head bowed against clasped hands. Looking pensive/praying. Looking sad. Black & white not colour		60	These two pictures aren't spoken about but almost seem to speak for themselves
27	A lighthouse being pounded by waves.		60	

How would you like rehab to be	30	Picture of the Holiday Inn with swimming pool	I'd have liked rehab to be like that but I wouldn't have been able to swim in the pool or on the stairs, been too hot …. stuck in a chair. Now I feel better I want to go on holiday	61	drawn to this picture first but quickly recognising it as fantasy with many impracticalities. His words speak of the limiting nature of TBI. Wanting a holiday now he is better.
	17	Man and a woman crouched down together in a garden. You can see that the woman is smiling and get the impression that the man is too	Attracted to the picture by the smiles "flowers, yeah, someone coming down to my level .... I mean there was in a way, sometimes" Sometimes females would come down to my level, attractive	62	Flowers and a pleasant environment The idea of not being talked down to in his wheelchair is also present. This brings to mind the literal change in his position in relation to women
Challenges faced in terms of sexuality and intimate relationships	18	Shows a man's head bowed against clasped hands. Looking pensive/praying. Looking sad. Black & white not colour	Not knowing where to turn	63 – 64	For sex? For intimacy? For advice?
	35	A desert scene with a broken down car that two people are trying to push. The back wheels seem to be embedding in the sand.	In a barren desert. A wasteland of intimacy	63 – 64	
Hope for the future	3	Man in a natural pool with waterfall	"because he looks content …. there's someone in the water under there making him feel content." Wanting a holiday	64	Desire for content but perhaps wishing there was content stemming from sexual satisfaction

28	Head and shoulders of a couple lying in bed together, intimate, looking into each other's eyes. Smiling looking happy.	Wanting “togetherness”	65	Desiring togetherness/intimacy. Wanting a long term partner. Someone to share the journey

Appendix A

John’s Last Word

A Letter to myself:

Dear John

I remember when you had to go to see a psychologist. I felt down and anxious and I didn't really want to see her, in fact I didn't go to the first session! But now I think psychology is GREAT!!

I have learned about techniques for reducing anxiety, like:- deep breathing and hypothesis testing. I have also found that brisk walking for 20 minutes can help.

I have noticed that I am more relaxed and able to do more things. I have even been able to go out in the evening.

Going to psychology has given me the chance to talk about some really difficult things but I have also talked about some nice memories.

I enjoyed doing the genogram because it helped me to remember people who had been important to me who I wouldn't have thought of otherwise; people like my mother and Mari Lewis, who I loved, and Simon who was my friend. It was good to remember them.

I have thought a lot about my dad in psychology too, despite him having his bad moments. When he died it shocked me in some ways, even though I knew he was dying. I missed him a lot. I have been able to think about the good things as well as the bad things and I found I was able to forgive him.

Psychology has meant enlightenment to me. I feel I know more about life generally. It has showed me the way to live my life. It has been important to me. I wonder what I will remember of it in a year?

Jane used to help me but she had a temper. My dad had a temper as well. In psychology no-one got cross with me.

I would like to remember the good things from psychology, like the times I have felt well and I would like to carry on feeling well.

Section E

Final Reflection – My Response as a Counselling Psychologist

When I began my course almost seven years ago it seemed like this moment when it came would be an ending, a full stop at the end of three years training. Now that the moment has arrived it feels not like an ending but like one more transition in a life long journey. Training has without doubt been a long, painful, expensive, frustrating journey but it has also been a joyful journey of learning and self-discovery and most importantly of meeting with and walking alongside others. It has undoubtedly been the right journey for me.

Just before I began my training Peter Kinderman asserted that he foresaw that clinical and counselling psychology training would ultimately become one (Kinderman, 2009) and while I can see many benefits to this, I hope that counselling psychology does not lose sight of its treasured philosophical foundations and remembers Van Deurzin's wish to mitigate the powerful influence of the spirit of experimental psychology (1990).

Whilst I am glad of my rootedness in evidence based therapy, and along with Cooper (2009) see that there is a value in nomothetic research which we allow to challenge our preconceptions, what I see represented across all the pieces of work herein is a deep respect for the glorious mystery of humanity; the resilience and potential of the human spirit, and the power of metaphor and the abstract. As psychologists we can observe and measure behaviour, and produce theories and models, but ultimately people do not fit in boxes. Neither do they belong in them.

As I write, what is rising to the surface like the cream spoken of by Stern (2007), is the work of McGilchrist (2009) on the split brain; of Schore on the science of the art of psychotherapy; and of Lewis, Amini & Lannon (2007) on the theory of love arguing that the neural systems for emotion and the intellect are separate (p4). Counselling psychology needs to root itself in neuroscience in the way that psychoanalysis is doing within the new field of neuro-psychoanalysis. This is where we will confirm the evidence for the importance of the humanistic philosophy that underpins our discipline. It has been shown repeatedly that it is not the model of therapy but the nature of the therapeutic relationship that is the most powerful factor in therapeutic change.

Beyond the measuring and observation, beyond the deployment of a particular modality, what I see is the need for a truly integrative approach. An approach which is aware of the damage that can be done by power. An approach which has a deep respect and understanding of what it is to be human; that recognises the need to integrate and attend to the whole person; that has a willingness to walk with people in the darkest places and, is rooted firmly in a place of knowledge founded on the broadest possible evidence base. An approach which allows invisible, unmetabolised losses to be explored.