A Foucauldian, Phenomenological Analysis Of Psychological Challenges Experienced Following Spinal Cord Injury

Thesis submitted to The University of Manchester for the degree of Professional Doctorate in Counselling Psychology (DCounsPsych)

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Abstract
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A Foucauldian, Phenomenological Analysis Of Psychological Challenges
Experienced Following Spinal Cord Injury

This study explores potential therapeutic needs of people who have recently incurred a Spinal Cord Injury (SCI) and consequently live with an acquired disability. There are currently more people living with SCI than ever, yet there is still apparently little awareness or understanding of the complexity of the many potential psychological challenges caused by the injury. Despite disability being an inevitable part of existence, it is not consistently theoretically conceptualized other than to involve issues of power and vulnerability, and therapeutic literature relating to physical disability is scant. An inductive approach to the study was taken in order to focus on personal experiences of SCI, and more than one epistemological framework is mobilized in order to more comprehensively understand issues relating to disability and SCI. Using the (apparently conflicting) works of Foucault and Merleau-Ponty to inform a discourse analysis, both the cultural and historical social constructions, and the phenomenologically embodied aspects of disability are balanced to create a more holistic understanding of the experiences of acquired disability as a result of SCI.

Seven participants were recruited for the study from an NHS specialist Spinal Injury Unit. Semi-structured interviews were conducted twice – once whilst participants were inpatients of the Unit, and once soon after they had been discharged. The main body of analysis is divided into three thematic sections: the Ecological – focusing on the roles of power relationships, institutions and culture through language and behavior, The Phenomenological – identifying the body as the primary site of ‘knowing-in-the-world’ and the implications to the sense of self of altered bodily experiences as a result of a new physicality, and The Existential – exploring how SCI can force a reconsideration of the possible significance or purpose(meaning) to be found in living. Trauma is acknowledged but not addressed as a primary focus, while the temporal element to the experience of SCI is identified. Focusing on the recently injured person’s perspective at two significant points post-injury, this study aims to challenge the static concept of disability, and reconceptualise it as something experienced as fluid and context-dependent. The importance and affect of reflexivity in the study is also explored, as well as issues/implications of researcher positioning.

The inter-relatedness of identified dominant themes is discussed in an attempt to illustrate the complex fluid interactions between SCI/acquired disability and individual life contexts. Identified themes are developed using critical disability theory, feminist literature, disability studies and Buddhist thought in order to advance understanding and conceptualisation of disability and the psychological experience of SCI. Education and reflexive awareness particularly regarding the machinations of widespread and embedded power relations relating to disability, as well as their consequences, are indicated as ethically necessary requirements (as an issue of social justice) for counselling psychologists to be able to practice appropriately. Ultimately, it is hoped that by investigating accounts of what affected individuals feel the dominant psychological challenges and difficulties are within their first year of injury, it may be possible for therapeutic services to become more effectively tailored to their specific needs.
Declaration

I declare that no portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

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I am always inspired by Erica Burman and am grateful for all her academic guidance, support and patience – particularly with my petulant self.

Without Thelma Handy holding everything together, I would have definitely fallen apart by now.

Without My Children, I might not have been so committed to my timeframe for completion.

But mainly, Bob Lister – we both know there is nothing that can make things how they were...however, you’ve enabled me to do so much more than I ever knew I could. Thank you.

I hope this will go some way towards empowering others too.
1. INTRODUCTION

1.1 The Study Topic

We (humans) make sense of the world and ourselves phenomenologically, and in relation to each other. Experiencing an acquired disability through Spinal Cord Injury (SCI) can fundamentally challenge this learnt knowledge, understanding and perception of reality for the individual, and consequently can potentially cause a significant amount of psychological distress and need for adjustment. After the initial physical trauma is stabilised medically, the goal of the recently injured individual is to adapt and adjust to a new way of living, often initially in a spinal injury unit (SIU) that is dedicated to specialist treatment and rehabilitation. The number of people living with SCI is constantly increasing as identification of secondary (physical) complications and medical interventions are improving; in 1943, over 90% of SCI patients died within twelve months – now the life expectancy of an individual with SCI is close to that of the general population (Strauss, DeVivo, Paculdo & Shavelle, 2006). This means that there are currently more people living with SCI than ever before, yet the awareness of the potential psychological implications of the injury is apparently not as well developed or addressed as it is of physical needs.

A SCI is a significantly disruptive and potentially devastating life event that can lead to many complicated health issues. The psychological distress that may be caused by the implications of the injury can be acute, and the effects can be enduring. Existing research into the process of adjustment to SCI has focused on issues of denial (Hammell, 1992), loss of control (Chung, Preveza, Papandreou & Prevezas, 2006; 2007), anxiety/depression (Bombardier, Richards, Krause, Tulsly & Tate, 2004; Kennedy & Rogers, 2000), chronic pain (Elliott & Frank, 1996; Galvin & Godfrey, 2001), psychological morbidity (Craig, Tran & Middleton, 2009), poor quality of life (Dijkers, 2005; Martz, Livneh, Priebe, Wuermser & Ottomanelli, 2005) and coping difficulties (Kennedy, Duff, Evans & Beedie, 2003; Kennedy, Lowe, Grey &
Short, 1995; Moore, Bombardier, Brown & Patterson, 1994). However, this (often conflicting) body of work has almost exclusively been written by healthcare professionals and non-disabled researchers observing the phenomena from an able-bodied perspective. A notable exception to this is Mike Oliver (who himself lives with SCI) who has developed the fundamentally transformative social model of disability (1986), which I discuss later in this section. Historically however, research into the effects of SCI has predominantly erred towards a presumption of pathological and inevitable depression, apparently leading to a greater risk of suicide and self-destructive behaviours (North, 1999). I believe that the experience is far more complicated than this, and that no small part of the difficulty for individuals with SCI is that the complexity of the psychological effects of the injury is not widely understood, recognised or addressed. Healthcare service providers are increasingly coming to share the view that ‘SCI will always be life-changing, but it need not be a tragedy and it need not be a burden’ (WHO, 2013), and it has been acknowledged across all disability literature that emotional adjustment is paramount to successful ‘rehabilitation’ (Craig, Hancock, Dickson & Chang, 1997; Galvin & Godfrey, 2001). Psychological interventions that help with coping early on in the rehabilitation process are reported to have beneficial long-term effects for individuals living with SCI (Mehta, et al. 2011), and along with this shift in understanding SCI as something that is not necessarily catastrophic, comes an increased awareness that attention to psychosocial issues and effective psychological interventions can perhaps significantly positively impact an individual’s ability to lead a full and meaningful life post-SCI (Post & van Leeumen, 2012). However, there is still a lot more to be understood about living with an acquired disability such as SCI, and what the potential issues really are. This study was designed with these notions in mind to enable the individuals who know best what it is like, to be able to voice something of their experiences of SCI at two significant points post-injury. The hope is that this research will enable a more in-depth understanding of what might be required from therapeutic practitioners working with SCI (and other
disabilities), as well as from rehabilitation staff, nurses, consultants and other agencies.

1.2 Thesis Structure

The rest of this opening chapter provides some background to SCI and disability, and considers the topics in relation to counseling psychology. It outlines key aspects of the study, the nature of already existing literature, and relevant conceptual frameworks from which to approach SCI and disability. Chapter 2 presents the methodology; epistemological frameworks and analytical approaches used to conduct the study are outlined before ethical considerations are discussed. The participants are introduced, stages of analysis identified, and issues of validity versus trustworthiness are considered. Chapter 3 constitutes a reflexive analysis that focuses on the importance of reflexive practice, positioning, offering an account of the research, situating the study and attending to broader political dimensions relating to disability. Chapter 4 presents the analysis of participants' interviews. It identifies dominant themes/issues and organises them into sections; the Ecological, the Phenomenological, the Existential, Trauma, and the Temporal. Finally, chapter 5 takes up emerging issues and reflections from the analysis, discussing time and SCI, and the interrelatedness of the identified dominant themes before developing emergent issues in relation to other existing literature in order to advance understanding of disability and the psychological experience of SCI. Limitations, omissions and implications of the research are identified before the thesis is brought to conclusion.
1.3 Spinal Cord Injury

1.3.1 Epidemiology

Globally, between 250,000 and 500,000 people incur SCI every year (WHO, 2013), although accurate figures of the incidence, aetiology and demographics are unreliable due to unrecognised injuries and injuries not treated in dedicated SIUs (Chen, Tang, Vogel & DeVivo, 2013). Also, the majority of such data has been collected from the Western world and so true global statistics are unclear (Soopramanien & Grundy, 2002). In the UK, there are approximately 1000 new injuries annually, and around 40,000 people are currently living with SCI (apparelyzed, 2017). Most SCI occur between the ages of 16-30 (Go, 1995), but as the general age of the population rises, so does the average of injury (Wilder, 2011). Adolescence and older age are the two most likely times to incur such an injury (WHO, 2013). Statistically, males are more likely to sustain a SCI than females at a ratio of approximately 4:1 (Jackson, Dijkers, DeVivo & Poczatek, 2004; NSCIC, 2005; Sarhan, Saif & Saif, 2012). The leading causes of SCI are road traffic collisions, falls and acts of violence, with sports-related injuries also significant contributors (White & Thumbikat, 2012).

1.3.2 Mechanism Of Injury

SCI occurs as a result of either traumatic (lesion or severance) or non-traumatic (infection, tumour or circulatory disorder) damage to the tubular bundle of nervous tissues that, along with the brain, constitute the central nervous system. Damage to the spinal cord results in the interruption of necessary and constant communication between the brain and body, and consequently causes loss of function and sensation below the level of injury (paralysis). The impact of the injury is directly related to the location of the damage to the spinal cord – the closer it is to the brain, the greater the proportion of the body is affected as it will disrupt motor and sensory
communication from the point of injury down the entire length of the cord. Medically, the spinal cord is described as divided into three regions; the cervical (C1-8), the thoracic (T1-12) and the lumbar (L1-5) spine. SCIs are described by their vertebral location, as it is good indication of how much of the body may be affected, and how it can be treated. Additionally, the International Standards for Neurological Classification of SCI (Burns, Biering-Sorensen, Donovan et al., 2012) describes all injuries as either ‘complete’ or ‘incomplete’, referring to the severity of damage to the spinal cord itself. With an incomplete injury, the cord is only partially severed, often allowing the injured individual to retain or recover some function and sensation depending on the extent of their injury (Burns et al, 2003). If the spinal cord is fully severed, then no function or sensation can be felt or regained below the level of injury; it is a ‘complete’ injury. Some patients initially presenting with a complete injury may transpire to have sustained an incomplete injury (Grundy, Swain & Fulton, 1997).

Sometimes referred to also as quadriplegia, tetraplegic injuries are the result of damage to the cervical spinal cord and are the most severe, typically creating (degrees of) paralysis in all four limbs. Tetraplegia is likely to produce problems with bowel and bladder function and sometimes also respiration/swallowing. Paraplegia occurs when the lower half of the body is affected and is the product of damage to the thoracic spinal cord. Again, issues with bowel and bladder control are common. Very low-level injuries to the lumbar spine don’t usually cause paralysis, but can cause significant nerve pain and interfere with bowel/bladder and sexual function.

1.3.3 Enduring Physical Effects Of SCI

The long-lasting physical effects of SCI vary significantly between individuals even with the same sort and level of injury, so accurate prognoses are difficult to make. The enduring outcome of SCI depends in part on the nature and level of the injury, but also on the quality/speed of medical care, luck, and, significantly, psychological health in order to meet
the many potential challenges of the injury. Rehabilitation time after SCI is dependent on the individual needs caused by the level/nature of injury, but usually lasts (in the UK) between three and six months. Ideally, this time is spent in a dedicated SIU where the individual can be assisted to adjust to their new circumstance both physically and psychologically. Typically, in this environment individuals are taught how to manage their personal care (e.g., bowel/bladder routine), learn wheelchair skills, and re-establish (often in new ways) relationships, independence and working/social life. The psychological adjustments and effort that must be made during this time can be as, or more overwhelming than the physical ones (Webster & Kennedy, 2007). New problems to be overcome or negotiated are potentially encountered daily by the injured individual during rehabilitation, as social participation and simple every day activities can be affected by restricted mobility. If arm/hand function is impaired, then previous experience of independence can be significantly compromised as the ability to eat/drink and self-care activities such as washing and toileting can be difficult, or even impossible. Consequently, the risk of poor mental health after SCI is increased (Chevalier, Kennedy & Sherlock, 2009), and feelings of inadequacy/devaluation are common (Mattlar, Tarkkanen, Carlsson, Aaltonen & Helenius, 1993), as well as reported lower levels of subjective wellbeing (Leduc & Lepage, 2002; Kemp & Krause, 1999). The World Health Organisation (WHO) have acknowledged this by classing mental health services as an ‘essential measure for improving the survival, health and participation of people with spinal cord injury’ (WHO, 2013).

1.3.4 Psychological Adjustment To SCI

Increased levels of psychosocial distress are common for the individual with SCI (and their significant others), particularly in the period immediately after discharge from hospital/SIU as it is at this point that the reality of the enduring disability is often most felt/realised (Povolny, Kaplan, Marme & Roldan, 1993; Scivoletto, Petrelli, di Lucente & Castellano, 1997; Tate, Maynard & Forchheimer, 1993). Coping ability is thought to affect quality-
of-life after SCI even more than the level of injury or functional impairment (Martz, Livneh, Priebe, Wuermsen & Ottomanelli, 2005), as living with issues such as chronic pain or high levels of distress (for example) can profoundly affect the individual’s experience of life (Frank & Elliot, 1996; Galvin & Godfrey, 2001). Consistent with this notion, early psychological interventions during the rehabilitation process that might help with coping with the enduring reality of acquired disability are reported to have beneficial and long-term effects (Metha et al., 2011). However, theories focusing on stage models (Livneh & Antonak, 1990), sense of self (Charmez, 1983), adjustment (Yoshida, 1993) and quality of life (Bishop, 2005; Livneh, Martz & Wilson, 2001) have all fallen short in their attempts to clarify specifically (or even particularly usefully) what might enable an individual to thrive post-injury. Whilst there is plenty of research in rehabilitation literature into understanding the dynamics of psychosocial adjustment/adaptation to acquired disability, there is little consistent or conclusive evidence to show that any current theories of adaptation (e.g., Frank & Elliot, 2000; Wright & Kirby, 1999) have been translated into effective therapeutic conceptualisations/interventions (Parker, Schaller & Hansmann, 2003). It has, however, been acknowledged that adjusting to an acquired disability such as SCI is likely a lifelong process (Kendall & Buys, 1998), and is one that is multidimensional, complex and individualised (Bishop, 2005).

1.4 Disability

Disability is a natural and inevitable part of human existence, yet there is no one definition of what we mean when we use the term; conceptualisations of disability are various and with often conflicting ontological perspectives (Olkin, 2012; Smart & Smart, 2006; Swain & French, 2000). The Merriam-Webster dictionary defines disability as ‘a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s
ability to engage in certain tasks or actions or participate in typical daily activities and interactions’. Under the Equality Act (2010), you are disabled ‘if you have a physical or mental impairment that has a substantial and long-term negative effect on your ability to do normal daily activities’. Issues of disability cross academic fields of medicine, sociology, history, politics, art and literature, psychology and counselling. A common component part of any concept of disability, however and from wherever it is approached, is that it cannot be discussed without acknowledging issues of power and vulnerability. Disability is commonly used as an umbrella term to bundle together individuals with a broad range of differing impairments that become the cause of a common experience of discrimination/oppression from the dominant able-bodied community. Whilst this study is specifically focused on issues arising from the experience of acquired physical disability caused by SCI, some issues may usefully translate to issues of disability more generally, be it acquired, congenital, physical, developmental or otherwise. Throughout, I use the terms ‘disability’ and ‘disabled’ descriptively.

When considering disability, two questions are regularly posited: Who is responsible for the disability? and Who is responsible for the solution? (Smart & Smart, 2006). Theories have powerful influence over research and healthcare interventions regarding disability (Smart, 2009), and it is necessary to know how these questions have been answered traditionally, and with what implications for those involved. Historically, models of disability have tended to be static, reductionist and time/culture bound, and as a consequence they fail to give complete account of the experience of disability (Johnston, 1996; Oliver, 1996; Thomas, 2007; Reeve, 2002; Watermeyer, 2012). Acknowledging some of the flux in the experience of disability, it has been suggested that it might be better understood as a series of changing identities over time (Darling, 2003), however this too seems to suggest that disability is static, and it is the individual who somehow changes around it. From the perspective of the affected individual, however, the challenge of living with disability is often as much about
managing the tensions between the various constructions of them as disabled (Crisp, 2002). For the last two centuries, Western society has viewed disability primarily as a medically incurable (and therefore tragic) individual issue (French, Gilson & Depoy, 2000; Lancet, 2009; Wilder, 2011). Economically, the consequences of disability have reduced individuals to being either needs or work-based subjects (Stone, 1984), whilst aesthetically, the current cultural demands for physical ‘perfection’ and total independence are often unobtainable. Combined, these constructions of disability subtly, but comprehensively, serve to brand disabled individuals as socially devalued, unattractive, biologically inferior and fundamentally disempowered (Shakespeare, 1993). I suggest that there is perhaps a very real benefit for all individuals (whatever our dis/ability) in (re)conceptualising disability by holistically integrating various ideas/values from opposing models as fundamentally fluctuating multiple versions of reality that are situation-dependent. With this in mind, the following sections outline dominant models that can be seen to permeate throughout society and affect how we approach our understanding of disability.

1.4.1 Medical Model

Undoubtedly, the primary and most influential cultural discourse in relation to the human body (Lancet, 2009), the medical model of disability locates ownership of the ‘problem’ firmly with(in) the individual as a defective, abnormal failure of their bodily system. It objectively and pathologically reduces the individual to some sort of categorisation dependent on diagnosis from a medical expert (Natiello, 2001; Oliver, 1996; Swain, French & Cameron, 2003; Thomas, 2007). The institutional positivist focus of the medical model on diagnosis, cure, reducing impairment/limitation, and rehabilitation maintains disability as deviation from normalcy. The assumption is that disability (as an abnormal condition that (necessarily) causes disadvantage) must be treated by first reducing the individual to what it is that is ‘wrong’ (Longmore, 1995), in order to then fix, manage or
minimise it. Being incurable, disabled people are perceived through this model to be of less worth than those with potential to recover ‘back to normal’.

The medical model is seen to be a model of limitations and ‘control by experts’ which reduces the individual to inferior, subordinate (and ideally passive) ‘patient’ who is in need of ‘fixing’ (Imrie, 1997; Smart, 2009; Smart & Smart, 2006). In return, disabled people are expected to obediently (and gratefully) spend time learning how to be helped by often dogmatic (even authoritarian) expert professionals (Natiello, 2001; Olkin, 2012). This maintains the understanding of disability as something firmly embedded in the medical establishment, and thus relinquishes society of any responsibility (Barnes, Mercer & Shakespeare, 1999; Oliver, 1996; 1998; Wilder, 2011). Instead, there is responsibility placed upon the individual to be fully motivated, compliant and infinitely adaptable in relation to their disability (Smart & Smart, 2006). The focus of the medical model on inability/limitation and dependency constructs disability as something pitiable and fundamentally disempowering by its denial of potential for independence, control and choice (Imrie, 1997; Olkin, 2012; Smart, 2009).

1.4.2 Social Model

For many years there was no challenge to the medical model conceptualisation of disability, and no consideration for the (subtle but important) difference between the concepts of physical impairment and disability (Oliver, 1990; Shakespeare, 1993). Since the middle of the 20th Century however, disability has become gradually redefined socio-politically as the detrimental consequence of a society that views restrictions caused by impairments as defects or flaws, and thus as social devaluation (Tremain, 2005). Formulated in direct opposition to individualistic, pathological models of disability, the social model focuses on the negative psychological impact for the affected individual of a disablist physical and social environment that systematically fails to accommodate impairments (Oliver
The restructuring of disability as the oppression of an impaired individual by their environment (Stubbins, 1998) counterbalances the dominant medical approach, and highlights the disabled person’s experiences of discrimination and segregation in an attempt to make society more inclusive (Oliver & Barnes, 2012; Olkin, 2012; Reeve, 2002). Using this model, disabled people can be empowered to take control of issues of social justice, and assert disability as a societal issue rather than an individual issue of physical abnormality (Oliver, 1996; Swain & French, 2000; Swain, French & Cameron, 2003).

1.4.2.1 Psycho-Emotional Model
The social model continues to evolve. In response to criticism that it has ignored, and therefore delegitimised, emotional and individual experiences of disability (Reeve, 2002; Thomas, 2007; Watermeyer & Swartz, 2008), the psycho-emotional model has built upon the social model to also acknowledge and address the emotional challenges of being constant recipients of negative attitudes/prejudice within society, despite fears that it might potentially aggravate and fuel existing stereotypes of damaged/helpless disabled people (Watermeyer, 2012). Without this acknowledgement of difficult experiences, ‘negative’ emotions regarding perceptions of disability can be inhibited for fear of risk of losing social support (Reeve, 2002), and there is a danger that affected individuals might become emotionally isolated by retreating from society altogether (Watermeyer & Swartz, 2008).

1.4.2.2 Affirmation Model
The Affirmation Model is grounded in the social model, but goes even further to directly challenge the non-disabled presumption that disability necessarily equates to personal tragedy (Cameron, 2008; Swain & French, 2000). It is a positive model of disability that has developed out of disability culture and celebrates the group disabled identity as valuable shared understanding of social barriers. The affirmation model validates feelings of frustration and anger as potentially appropriate reactions to institutional
discrimination/marginalisation, but also celebrates individual differences in experience and perception by addressing the various meanings of disability in people's lives. The affirmation model, as the name suggests, prioritises positive aspects of disability, and asserts the view that many disabled individuals can(do) lead full, satisfying lives (French & Swain, 2004). As a model that is not based on able-bodied presumptions of living with disability, the affirmation model has a tendency to be rejected by mainstream culture as unrealistic; the notion of pride in disabled identity is hard to imagine from a non-disabled perspective as there is such a divide between the experience of being disabled and non-disabled. Consequently, collective expressions of strength and pride (for example, in the disability arts movement) are sometimes reinterpreted (oppressively) as a lack of acceptance, or (patronisingly) an expression of courage/bravery (Cameron, 2008; Swain & French 2000).

It is now widely accepted amongst the social sciences that disability is more than just a physical issue for an individual. A more holistic perspective of the experience of living with disability can enable recognition and develop awareness that there is embedded societal oppression and discrimination loaded upon disabled people at an institutional level that permeates attitudes on all strata of society (Oliver, 1996; Oliver & Barnes, 2012).

1.5 Rehabilitation

Immediately after an injury to the spinal cord in the acute stages, prioritising medical interventions is imperative as SCI is ultimately life-threatening. The chronic phase of care, ideally in a specialist rehabilitation SIU, focuses on sensory, motor and autonomic dysfunction treatment, and is most effectively undertaken with a multidisciplinary team-based approach (Saulino, 2017). The notion of rehabilitation – ‘to return someone to a good, healthy, or normal life or condition’ (Cambridge dictionary) fits with the
medical construction of disability as something abnormal to be fixed or managed. The primary goals of rehabilitation following SCI are necessarily medically focused on the prevention of secondary complications, maximising physical functionality, and finally reintegration into the community (Saulino, 2017). Functional goals (in both the short and long term) are determined by specialist physicians based on the individual’s injury diagnosis, as well as their more general medical and social status (Nas, Yazmalar, Sah, Aydin & Ones, 2015). During rehabilitation, there is emphasis given to maximising ‘potential and independence (so individuals can) have choice and control over their own lives’ (National Health Service [NHS], 2016). This takes the form of physiotherapy focusing on the function of the lower extremities/mobility, occupational therapy focusing on difficulties in daily living activities, and management of bowel and bladder dysfunction (Saulino, 2017). An important feature of this rehabilitative period, that is perhaps not always fully acknowledged medically, is the need to restore, improve or maintain the affected individual’s emotional and psychological state. The National Institute for Health and Care Excellence (NICE) guidelines for rehabilitation after critical illness in adults (2009) identifies that an individual may be at risk of developing psychological co-morbidities if they display symptoms of low self-esteem, poor/low self-image, relationship difficulties, and/or new or recurrent somatic symptoms of anxiety, depression and post-traumatic stress disorder (PTSD). Whilst depression is not an inevitable natural process post-SCI, it is a common and serious potential complication of the injury; around 1/3 of affected individuals will experience symptoms of depression in the first six months after injury, and suicide is one of the most common causes of death after SCI (Nas et al., 2015). The same source reports frequency of PTSD post-SCI at 17% and usually occurring in the first five years after injury. The intensive rehabilitative period after SCI usually lasts 12-24 weeks. It is likely, therefore, that people regularly get discharged from a SIU into a home environment with ongoing (and perhaps unrecognised) mental health needs.
1.6 Counselling Psychology, Disability and SCI

The counselling psychologist is as vulnerable as any other individual to ingesting the commonly held negative constructions and attitudes towards disability that permeate society. As a member of a profession that proudly aligns itself with the notion of social justice, however, there is an ethical obligation to embrace issues of inequality and discrimination in both practice and research, and become ‘knowledgeable about the diverse life experiences of the clients they work with’ (British Psychological Society [BPS], 2013, Pg. 7) -not least to be able to question inequitable political, economic and social practices. Regarding issues concerning disability, this appears to have been left consistently unaddressed in counselling training (McLeod & Machlin, 1998; Parkinson, 2006), and consequently unconscious assumptions can be left unchallenged, despite the widely acknowledged fundamental importance of a non-judgmental approach to counselling (Merry, 2002). Despite the concerted efforts of the social disability movement, disability remains largely invisible in society through segregation and discrimination, so the majority of non-disabled people (therapists included) form their perceptions of disability through media portrayal, which tends to rely on negative and inaccurate stereotypes (e.g., the ‘suffering cripple’ in need of charity and pity [Olkin, 2012]). Without identifying and addressing the chasm between the (absent and oppressed) disabled and (prevalent and privileged) non-disabled communities, there is little or no chance for the able-bodied population (including psychological therapists) to begin to be able to comprehend the experiences of disabled people (Rosenberg, 2009). I hope that this thesis will help counselling psychologists and other therapists to develop a more nuanced conceptualisation of disability by privileging the voiced phenomenological and existential experiences relating to disability of affected individuals themselves.
1.7 Current Research (And Limitations)

What follows is an overview of existing literature pertaining to disability and SCI.

1.7.1 Disability Literature

Psychological/counselling therapy provision for (particularly newly acquired) disabled individuals is likely to present some common issues of disability experience such as living/coping with pain/physical limitations or managing medical interventions. It is also important to be aware of the potentially equally (or more) disabbling and devastating effect of issues of prejudice and discrimination, and possible internalised oppression, that a disabled individual may well experience (Reeve, 2000). Despite the potential for struggle with any/some of these difficult issues on top of anything else a client might bring, counsellors seem to have avoided disabled people as a client group (Reeve, 2014). Counselling psychology literature appears to reflect (or even contribute to?) this. In my experience of training, issues of ‘diversity and difference’ are routinely addressed regarding gender, sexuality, race, religion and social class, yet there is scarcely a mention of issues of disability. This is despite the BPS ‘Standards for Accreditation of Doctoral Programmes in Counselling Psychology’ (2017a) specifying the need to ‘be aware of attitudes towards disabled people and the social construction of disability, and appropriate models for practice’ (pg. 17). The scant attention that is given to the topic is almost less helpful than perhaps if there had been none; disability is predominantly presented as a pathological issue of loss (Parkinson, 2006; Reeve, 2000; 2004) or, worse, the disabled individual’s struggle for autonomy and independent identity has been likened to developmental issues in adolescence, asserting significant parallels with the infant/caregiver relationship (Wilson, 2003). This is, to my mind, an irrefutably dangerously patronising construction of disability. There are a few notable positive
perspectives from which to consider issues relating to disability such as from Corker (1999), Reeve (2002), Parkinson (2006) and Olkin (2012) – all authors who themselves live with disability and openly challenge the medical model paradigm, however these are not all presented in mainstream therapeutic literature. Generally, the disabled lived experience is not very present or strongly voiced in disability literature concerned with psychological therapy (Rosenberg, 2009), and so the dominant perspective is one of able-bodied assumption generally based in the medical model.

1.7.2 Depression/Grief

The perceived inevitability of depression and/or grief following SCI (e.g., Judd, Burrows & Brown, 1986) was challenged as much as 25 years ago by a study that came to the conclusion that ‘psychological morbidity is not an inevitable consequence of SCI’ (Hancock, Craig, Dickson, Chang & Martin, 1993. p.354.). The same paper also questioned the widely-held assumption that the individual who has recently sustained SCI must inevitably pass through the Kubler-Ross (1969) stages of grief. More recent research is less inclined to position itself absolutely either way (see Hassanpour, Hotz-Boendermaker, Dokladal & Curt, 2012 vs. Fann, Bombardier, Richards et al., 2011), yet whilst it is (of course) relevant and important to consider, the volume of psychological/therapeutic research concerned with SCI that focuses on an assumed inevitability of loss/depression/grief seems disproportionately large and not necessarily representative of lived experiences.

1.7.3 Wellbeing/Quality-Of-Life

Positive psychology has shifted the focus of post-SCI psychological investigation to issues of wellbeing, resilience and quality-of-life (for example, Dorsett, 2010; Kilic, Dorstyn & Guiver, 2013). However, to measure an individual’s psychological health after SCI purely in terms of resilience,
hope or acceptance could serve to deny or forget the inevitability of periods of understandable and appropriate sadness and/or anger that may fluctuate simultaneously alongside these concepts. Measuring quality-of-life is also difficult; it is a particularly subjective and fluid notion that is typically focussed on health, environment and social interaction – and from an able-bodied perspective. If these areas are measured quantitatively and comparatively with the able-bodied population, quality-of-life post-SCI can potentially be misinterpreted as poor (Middleton, Tran & Craig, 2007).

1.7.4 Enablement/Participation

By definition, rehabilitation literature concerned with SCI focuses on research dedicated to issues of enablement that may assist the transition from being a patient to an active member of society. All efforts appear to be focused on factors that make participation possible, including the attitude of the recently disabled individual - thus making rehabilitation solely their responsibility. Not commonly addressed (or even acknowledged) in this literature is the (mainly negative) attitude of society towards disabled individuals and the barrier this might form to being able to lead a meaningful life. As expected, nursing literature is primarily concerned with how individuals might practically (and as independently as possible) deal with specific physical issues that are common comorbidities alongside SCI; bowel and bladder/spasticity/pressure sores etc., as well as trying to understand and promote the impact of good professional care. For a typical example of this sort of literature, see Hammell, 2013.

1.7.5 Adjustment

Specifically relating to individuals who have recently acquired SCI, the body of research concerned with treatments/interventions for psychological adjustment emphasises the role of learned coping strategies (Elfstrom, Kreuter, Ryden, Persson & Sullivan, 2002; Kennedy, Duff, Evans & Beedie,
2003; Pollard & Kennedy, 2007), although it is not universally agreed that this training is necessarily effective (Chevalier, Kennedy & Sherlock, 2009). It is also not clear what the focus is of the ‘coping’; historically it has been problem-based, but Song’s (2005) research found that emotion-focused coping had more influence on lowering levels of stress and successful social reintegration. Other research has asserted that psycho-emotional self-empowerment through counselling can be of huge benefit to individuals with physical disabilities (Johnson, 2011; Oliver, 1995), whilst an interesting sociological paper explores the idea of a possible need to reshape ‘self’ after traumatic SCI through a model of identity reconstruction and transformation (Yoshida, 1993). This alternative focus on exploring the subjective experiences of those living with acquired disability seems to bring into relief the potential importance of understanding the notions of both self and disability as fluid and situation/time dependent.

1.8 Conceptual Frameworks

In this section I outline the main conceptual frameworks informing this study. Whilst the combination of Foucauldian and Phenomenological approaches may be unusual and potentially give rise to some tensions, I suggest below that they might also be complementary and mutually informing for both the methodological approach and analytical process of this thesis. These theoretical frameworks, once independently mobilized, do not remain independent of each other in this thesis – instead, they become integrated through the analysis of the data to create a synthesized understanding that I attempt to illustrate diagrammatically in the Methodology chapter (2.2.5).

As potential advocates of the humanist assertion that the phenomenological experience of clients is always valid/valued, it seems perverse that counselling psychologists have so little research on which to base the
facilitation of holistic wellbeing for individuals recently injured by SCI that pays ‘particular attention to the meanings, beliefs, context and process that are constructed both within and between people’ (Orlans & Van Scyoc, [2008] pg. 18). Primarily informed by my own personal experience of SCI (albeit not one of particularly significant enduring consequence) alongside some anecdotal knowledge of the experiences of friends/acquaintances, I have been acutely aware for some time of a general lack of understanding of the complex and fluid experience of ‘being-in-the-world’ after SCI amongst and from practitioner psychologists and other counselling therapists. Existing research, as previously mentioned, is dominated by ‘experts’ investigating specific phenomena in various disciplines, predominantly from an empirical and able-bodied perspective that assumes disability to be static. I do not feel that this illustrates well enough the complexity of the challenges and particular experiences of SCI and consequently, in preparation for this study, I conducted a qualitative systematic review of first-person narrative accounts of the experience of SCI. Only six papers and one book were identified as focusing exclusively on first-person accounts of the experience of SCI and did not pathologise disability (see appendix 1). From these, it became clear that the (political as well as personal) effects of social constructions of power, and the phenomenological (fundamentally existential) challenges and questions created by the injury are intrinsically bound to the nature of SCI. I outline conceptual frameworks that help focus on these issues in the sections below.

1.8.1 Foucault And Bio-Power

Common to all disability discourse is the issue of power inequality. Foucault (1926-1984), whilst not dealing specifically with physical disability, focused in his later works (e.g., 1982) on analyses of cultural and historical discursive constructions of power relations between institutions and the body. He described a ‘carceral archipelago’ (1977. Pg 297) which consists of judicial, educational, industrial and medical institutions that utilise the disciplinary practices of penal institutions (which ‘rehabilitate’ individuals
who deviate from the norms, as created by the institution itself) and bring them into the mainstream. In contemporary society, hospitals fundamentally exercise disciplinary power in the form of ‘bio-power’ (Foucault, 1978) as they are focused specifically on the capacity and potential of the body, and employ dividing practices (Foucault, 1982) that serve to objectify the individual as healthy/sick or curable/non-curable (Sullivan, 2005). Medical experts possess extraordinary (often unchallenged) power over individuals and make judgements of them that are essentially defining ‘normal’ from ‘abnormal’. These constructions are focused on producing a certain type of body that may be ‘subjected, used, transformed and improved’ (Foucault, 1977. p136), but also subjectify those who deviate from the institutionally defined norm. This process of subjectification establishes a potent power imbalance (whether the ‘subject’ is at the mercy of a dominant individual or institution) (Foucault, 1982), and the individual’s existence becomes restricted by the subordination imposed upon them as dis-abled. For those who have sustained enduring physical injuries and experience their bodies as technically restructured within a medical, rehabilitative discourse, their subsequent way of being becomes restricted by the disciplinary techniques this form of knowledge accords them (Sullivan, 2005); they have become subject to a new law of bio-medical truth, which, by the process of normalisation, imposes upon them a new and total disabled identity.

1.8.2 Merleau-Ponty, The Body And ‘Being-In-The-World’

Merleau-Ponty was an existentialist who challenged the Cartesian mechanistic view of the body (1962). He rejected the fundamentally dualist subordination of the body to the mind which had hitherto governed most philosophical and metaphysical thought, instead positing a holistic unification of mind and body on a continuum that is constantly aware and prioritising one or the other depending on circumstance; when needed, the mind comes to the fore and the physical recedes into the background, and vice versa (Bullington, 2009). This is an important notion when considering
the lived experience of acquired disability, as this fluctuating sub-conscious awareness becomes intensified and is potentially brought more into conscious experience. Additionally, the re-conceptualisation of conscious embodied subjectivity (phenomenology) is dependent on perception, as it simultaneously locates the body as subject (perceiver) as well as object (perceived) (Crossley, 2001). If the body is the vehicle through which we both perceive and inhabit the world, it must then be both sentient and sensible (Crossley, 1995) and constitutes reversible aspects of the same being. The body as ‘being-in-the-world’ then becomes the ‘zero-place’ (Svenaeus, 2015) that locates the self relationally in space and time. By accepting this, one must also accept the necessarily perspectival nature of perception through the articulation of body and world (Merleau-Ponty, 1968). The behaviour of others effects a physiognomic meaning for those observing it. Behaviour is experienced/understood as immediately meaningful as it assumes a commonly held cultural form; it is not an outer representation of an inner state, but is what we are – it is subjectivity (Merleau-Ponty, 1964). This also means that perception is based in acquired habit and culturally-based behaviours that are actively inquisitive and engaged. Thus, the active body embodies meaning. This notion has significant implications when we suddenly experience (through acquired disability) our body as in-active. Considering embodied directedness, it is possible to understand how our interactions with others give us another perspective on ourselves so that we can experience ourselves as something other. This process, according to Merleau-Ponty (1964) is significant in forming self-identity, and becomes especially important to consider after our vehicle for ‘being-in-the-world’ (the body) becomes altered and/or compromised by disability.

1.8.3 Sartre and Existentialism

Using Sartre’s assertion that ‘existence precedes essence’ (1956) as a starting point, life immediately after SCI can be understood as with potential
for existential crisis as the consequences of the injury potentially force a reconsideration of the significance or purpose to be found in living and existing. Personal independence and the notion of existential agency are also fundamentally challenged by the injury. The attempt to find personal meaning, in what could be experienced as a possibly meaningless universe, leads to the potential for existential contemplation of both/either religion and suicide, and thus ‘finding meaning/purpose’ may be of fundamental concern for individuals post-injury.

1.8.4 Critical Disability Theory

Originally emerging from Black Civil Rights and Women’s Liberation movements, identity politics movements have arisen focused on marginalised and oppressed positions/identities, and are concerned with challenging cultural and political issues of repression and injustice (Bernstein, 2005). Not every citizen lives an equitable life, or feels adequately included in society, and such movements spread to give voice and empowerment to other marginalised groups (e.g., those identified by sexual orientation). Amongst individuals who face recurring issues of discrimination and social exclusion are disabled people who have been traditionally identified as subjects of social welfare or charity. The daily experience of a disabled person is often one of cultural, social, political, legal and economic inequality where issues of access, participation, rights, liberty, exclusion, agency and identity have all been compromised because of their disability (Devlin & Pothier, 2006). Disability groups have been painfully slow to come to the identity politics movement as it was originally fiercely resisted by key figures within disability studies (in case of compromise to the central focus of subjective experience). However, so long as people are marginalised or oppressed because of their identities, there will be a need for such activist alliances that demand recognition precisely on the basis on which they have previously been denied. Critical theory evolved from Marx’s critique of capitalism and effectively conjoined with feminist, race and queer theories has encouraged a move towards critical disability studies which
fundamentally views disability as ‘both a lived reality in which the experiences of people with disabilities are central to interpreting their place in the world, and as a social and political definition based on societal power relations’ (Reaume, 2014. pg. 1248). Critical disability theory (CDT) has emerged from this formulation as a useful conceptual framework which situates issues of power and context in relation to disability as essential component parts of addressing oppression and marginalisation from the embodied experience (Hosking, 2008). This theoretical approach establishes disability as essentially a question of politics and power(lessness), rather than one of health, medicine or compassion, and works to deconstruct and defamiliarise common practices as tools that establish power through the objectification, management and control of a-typical bodies (Meekosha & Shuttleworth, 2009).

1.8.5 Combining Epistemological Standpoints

Traditionally, the works of Foucault and Merleau-Ponty have not been considered to be compatible epistemological standpoints from which to consider issues of the body. Whilst apparently divergent in their conceptualisations and focus of attention, they are, however, not necessarily incompatible merely because their respective approaches/formulations do not acknowledge the presence of the other (Crossley, 1996; Hetterley, 2015; Hughes, 2005). By adopting a more holistic perspective, it is possible to understand the body as both inscribed and lived (Levin, 2008). For this thesis, I propose that the work of Foucault can be used to focus on cultural and historical constructions of the (dis-abled) body, and explore issues of oppressive power that are created and actively maintained through societal and institutional discourses, ensured by normalisation and control of the subjected, objectified individual. To balance this post-structuralist view of the disabled body as (potentially) lacking agency (Hughes, 2005), Merleau-Ponty’s conceptualisation of the body as active perceiver(subject) as well as perceived(object)(Crossley, 2001) serves to assert that the body itself is the source of subjectivity and agency. This acknowledges that the
phenomenological everyday embodied experience needs to be understood as significantly affecting an individual’s perception of self (perhaps especially in relation to others) when the body has become altered by acquired disability. Consequently, by combining these epistemological standpoints, the disabled individual can become more comprehensively understood as both a contextualised and embodied being.

1.9 Research Aims

The aims for this thesis are threefold: Individuals adjusting to life after traumatic SCI have many more psychological needs than current literature (from whichever discipline) might suggest. There is a noticeable glaring void in counselling/psychology literature concerning disability generally, and many of the specific psychological issues of the experience of self and disability for those with SCI are overlooked. Existing research has been dominated by experts empirically investigating specific phenomena and consequently is narrow in its assumptions and conclusions. The rationale for this research is that by focusing on the recently injured person’s perspective of what they themselves feel the dominant challenges and difficulties are, and how they understand themselves/feel understood in relation to disability, I hope to be able to provide a truer picture of some of the biopsychosocial issues that might arise as a result of SCI. I also hope to challenge the static concept of disability and develop an understanding of it as something experienced as fluid and context-dependent. This will then go some way towards enabling counselling psychologists, therapists and other service providers to be able to more effectively tailor their services to the specific needs of the SCI service user. To this end, my specific research aim here is to investigate potential psychological challenges for individuals who have recently sustained SCI via an interview study.
2 METHODOLOGY

2.1 Introduction

This chapter outlines the epistemological frameworks and analytical approaches used to conduct the study. It discusses the ethical considerations of the research before going on to specify practical details. The seven participants of the study are introduced and contextualised, and finally the method of analysis is explained and issues of validity/trustworthiness are explored.

2.2 Epistemology

For the purpose of this research, I am mobilising more than one epistemological framework in order to attempt to more comprehensively understand issues relating to disability and SCI. The apparently conflicting epistemologies of Foucault and Merleau-Ponty (as previously acknowledged) will be combined with the humanistic philosophical values and social justice agenda of counselling psychology to form a holistic epistemological foundation for an inductive, analytical approach to the analysis.

2.2.1 Counselling Psychology Philosophy

The definition of counselling psychology given by the BPS (2017) firmly emphasises the core importance of humanistic values. The profession's philosophical rootedness in a postmodern and socially constructed understanding of multiple ‘truths’ (Orlans & Van Scyoc, 2009), converges with this humanistic perspective to create a committed interest in the human condition that is constantly seeking to develop understanding of the essence of humanness/relational being (Cooper, 2007; 2009; Joseph, 2008).
Consequently, the essential commitment of the counselling psychologist is to both recognise and give value to a client’s (inter)subjective experiencing of the world in order to help facilitate their empowerment and self-actualisation, whilst also appreciating and recognising the forces of their social context (Cooper, 2009; Strawbridge & Woolfe, 2014).

2.2.2 Epistemological Marginalisation Of Disability

To date, most existing research into the psychological effects of (acquired) disability has been conducted from a medical epistemological basis, which perpetuates and legitimises the marginalisation of disabled people (Kitchin, 2000) by continuing to alienate, disempower and disenfranchise them in order to strengthen ‘expert’ knowledge (Barnes & Mercer, 1997). It is also generally not representative of people’s lived experiences of disability (Barton, 2005). Historically, disability discourse has been dominated by the non-disabled, and despite much discussion within disability studies over how research should be conducted, the voices of disabled people themselves have long been excluded (Kitchin, 2000; Oliver & Barnes, 2012). To attempt to address these inadequacies of disability research, Stone and Priestley (1996) outlined key principles of a reformulated research strategy that might give voice to personal experiences as part of gathering collective commonality of disability experience. This also involves the adoption of the social model of disability, as well as a commitment to conducting research that will benefit disabled people through empowerment.

2.2.3 Foucauldian Social-Constructionism

A post-structuralist, Foucauldian epistemology primarily concerned with the broader cultural systems of meaning that establish power relationships in society, culture and institutions (Foucault, 1980; 1982), and particularly that of the government of disability and biomedical power (Sullivan, 2005), influences the initial analysis. From this social-constructionist position,
truth and reality are viewed as subjective concepts that are restricted by, and entrenched in, their sociocultural and historical context (Burr, 1995). In this vein, language, as the combined understanding of rationalising of human experience (Leeds-Hurwitz, 2009), is analysed in order to expose these essential systems, through which communication of beliefs and notions of reality are both constructed and maintained (Hacking, 2001).

2.2.4 Merleau-Ponty and Subjective Epistemology

To balance this post-structuralist view of the disabled body as potentially lacking agency (Hughes, 2005), the current research strives also to recognise the body as active subject as well as object (Crossley, 2001). In order to do this, Merleau-Ponty’s (1964) assertion that the body is the source of subjectivity and agency is mobilised; a phenomenological understanding of embodied being acknowledges the personal every-day experience of the disabled person (Marks, 1999), by focusing on and prioritising the inherent subjectivity of behaviour, and the relevance of relational perspective on the perception of self.

Consequently, the analysis of the present study will be conducted unconventionally from these two traditionally divergent epistemological approaches. Its rationale is that, by balancing Foucault’s focus on cultural and historical discursive constructions of the body alongside Merleau-Ponty’s existentially-based investigations into subjectivity, body image and embodied being, the disabled individual can become more comprehensively understood as both contextualised and embodied through a potentially emancipatory piece of research.

2.2.5 Synthesis of theoretical frameworks

The rationale for combining these approaches is in order to attempt to more comprehensively illustrate how the recently injured/newly disabled
individual might feel forces acting both upon them, but also from within them and potentially significantly affecting their understanding of themselves and themselves-in-relation-to-others, as well as themselves-in-relation-to society. The following diagram attempts to pictorially indicate these influential forces and how they combine to affect the individual:

![Diagram](image)

**Figure 1:** diagrammatic representation of Foucauldian, Phenomenological and Existential influential forces affecting the individual with SCI

The blue arc represents the social constructs of society – the Foucauldian focus of the research. This arches over the individual and all other members of society, subjectifying the individual with SCI whilst also creating and perpetuating social structures and power dynamics.

The orange arrows illustrate the focus of the Phenomenological framework. This part of the analysis investigates how the individual experiences their
own body in a new way, and how this affects their sense of self and consequently impacts on their capacity to engage and interact with the world they live in. The recently injured individual is challenged to find a way to come to a new understanding of their own physical capacity for themselves, but also in the way others see and interact with them.

For the (indicated in purple) individual with a SCI, these combined considerations and affects are likely to ignite fundamentally Existential consideration regarding agency and purpose.

By synthesising these divergent epistemological frameworks, it is possible to have a more holistic understanding of how they combine – top-down and bottom-up to ‘fill in the gaps for each other’ (representative colours stay the same):

![Figure 2: abstract illustration of how Focauldian and Phenomenological(Existential) frameworks can integrate and complement each other](image)

**Figure 2:** abstract illustration of how Focauldian and Phenomenological(Existential) frameworks can integrate and complement each other

### 2.3 Inductive Approach

By conducting predominantly (loosely) semi-structured interviews to be used as material for analysis, I hope to have minimised the risk of presuming what the issues faced by those with SCI may be (although I have, of course, experienced something of this myself and this is addressed further in the
reflexive analysis). It is hoped that this, combined with the analysis of the language expressed by participants will help to illustrate how they themselves feel they are constructed and made ‘different’ in order to fit into particular categories, thus constituting it as inductive research (Hayes, 2000) committed to adding to an important body of work focusing on personal experiences of disability.

2.4 Analytical Approach

Qualitative research seeks a different sort of knowledge to empirically-based quantitative enquiry. The aim of a qualitative investigation is to contextually understand phenomena, producing interpretative findings that come from a naturalistic approach to real-world settings (Patton, 2001). As such, a qualitative analysis seems to be the most appropriate approach for the focus of this study, which explores some of the psychological difficulties posed by (largely under-recognised) constructions and experiences of self and self-in-relation-to-other post-SCI.

2.4.1 Language

Humans create a combined understanding of the world by rationalising their phenomenological experiences through communication (Leeds-Hurwitz, 2009). Language is used as the essential system through which these notions of reality are constructed, and this therefore also involves the communication of beliefs (Hacking, 2001). Language is also considered a form of social action; people use language to achieve certain interpersonal goals (such as apportioning blame or attributing responsibility, for example), and subject positioning is created/established/perpetuated. This has direct and fundamental consequences for the expectation/entitlement for certain actions to be performed by certain individuals. There is a mutual relationship between discourse and institutions, whereby institutional
practices produce and disseminate language that legitimate their practices. Perhaps inevitably then, language is also very much a part of the creation and maintenance of power, as it makes readily available some versions (constructions) of reality, and marginalises alternative knowledges/practices. Discourse, then, can be defined as ‘a system of statements that constructs an object’ (Parker, 1992), and is fundamentally interactional and related to the wider sociocultural context (Potter & Wetherell, 1987).

2.4.2 Social Constructionism

The examination of the theory of knowledge in communication as social constructionism (Burr, 1995) emerged from social psychology in the 1980s and developed throughout the 1990s (Elder-Vass, 2012). A social constructionist perspective approaches communication as more than merely the transfer of information – instead, as the primary vehicle through/by which socio-psychological phenomenon can be created and perpetuated. Notions of truth and reality are thus relative from this positioning, as they are entirely subjective concepts, embedded in and constrained by their context (Burr, 1995). In opposition to essentialism, a socially constructed understanding of a phenomenon would view it as negotiated, created and maintained in co-ordination with other humans through communication. The focus of social constructionism therefore, is to decipher and illustrate the communicative processes through which individuals, groups and institutions participate in the creation and maintenance of their various perceived social realities (Burr, 1995; Hacking, 2001). It is necessarily a dynamic process, and thus is constantly subject to change and reinterpretation.
2.4.3 Discourse Analysis

Discourse analysis examines the ways in which particular discourses permeate speech and how they affect our experience of ourselves and how we relate to each other - either producing, maintaining, reproducing or challenging the status quo (Parker, 1992). Because of the emphasis given to construction and function, discourse analysis neither questions nor makes claims about the reality of the experiences of individuals, but instead systematically examines the ways in which these expressed realities and experiences are constructed through social and interpersonal processes. It does not share the aims of quantitative research to produce a tangible answer to a specific problem based in scientific research. Instead, discourse analysis is a critical, de-constructive and interpretive (but still rigorous) way of approaching an issue/phenomenon in order to enable the unveiling of (hidden) agenda/politics within socially dominant discourses. By making explicit the assumptions and conditions behind the phenomena to be examined, a broader and more comprehensive position can be adopted which includes ourselves (in whatever role) in relation to that problem. Ideally, a discourse analysis can create a higher awareness of hidden (socially structured) motivations (ours or others), and reveals that which is usually outside of our awareness - things we don't usually see or think about.

Discourse analysis is a particularly appropriate qualitative methodology to use to examine psychosocial issues for individuals adjusting to life post-SCI, primarily as it has no particular ‘question’ – instead it focuses on the use of everyday language to form social bonds that create and maintain power relationships/imbalances, with direct implications for perceptions and understandings of self (Parker, 2005). In this respect the approach is consistent with the ideas and theories of Foucault which are concerned with power relationships expressed through language and behavior (Fairclough, 2001). Discourse constructs knowledge (Gee, 2004), and consequently governs/maintains the assumed rules of inclusion/exclusion of social groups.
(Arribas-Ayllon & Walkerdine, 2008). As such, it simultaneously (re)produces both power and knowledge. A discourse analysis that employs the theories of Foucault can therefore examine established regimes of power through the deconstruction of language.

Much of the existing research focused on potential psychological issues resulting from SCI and disability (such as there is) has been dominated by empirical investigation of specific phenomena and has been narrow in its conclusions. A discourse analysis that shifts some of the focus from psychological phenomena to interpersonal processes and sociocultural systems of meaning, can hopefully also create opportunity for alternative understandings (Coyle, 2000: Willig, 1999). There is perhaps particular purpose and value for counselling psychologists in this method, as it investigates the role and perpetuation of hegemonic discourses in shaping individual client’s problems, as well as potential solutions to them.

2.5 Ethical Considerations

Ethical consideration was given to every aspect of the research, and I hope is illustrated throughout the study, particularly in the analyses. I will specifically outline the fundamental practical issues of the current research here.

2.5.1 Obtaining Approval

Due to the necessary contextual positioning of participants for the study, I needed NHS Health Research Authority (HRA) ethical approval in order to conduct the research. This transpired to be a lengthy and difficult process. Firstly, I needed to approach a SIU (not identified here in order to maximise anonymity for participants), propose to them my research, and get their provisional approval/facilitation. This allowed me to then apply for an
honorary research contract, which required a full CRB check and blood tests/Occupational Health interview. Once I had this, I submitted a research proposal application to the regional Research Ethics Committee (REC). After requested amendments were made and I had received a favourable opinion from them, I was able to gather the documentation to apply for and finally obtain the necessary Integrated Research Application System (IRAS) approval to begin to collect data. I first had communication with the Lead Clinical Psychologist of the identified SIU in July 2016, by which point I had already spent some months with the HRA ethics documents and communicating with the University of Manchester Ethics Committee to create my own additional documentation (see appendices 1-4). Despite the Unit being a three-hour drive away, I needed to visit it twice in August 2016 in order to obtain the honorary contract. The REC approval came in late October 2016, and final ethical approval from the HRA was given (after numerous revisions and amendments) in December of the same year.

This research is carried out in accordance with the ethical frameworks of both the British Psychological Society (BPS, 2010) and the Health and Care Professionals Council (HCPC, 2016). Morally responsible research behaviour relies on the integrity of the researcher and their sensitivity, honesty, knowledge and experience (Gair, 2012; Brinkmann & Kvale, 2008). Power is always an ethical issue in research, perhaps particularly acknowledged to be so in qualitative studies where everything is recognised to be positioned and unavoidably subjective. I was acutely aware of the position of power that I held at many points of the research process, and hope that my genuine respect and empathy for the participants and their expressions of their experiences is reflected throughout the study.

2.5.2 Access To Participants

Potential recruits for the study were initially identified by the in-house psychology team who acted as gatekeepers. The notion of ‘gate-keeper’ has been frequently identified in sociological research in particular (Miller &
Bell, 2002), and is an important ethical consideration as it implies a potential exercising of power - the motivations and consequences of which need be examined (yet often remain obscure). Access to participants for research (especially in marginalised communities) is crucial, and yet the overriding concern for ethical bodies of issues of potential for exploitation and coercion can afford gate-keepers great power and control (Emmel et al, 2007; Reeves, 2010). I felt (as discussed in more depth in the reflexive analysis) that in an attempt to protect the inpatients of the Unit, and possibly also facilitate and protect myself, the process of gate-keeping might have unnecessarily (and illogically) restricted or limited my access to ‘willing/compliant’ individuals.

2.5.3 Consent And Confidentiality

Consent is not an all-or-nothing matter, but an on-going process. I endeavored to ensure that participants were well informed about the study before they gave consent to participate. They were given written information about the study days before they were approached, and at each meeting the participants were given opportunity to ask questions about the study and assert their right to opt out (with no consequence) if they so desired. In acknowledgement of the potentially sensitive discussion topic, participants were given the chance to ‘debrief’ after interviews if they felt it necessary, and any concerns could have been registered with the resident Psychologist for provision to be made for follow-up counselling.

Regarding confidentiality, recordings were encrypted and transcriptions of interviews were kept in password-protected documents to protect participants’ privacy. Participants were given choice (described below) as to how they would be identified in the study, including the option of using a pseudonym. To protect their identity, this conversation is not disclosed in the study, and only a final generalised description of each individual is given. Transcription of the interviews, in recognition of the task constituting an interpretation in itself, was conducted as the first stage of data analysis and
was not outsourced. The transcripts themselves are not included in the thesis to maintain participants’ confidentiality, however an example extract can be found in appendix 7, and direct quotes are used to illustrate the analysis.

2.6 The Interviews

This section outlines the particular nature of the interviews and the practical considerations involved in conducting them, before describing and contextualising my experience of each participant.

2.6.1 Semi-Structured Interviews

Individual in-depth interviews are widely used by psychologists and health-care researchers to co-create meaning and improve understanding of experiences related to health and health-care delivery (DiCicco-Bloom & Crabtree, 2006). Conducting loosely semi-structured interviews composed of minimal open-ended questions would best enable (and if necessary, direct) participants to talk in their own way about their experiences of their environments and their sense/understanding of disability and the impact it had/has on them (Knox & Burkard, 2009). Whilst I did not want to direct or influence the interview too much (see appendix 5 for interview structure example), it was impossible for me not to impact upon the generation of material as I was a necessary co-creator of the interview conversation. The implications of this are discussed in more detail in the reflexive analysis.

A distinctive and important feature of this study is a particular longitudinal element to try to acknowledge and investigate the fluidity of disability, both constructed and felt. Interviews were conducted twice; once whilst in rehabilitation, and again when the participant had been discharged and was relocated outside of a medical environment. I did not assert any minimum or
maximum duration for interviews, instead allowing each participant to fully control how much or how little they felt comfortable/willing/able to engage with the research. The duration of each interview is recorded in the respective participant sections below. With participants’ consent, each interview was audio recorded. I had long drives (approximately three hours) to and from the SIU, and similar or longer drives to the various locations of the second interviews (purposefully not identified in order to maintain the anonymity of both the institution and participants). This time was used to reflect on the interview process, and was where much of the content of my reflexive journal was conceived.

2.6.2 Participants

A brief description of gathering interviews forms part of identifying and contextualising each participant in the following section.

2.6.2.1 Sample Size

Seven participants were recruited for the study, five of whom completed both interviews. A small sample group (of four to six) is commonly considered appropriate for discursive analysis (Parker, 2005) as the data is so information-laden, and the process is detailed, multi-layered and labour-intensive. Because of the longitudinal element of this study, and also the fact that much was dependent on participants’ physical wellbeing, I initially aimed to recruit a sample group of nine to allow for eventualities reducing the numbers able to take part at both stages. I had been consistently warned by both academics and clinicians involved in the study design that it would likely be very difficult to get enough sets of both interviews. Partly also for this reason, I did not want to set limiting criteria for participation in the study; by necessity, all participants needed to be inpatients in an NHS SIU in the UK at the outset of the study. Otherwise, the study exclusively involves adults (over 18) who can speak English, and it was decided to exclude individuals that might have suffered any additional brain injury as it would
distract from the intention and specific focus of the research on the experience of SCI.

2.6.2.2 Recruitment

Participants were initially identified and approached by the in-house SIU Psychiatry/Psychology team who were responsible for the psychological wellbeing of all the inpatients in the unit. More about this gatekeeping process is discussed both earlier and later in the study. Potential recruits were given my written description of the research and its intentions. This document also clearly stated that participation was voluntary, and would have no effect on current or future treatment in the unit, as well as the fact that it was being conducted by an outside body. On a later date, I approached the identified individuals (for the first time) to introduce myself, talk about the research a little more, see if they would like to participate and, if so, set up a time for interview.

2.6.2.3 Times and Locations

I visited the SIU three times to obtain the first set of interviews; three on 16/01/17, one on 17/01/17 (two other scheduled interviews that day were cancelled due to illness and exhaustion), and three on 06/02/17. At the end of these interviews I was given personal contact numbers from the participants and it was agreed that I would call them again in late March/early April to see how they were faring and potentially set up the second meeting, post-discharge. This was followed up as agreed, however it was prematurely timed and so further communication was made in late April in order to secure times/locations for the second interviews. At this point, it was clear that two participants would not be able to take any further part in the study. The second interviews took place in five separate locations and so were logistically challenging. Two were conducted on 03/05/17 in towns approximately one hour away from the SIU. One was arranged and then unavoidably cancelled (by the participant) on 07/05/17. It actually took place on 09/07/17 in a location approximately five hours
from the SIU. The final two interviews took place on 20/06/17, one very close to the Unit, and one in a village around ninety minutes away.

2.6.3 Descriptions

For purposes of participant anonymity, those willing to take part in the study were given opportunity to choose how they would like to be described. None of the participants seemed particularly concerned about anonymity, however, and only engaged with this minimally. Their responses constitute the following sub-headings. I purposefully did not ask anyone to tell me the exact nature of their injury as I did not want to contribute to any potential resultant feeling of objectification (something discussed in detail in both the reflexive and main analyses). Consequently, the following sections introduce each participant quite generally - focussing more on location and context - in order to provide some extra background for understanding the analysis.

2.6.3.1 Participant 1: ‘Ooh, erm...a fifty-year-old Dentist’

First interview: 16/01/17. 11.20am

This participant was using a motorised wheelchair due to limited functioning of his arms and hands. We conducted the interview across a table in a meeting room on the first floor (that we were both already on). He could not easily sign the consent form and so also gave verbal consent to taking part in the research. He seemed very happy to give his time to the study, and our interview lasted an hour and ten minutes. The participant’s clear identification with (and references to) dentistry as a profession led me to think of him as ‘the Dentist’.

Second interview: 20/06/17. 10.30am

Communication over where this second interview was to be held was muddled and I initially went to the wrong location (his family home). I spoke with the participant’s wife and adult son to ascertain where I should have gone. The Dentist had only very recently moved (and forgotten to mention!) into a flat a few miles from there (quite central to the city centre) owned by
Aspire (a UK charity that provides practical help to people with SCI) that had been fully adapted with widened doorways, a wheelchair lift and fully-equipped wet-room. He also had 24hr care. When I arrived, the community nurse was just leaving and so I was given coffee while I waited for her to book another appointment. This second interview was around an hour and a half in duration, and again the Dentist seemed very willing to give his time to the interview. At the end, he offered me some lunch before I left.

2.6.3.2 Participant 2: 'Just call me Mohammed'
First interview: 16/01/17. 1.30pm
Mohammed was apparently not yet using a wheelchair due to the nature/extent of his injury. Consequently, we remained on the ward and could only pull the curtain around his bed as a gesture towards privacy. He was experiencing a lot of pain around the time of the first interviews and didn’t want to risk moving to sign his consent form (although his level of injury had not compromised mobility/functionality of his arms), instead giving verbal consent at the beginning of the interview recording. He remained lying in bed but propped up a little for the duration of the interview. I sat beside him. Mohammed was very softly spoken on a noisy ward, and English was his second language. The combination of these factors alongside high dosage medication, some missing front teeth and a strong Punjabi accent made the interview particularly challenging to conduct as I struggled at times to both hear and understand. The interview was only thirty-five minutes long as he was clearly exhausted and was beginning to struggle with pain again.

Second interview: 03/05/17. 1pm
Arranging the second interview proved challenging as I could not always understand over the phone what was being said, and neither could I be sure that I had been understood. Consequently, when I arrived at Mohammed’s house (an end-of-terrace on a quiet residential street in a large town), I was not totally sure that I was expected and so when the door was not answered for some time, I almost left. It transpired that I was expected, and that the
door had been left unlocked for me to just go in (it hadn't occurred to me for a moment that this might have been the case!) as his wife was busy upstairs and Mohammed was not able to leave his bed as he had no wheelchair. There was no-one else home because all the children were at school. They offered me food and drink on arrival and I accepted a drink. Mohammed seemed keen to talk with me, and his second interview lasted just over three quarters of an hour before he became exhausted. Both he and his wife seemed to be quite overwhelmed at the situation they found themselves in – they clearly felt isolated, under-resourced and poorly-informed. They voiced their appreciation at my having visited them when I left.

2.6.3.3 Participant 3: ‘I’m a Soldier’

First interview: 16/01/17. 3pm

The Soldier was on bed-rest on the day we had scheduled his first interview so he couldn't come up to the designated room. Instead, he sat on his bed and we pulled the curtain around for a degree of privacy. His injury had not affected the functionality of his upper limbs at all and he gave written consent for participation. He was interested in both the research process and my own injury experience/life post injury. His first interview lasted around one hour and forty-five minutes.

Second interview: 09/07/17. 11.30am

This was an extraordinary experience that cannot fully be explored in this paper. The Soldier had been transferred to a Ministry of Defence (MOD) Medical Rehabilitation Centre that catered for all traumatic injury. He arranged for us to meet inside this centre which required me to pre-register, sign in, and be escorted (by him) at all times. He used a neat manual wheelchair and took me across the (fully-accessible) site to an empty attractive outdoor seating area for us to conduct the interview (ironically, I struggled with the distance I needed to walk for this). This interview was split into two parts as it ended up straddling lunchtime in the canteen. I was invited as a guest for lunch, and gratefully accepted, however we decided that we would suspend the interview whist we ate, as it could not be private.
Consequently, the recordings are forty-seven and twenty-six minutes long, however we actually spoke for considerably longer.

2.6.3.4 Participant 4: ‘Just Denis will do me’
First interview: 17/01/17. 1pm
I met Denis on his ward and we went together up in the lift to the meeting room that had been designated for me to conduct interviews privately. He was using a manual wheelchair, and had some limited function of his hands. He was very willing to participate in the study, but had a full schedule with physiotherapy and a gym session that day also. Our time together was limited therefore to a maximum of fifty minutes, of which we used forty for the recorded interview.

Second interview: 20/06/17. 1.30pm
Denis and his wife are both retired and I was invited into their quiet village home for our second meeting. I arrived late for this interview but this turned out to be useful as Denis was busy with a care-giver when I arrived. His wife offered me coffee and we sat together in their living room whilst we waited for Denis to be ready. It transpired that it was a significant day for them as they were switching that afternoon to privately paid-for care, and consequently it was their last meeting with that particular care-giver. There was a distinct feeling of anxiety about what this notable change might mean for them. Denis’ wife stayed for the duration of the interview, often also participating in the conversation. The recorded interview lasted just over one and a half hours.

2.6.3.5 Participant 5: ‘How I used to be? A sporty...sociable guy’ (The Roofer)
First interview: 06/02/17. 3pm
I met this participant on his ward and we went together across the Unit and in the lift to the seminar room in order to conduct his interview. He was using a manual wheelchair with adroitness that attracted my attention and respect (having not mastered the art well myself at all). He described
himself before the interview as ‘not much of a talker’, yet was very willing to take part and our recorded conversation lasted forty-five minutes. He gave written consent to participate in the research as his physical injuries had only affected the lower half of his body. Early in the interview it transpired that his accident had happened at work, and yet not in the way one might have assumed; he identified himself as a Roofer, and immediately followed it with ‘I never fell off a roof’. Consequently, I have always thought of him as ‘The Roofer’, and refer to him as such throughout the study.

The Roofer had suffered multiple significant, complicated and life-changing physical injuries as a result of his accident, and for this reason his medical needs were on-going during the time I was conducting the second meetings. Because I had given myself a cut-off point (mid-July) for data collection, and was also keenly aware of the many potential complications for him, I was not persistent in my attempts to get a second interview with the Roofer.

2.6.3.6 Participant 6: ‘Oh, I’m David’

First interview: 06/02/17. 1.30pm

We met on the ward and David was keen to participate in the study. However, when we had gone up to the designated room and I asked for him to sign the consent form (he had full use of his arms) for me to record the interview, he became reluctant and mistrusting (despite having read the participant information sheet, and me explaining my position/intentions further). He was very eager to talk however, and so we sat just chatting for a long while (approximately forty minutes). After this time, David said that he found me ‘easy to talk to’ and that I ‘seemed honest and kind’ and he agreed to take part in the study after all, although he still wasn’t keen on it being recorded – he wanted me to write things down instead. I agreed, and we conducted an interview that lasted around forty minutes. He became increasingly relaxed during this time and the interview ended with him ‘looking forward’ to a second meeting, post-discharge. This experience really highlighted the need for trust to be established as a necessary requirement for interview studies such as this (Douglas, 1985; Warren, 2002), and
significantly contributed to my reservations about gatekeeping in research, discussed elsewhere in this study.

Second interview: 03/05/17. 10am
David and his wife were very welcoming when I visited their family home. He had regained the function of his legs and no longer required a wheelchair, but had not disclosed as much over the phone so it was a great surprise when he opened the door to me. They offered me coffee and biscuits, and had brought together lots of photos and documents relating to his injury for me to see. David had made copies of some of these photos (that were particularly significant for him) in order for him to be able to give them to me. I found this very humbling. They conducted the interview (lasting around an hour and twenty-four minutes) together, often inviting each other to speak or finishing each other’s sentences. As they were both retired, they had the rest of the day free and invited me out to lunch once we had concluded our recorded conversation. I gratefully declined as I had another interview scheduled.

2.6.3.7 Participant 7: ‘Call me Luci’
First interview: 06/02/17. 12.30pm
Luci’s interview was conducted bedside, during which time her lunch was also brought onto the ward as she could not get to the canteen. Her injury meant that she did not have use of her arms, but Luci felt happy for me to help her with her lunch whilst we simultaneously conducted the interview. She gave verbal consent to participate in the study. It had been mentioned by staff on the ward that Luci was ‘difficult and hard work’, yet my experience of her was more one of passivity and vulnerability, especially when she got something in her eye and needed my help to make her more comfortable. Her interview ended when she was clearly too tired to carry on and was experiencing significant waves of intense pain. It lasted half an hour.
Due to Luci’s many pre-existing medical issues, her circumstances were complicated and it later transpired that it would not be possible for her to conduct a second interview.

2.7 Method Of Analysis

There is no step-by-step method for conducting a discourse analysis as it is an emergent process concerned with establishing contextual meaning and connections created between language forms and functions (Carbo, Vazquez Ahumada, Caballero & Lezuma Arguelles, 2016). Discourse acts upon and through society to create, perpetuate and legitimise particular ideologies over others. Research is situated within society, and the researcher is (to some degree) also a product of that society. Consequently, a comprehensive discourse analysis must begin at the moment of design with continuous attention paid to all aspects of the study, including decisions made about what is omitted/included, how it fits together, and what the purpose is (and for whom). Analysis, therefore, happens throughout the entire research process; beginning with reflexive engagement throughout research design, data collection/transcription, and into the main body of analytic work (Etherington, 2004).

The process of conveying knowledge through language involves both textual features and linguistic discourse strategy. A textural analysis describes main features of the text and identifies employed theme types. A analysis of discourse linguistic strategy, as adopted in this thesis, interprets the practice of the text through content and intertextuality (Aman, Mat Awal & Jaafar, 2013). Crucially, it focuses on relevant thematic linguistic strategies used by people in order to understand each other within the context of a particular conversation. In order to achieve this, focus is given to the interpretation of intertextuality (the relational interplay and positioning of text), and content: what linguistic constructions, and how, have they been utilized (Fairclough,
1995). It is important to note that some apparently relevant themes might not significantly appear, and other additional discourse strands may well emerge.

The following sections outline how I undertook the current analysis.

2.7.1 Transcription

Analysis of the gathered material began with the process of transcription. This is itself an interpretative task (Kvale & Brinkmann, 2008) as decisions about how and what to translate from speech to written text need be made. I chose to transcribe all the interviews myself (despite it being a lengthy process) as it felt important to try to be as accurate as possible; I did not want to ‘tidy up’ what was said and possibly risk losing potentially significant material. Consequently, my transcriptions include recognition of pauses as well as laughter, sighs, particular dialectical idiosyncrasies, and ums/aahs. Transcribing also seemed to be an extra opportunity to engage intimately, yet simultaneously from a retrospective distance, with what I had helped to generate. After conducting the interviews, I had time to reflect on the experience during my lengthy drives home. I made notes in my research diary about this at the time, and when it came to transcription I consulted these notes again to remind myself of the context. I chose not to transcribe any of the first-stage interviews until I had conducted the second-stage ones. This was because I wanted to approach the second interview with (as close to) the same level of openness as I had done the first, and I felt that analysis of any previously recorded conversation might hinder that sense of open-mindedness. Instead, I transcribed both interviews from each participant (if I had them) in sequence in order to try to get something of a narrative flavour to my understanding of their experiences and how they might have related to and influenced each other. This was a conscious decision as there was also the option of transcribing the interviews grouped by time/location rather than by individual. I am aware there are potential losses to either choice (no qualitative analysis can be complete), yet I felt
that there was potentially more to be gained in forming an understanding of individual experiences spanning a period of time and involving two locations/environments as it was better able to acknowledge, illustrate and explore the fluidity of both the experience of SCI and disability. I found that just engaging at these various points (co-creating/reflecting/transcribing the material) highlighted different aspects of the (overwhelmingly rich) discourse, and the need for careful, sensitive and intensive (re)reading was reinforced.

Each line of each transcription was numbered for ease of reference. Throughout this thesis, quotations from participants are identified firstly by which interview (1 or 2) followed by the line number – for example; (2. 100) would indicate interview 2, line 100.

2.7.2 Stages Of Analysis

The analysis was conducted twice in order to focus on different aspects of post-SCI experience, and attempt to provide a more comprehensive understanding of some of the challenges faced in the immediate aftermath of SCI. Initially, a discourse analysis drawing on Foucauldian socially-constructed concerns was employed to explore the roles of institutions, power relationships and culture through language as significant contributing factors to individual experiences of subjectivity (Willig, 2013). The material was then scrutinised a second time from an individual life-experience perspective that employed Merleau-Ponty’s theories of existential subjectivity and agency (e.g. 1964). This second analysis investigated the everyday embodied experiences of being a (newly)disabled person, in an attempt to illustrate how this might impact an individual’s existential perception/understanding of self. The intention of approaching the material through these two analytical lenses was to endeavour to comprehensively illustrate (through their synthesis) the strength and conflict of multiple forces acting both upon and within the individual who
must learn to adjust to a new, dis-abled self. The socially constructed forces imposed in different environments could be identified, alongside the way the individual subjected to those forces experiences both themselves and disability.

The analyses predominantly consisted of independent continual cyclical processes of exploration and evaluation of the transcribed texts to identify constructions, discourses and positionings according to their individual frameworks. Particular attention was paid to the stages of analysis set out by Willig (2003; 2013), which began independently for each analytical framework, and became increasingly combined as the inter-relatedness of the various emergent themes became apparent. This process is outlined below.

- **Discursive Constructions:** This initial stage simply looked at how the subject of analysis was constructed through language. This was done by using assigned colour marker pens to identify the various constructions.

- **Discourses:** The second stage looked at the linguistic strategies used to locate the specific subject of analysis within broader social discourses. These particular constructions of the subject adopted a series of expectations, assumptions and specific positions of truth to formulate the discursive object in a specific way. This was identified by underlining and annotating relevant parts of the transcripts.

- **Action Orientation:** At this level of analysis, investigation was made into how the specific systems of meaning and practice that were used to construct the subject of discourse had implications on the moral positioning of the speaker; whether to attribute them with authority, assign responsibility, or assert a version of truth. Notes and diagrams were made in the research journal during this stage of analysis, as it was here that the two previously separate analyses began to cross
over thematically and, when combined, created a more comprehensive inter-related understanding of expressed experiences.

- **Positioning:** Closely linked to the third stage, the fourth reading of the text looked at how each particular discourse constructed positions for both the speaker and subject, and defined the relationship they have to each other. This positioning (especially within a Foucauldian framework) necessarily involved notions of power, entitlement and responsibility. The impact of this on the affected (subjected) individual was found to have an effect on their phenomenological experience of themselves in relation to the world, and often directly instigate existential consideration – themes already identified through the phenomenological analysis.

- **Practice:** This stage investigated the implications and potential for action for both the speaker and the subject as constrained by specific discursive constructions. It also looked at the relations between the various discourses of the subject and how they may support or conflict with one another. This stage directly parallels the identified challenges posed by SCI and acquired disability to the notions of existential agency and phenomenological embodiment. Combining the analyses at this point helped to illustrate the fundamentally inter-related and contextual nature of the experience of SCI, as well as its constantly fluctuating nature.

- **Subjectivity:** By necessity this was the most subjective stage of analysis, but also the stage that synthesised both strands to create an over-arching and (hopefully) more comprehensive analysis overall. Critical attempts were made to make distinct links between discursive constructions and the various possible implications for the
subjective experience of those involved, making use of the phenomenological analysis to further support and illuminate some of the potential challenges faced. It is, of course, impossible to be definitive as to the nature of a particular subjective experience, and so any connections made were primarily intended to help illustrate the on-going constructive relationship between language systems, subjectivity and social relations, and the existential implications this may have for the individual who is living with SCI.

The very final stage of analysis involved my attempts to diagrammatically try to understand the inter-relatedness of all of the identified themes from both analyses, and how they are together impacted by a temporal element. This is expanded upon in the discussion chapter as the outcome of the longitudinal dimension of the study in recognition of the fundamental fluidity of disability. As such, it is not an identified ‘theme’ of the analysis, however it is a significant and vital factor to be considered for a more holistic understanding of the experience of SCI.

2.8 Validity Or Trustworthiness?

For research to be taken seriously it must acknowledge and address some kind of measure of quality control. The follow section discusses how this can purposefully and effectively be considered/established when undertaking qualitative discourse analysis.

2.8.1 Validity Versus Trustworthiness

The notion of validity is potentially a problematic one in qualitative research as it is itself a contingent construct (Winter, 2000). To attempt to engage with traditional positivist inquiry criteria for validation (such as
triangulation, replicability and generalisability) is inappropriate for a discourse analysis (Hammersly, 1992), not least because it disallows consideration and exploration of the existence of alternative experiences of reality and truth (Parker, 2005). However, for the scientific and academic communities to accept the current research, some notion of validity must be considered (Cypress, 2017) in order for a ‘standard of quality’ to be achieved. There are no formal rules of quality validation for discourse analysis – it is an area that is constantly being redefined (Burman & Whelan, 2011) as it too is as subject to the notion that truth is always partial and incomplete (Richardson, 1990) as all other constructs. According to the Merriam-Webster dictionary, to be ‘valid’ can be defined as being ‘well-grounded or justifiable’, ‘being at once relevant and meaningful’, and ‘appropriate to the end in view’. To be ‘trustworthy’ (according to the same source) is to be ‘worthy of confidence’. Hence I turn to the notions of reflexivity, integrity, dependability and catalytic capacity as apparently more legitimate aims of determining the trustworthiness(validity) of this research.

2.8.2 Reflexivity (And Subjectivity)

The role and reflexive awareness of the researcher is increasingly acknowledged to be significant in qualitative research (Golafshani, 2003), and is an important element in establishing credibility of research. To be in a position to attempt to make explicit the value-laden nature of cultural, social and political meaning, the trustworthy researcher must engage with reflexive practice at all stages and dimensions of the research process. In the continuous (documented and transparent) reflexive analytic practice of deconstructing and reconstructing meaning, validity thus becomes an ongoing methodological consideration that is convergent with reflexive practice (Cho & Trent, 2006). There can be no position of neutrality from which to approach a discourse analysis, as all people are subject to the influence of their own phenomenological experience and are thus necessarily positioned somewhere. All compelling qualitative research
(being in some respect interpretative) must take care to pay due attention to issues of trustworthiness in order for there to be good argument for it to be taken seriously (Polkinghorne, 2007). Clearly, my own beliefs, values and biases have shaped this entire thesis, and my assumptions have certainly influenced the research process (Willig, 2013). I am also keenly aware of my subjective reaction to the research topic as something pertinent to myself, and this is discussed as a potential (dis)advantage in more depth in the reflexive analysis. Indeed, the balance between reflexivity and subjectivity constitutes an important element of research, and is key to establishing the trustworthiness of a study - alongside integrity and clear communication of the findings (Morrow, 2005). I have correspondingly endeavoured at all stages of the study to be as aware of, and transparent with, my biases, intentions, strengths and weaknesses, as well as my difficulties and errors, as possible and it is my hope that this can be identified throughout.

2.8.3 Integrity

Establishing the integrity of a research study as indicative of trustworthiness (Williams & Morrow, 2009) involves mapping out, critically (and reflexively) evaluating and ‘evidencing’ each stage of the process undertaken - from epistemological positioning to the presentation of the findings. Being careful to ground the analysis, as I have, in the gathered material by using interview extracts and quotations as supportive illustration, adds to claims of integrity (Elliott, Fisher & Rennie, 1999; Schwandt, Lincoln & Guba, 2007), and allows for the reader to make their own (interpretative) evaluation of the findings produced by the author of the study. By placing particular import and attention to embedding the findings of this research in the expressions of the participants, who are, after all, the focus of the study, I have endeavoured not to appeal to any experience or meaning-making outside of the study, including my own. This has been a muddy distinction to try to make at times due to my own
constantly shifting positioning as insider/outsider/somewhere in the middle researcher and the potential for personal identification. In anticipation of this, and to attempt to avoid compromised integrity, I have kept a research journal to document my honest and personal reactions to content. An extract from this journal, as well as an example of the early analytical process, are included in the study in appendices 6 and 7. The content of the journal also constitutes a substantial focus of the reflexive analysis and illustrates how I have understood research integrity (validity) to be an ever-present and recursive process of consideration throughout the research (Cho & Trent, 2006).

2.8.4 Dependability

In quantitative studies, reliability (dependability) issues concern measurements and so perhaps seem irrelevant to interpretative analyses (Stenbacka, 2001). Instead, dependability can be ascertained and established by detailing each step of analysis; in the case of this study, by making use of a detailed research journal to record how the data was deconstructed, analysed and synthesised, as well as documenting process notes and personal reflections. In research that is concerned with the interpretation of constructed meanings, it is imperative that any understanding of a reality is holistically situated and understood. For this purpose, it is necessary for the researcher to build contextual understanding and awareness of participants’ experiences (Aveling et al., 2015; Elliott et al., 1999). Having personal experience of SCI and rehabilitation was useful in this respect, as it (hopefully) gives some significant sense of dependability to my competence in making sense of the daily experiences of participants. Finally, in order for the reader to see for themselves how individual realities have been expressed and experienced, and are then understood (interpreted) as constructed within particular contexts and at certain times, the clear communication of findings is essential for generating a dependable understanding of phenomena that might otherwise be enigmatic (Eisner, 2017; Elliott et al., 1999). It is hoped that both the main
and reflexive analyses illustrate how this was done in a way that feels dependable to the reader.

2.8.5 Catalytic Capacity

The idea of validity as ‘transformational’ (Cho & Trent, 2006) is useful in research focussed on examining meaning in order to purposefully engage with marginalised or oppressed communities. The credibility of an interpretive analysis concerned with how language is (often unconsciously) used to maintain and perpetuate inequality, is enhanced by adopting a critical theoretical perspective that focuses on power relations within and between individuals and institutions. Using key constructs from critical theorists as part of the research approach in order to identify what is potentially behind an experienced phenomenon can also help identify how it can be changed. Research informed by critical theory typically situates the entire study within a broad social/political perspective that can enhance the credibility - and therefore trustworthiness - of the research (Jaipal-Jamani, 2014). Rather than being overly concerned with issues of methodology to determine research validity, it would perhaps be more meaningful to focus on resultant action that might be prompted by the research (Burman & Whelan, 2011). In other words, the degree to which the research becomes ameliorative in emancipating and empowering the researched subjects (Scheurich, 1996). This study makes use of critical disability theory, as well as some feminist theory, and is based on Foucault’s pragmatic concern with issues of power. Consequently, it is hoped that the convergence of the explication of key constructs in critical theory with a well-grounded interpretation of the expressed experiences of individuals with SCI will have something of a catalytic effect on how common issues might be conceptualised and understood by both researchers and practitioners. This would then provide some confirmation of how the study might be deemed ‘worthy of confidence’, or trustworthy.
3. REFLEXIVE ANALYSIS

3.1 Introduction

This chapter focuses on the importance and effect of reflexivity in qualitative research. It offers an account of the research and considers issues of positioning and situating the study. The focus of the chapter is then widened to attend to broader political dimensions relating to disability and SCI.

3.2 Reflexive Practice

I will endeavor to make my research process transparent by candidly describing and investigating some of my personal experience during this time (and the preceding informative years). Incorporating my reflexive efforts into the study will provide both an important informative element worthy of some analysis in itself, and also some sort of accountability that may add to overall understanding of the entire research. This reflexive analysis is not specifically an attempt to bolster the credibility of the study (although perhaps it might) – rather, it is to try to make (more) visible the post-modern, socio-political context of the research, and to explore the socially constructed, negotiated and co-constituted nature of the research experience.

Reflexivity is an inherent part of my practice as a trainee counselling psychologist (Mearns, Thorne & Mcleod, 2013). Exploring my contribution to the creation of therapeutic relationships/processes is key to my understanding of what happens in therapy and how it is worked with. Like therapy, qualitative research of a discursive nature is co-constituted between participants and researcher, and themes/meaning are negotiated together within particular contexts (Angen, 2000; McLeod, 2001). Another
researcher interviewing the same participants with the same purpose as I, would unfurl a different picture of what the therapeutic needs of individuals might be, post-SCI. If one is to adopt the pluralistic humanistic valuing of phenomenological experience that is the philosophical foundation of counselling psychology (BPS, 2017), neither study would be any less ‘valid’ because of this (Jain, 2017). However, the exploration of how mutual meaning emerges within the relationship does demand a reflective awareness of self-in-relation-to others in order to gain better understanding of what is created and explored as only (ever) partial and emergent. It is with this in mind that I feel the positioning and interests of myself as researcher need to be explicitly stated as vital factors that affect all stages of the research (Herz, 1997). In order to increase my awareness of the complex intertwined-ness of shifting power and subject positioning and relationships throughout the entire process, I was encouraged to engage with reflexive journaling. This next chapter is predominantly borne of that exercise.

### 3.3 Situating The Researcher

This thesis began with a personal experience that took place almost exactly five years ago from writing these words. After a near-fatal road traffic collision in December 2012, I sustained extensive injuries, including an ‘exploded’ C7 vertebrae which, after some serious medical intervention, was ‘fixed’ and stabilised enough for me to be transferred to a SIU for care/rehabilitation. In this Unit, where I had become classified as an incomplete tetraplegic (see introduction for terminology), I found myself the subject of (what I now realise was) a psychological assessment. After a series of questions, the expert psychologist leant back and said ‘Well, as far as I can tell, you only have two problems’. This statement alone fascinated me: I was a self-employed, single mother of three small children and I was trying to recover some semblance of physical ability from being unable to move from the neck down. As far as I could see, I had more problems than I
had ever encountered previously, and all within a personal framework of pressing urgency and fundamental importance...I couldn't imagine what two things he thought were most significant. I asked him, and his answer changed everything for me; ‘You are intelligent and articulate’. I had no idea what this psychologist could possibly mean by this statement, but I did know absolutely that to focus on these things in such a negative way at that moment was totally wrong and destructive. I have spent the last five years researching (in various ways and disciplines) why I had experienced this statement as so offensive and oppressive, and, more importantly, how it could be that someone in his position could feel it could be an ok thing to say.

My time in the SIU was one of the most formative periods of my life in terms of what I found out about myself, and also in realising how much I didn’t know about everything. Everyone admitted to the Unit had experienced something that had changed their lives forever in an instant, and everyone was striving to the very best of their capacity to recover anything/something/everything, yet nobody knew how far that would or could be. We (the patients) were all acutely aware of how vulnerable we had become, but less consciously aware of what we were vulnerable to. Whilst we knew we were all in very different circumstances, we had all been thrown together into a (disparate) group and yet it was here, amongst ourselves, that many of us seemed to find a sort of comfort, understanding and unity that we could find nowhere else. We all wanted and needed to talk (endlessly!) about what had and was happening to us, and yet the specific elements of the common topics of conversation were different for each of us, as well as the same. We weren’t all distressed by the same things, yet I think we were all distressed by some things. There was one subject however that we were all absolutely in agreement on; whilst the attention to our physical rehabilitation was dedicated and comprehensive, our mental and emotional wellbeing was hardly even acknowledged, let alone attended to.
3.3.1 Positioning

The nature of the injuries I sustained meant that for a period of time I had no bowel/bladder function, and was entirely dependent on others for everything. My recovery enabled me to reclaim all of this, and I am left enduringly with only chronic pain and a degree of compromised mobility due to impaired control and movement particularly in my left leg. I can(do) walk, sometimes with a stick, and I am slower than I used to be. Twice in the last five years pain has become intense to the point that I couldn't function for a while, although generally I manage it well enough that it doesn't affect my everyday very much(if) at all. This information is pertinent to this research as I feel I regularly straddle the divide between identifying, or being identified as, disabled and able-bodied. I was able-bodied, then I was totally dis-abled, and now I can feel I am (and can be seen to be) either - dependent on the context, my body and my frame of mind. Although I will examine it in more detail later in the chapter, it is useful to question and set out my positioning at this early stage: Am I then an ‘insider-researcher’ (Bonner & Tolhurst, 2002)? My only answer can be yes and no. At various points of this study I have felt more identification with the role of researcher as I do not have the experiences caused by enduring significant physical compromises that the participants do, and yet I cannot say for a moment that I haven't identified with things they have said, to varying degree. I am also aware that the participants all felt I was ‘one of them’, and that for them I potentially symbolised something in their future as someone with SCI who was living years down the line from their present (this is discussed in more detail in the analysis and discussion). Ultimately, research outcomes can only be the understanding and interpretation of the researcher (Etherington, 2007), and whilst I am driven by wanting the experiences and challenges of an almost silent group of people to be made visible/heard in order for them to be addressed and supported, the ownership of the observations, interpretations and conclusions resulting from this work must be only mine. I am aware I come from a peculiar position of being both inside and outside, and of having had these sorts of conversations with the
participants of this study, internally with myself, and also with my fellow inpatients and friends with SCI repeatedly over the last five years. I steadfastly challenge any notion that might assert that this positioning could make this research less valid/reliable (e.g. as discussed by Rodriguez, 1998) – instead, I feel that evidence of reflexivity throughout the research, as well as in this dedicated chapter, can strengthen the study - not least through transparency about the possible implications of when I have been researcher and when I have also been the researched (Pillow, 2003).

3.4 An Account Of The Research

The following section outlines how and why I felt the study needed to be designed and conducted the way it has been.

3.4.1 Study Design

It was in the first months after I had left the SIU that I began to realise the fluidity of the enduring effects of SCI. Whilst in rehabilitation, I had felt more that I was injured than I was disabled – a significant difference, perhaps. It wasn’t until I returned home that the full implications of what had happened hit me, and I realised that my life was going to be forever different. However, it was only when I was going through the process of a Personal Independence Payment (PIP) assessment (GOV.UK, 2018) that I began to feel angry about the fundamental disconnect between my experience of disability as something absolutely contextual and ever-changing according to many (often external) factors, and the rigid, static pathological criteria needed to be met in order to achieve the unenviable position of being granted financial assistance in recognition of being ‘disabled enough’ (Clark, 2017). Throughout the last five years, my experience has been a fortunate one – I have had resources enough, both internally and externally, to be able to ‘be ok’ in every regard, and I have always been aware of this. It was the
closeness that I felt (and saw) at this time between my position of privilege and the potential for everything to be so different which has perpetually bothered me. I personally know five people (not participants) who have incurred SCI - four of whom were my contemporaries in the SIU - and we have all had very different experiences. The common thread amongst us all, again, is the perception of a total lack of awareness of what life has been (and is) like with SCI, and little (if any) acknowledgement of the complexity of the psychological challenges involved. The design of this study is a direct consequence of this.

The study was set up with a longitudinal element that would also be environmentally aware. The intention was to interview individuals whilst they were in rehabilitation and in a medical environment, and then again once they had been discharged into a community. This two-part design was intended to try to capture some of the fluidity of the experience of disability, and also to identify when/where predominant difficult issues might arise. I wanted it to reflect something of what I had felt of both the external forces exerted upon the individual as a result of being classified disabled, and also some of the personal phenomenological experience of an altered physicality. I also felt that it might highlight something of what I had personally experienced post-discharge; that all previous support disappears at just the moment that the reality of the situation the individual faces is made starkly apparent, and potentially when some psychological support might be most appreciated. I must take a moment here to make what is, for me, the most fundamental point of this research. Out of the people I made a strong bond with during my time in the SIU, one may not have got the dedicated professional support he possibly needed, and he decided to end his life. Another of us endlessly uses his time and resources to enable others wherever he can, and he has funded my training to become a Counselling Psychologist in order to go some way towards trying to ensure the therapeutic void we all experienced might begin to be filled. Despite existing counselling/psychological literature suggesting that the predominant issue faced by individuals post-SCI must be one of devastating loss, I personally
have not experienced this to be necessarily so, and it certainly needn’t be anything close to a presumption. Rather, I believe that the experience is far more nuanced and complicated, and that a major difficulty for individuals with SCI is that well-informed psychological support is not routinely/readily available.

### 3.4.2 Method

In terms of method of analysis, it seemed that a discourse analysis influenced by the work of Foucault was the obvious choice as it would explicitly focus on the use of everyday language as creating and maintaining power relationships and imbalances, with direct implications on perceptions and understanding of self (Parker, 2005). I have previously used this method of analysis to good effect for a Masters dissertation on the impact of bowel/bladder routines on an intimate relationship post-SCI, and so felt confident of its effect in application. However, this epistemological standpoint alone does not, in my opinion, provide a comprehensive picture of what is commonly experienced as a result of SCI, as the body becomes altered in an instant, and the individual must learn to understand their physical self in a new way, as well as being differently placed contextually. For this reason, I felt that the existential phenomenology of Merleau-Ponty (focusing on embodied being and subjectivity) would also benefit the analysis, as it would enable the reader to better understand the individual as both contextualised and embodied. Despite these being potentially divergent epistemological approaches, they are not necessarily mutually exclusive (Crossley, 1993; 1996, Hughes, 2005), and even might be able to ‘fill in the gaps’ for one another. In short, the design and methodology of this research were both overtly inspired by personal experience.

### 3.4.3 Ethics

I wanted to interview participants initially whilst they were in a SIU, in order to try to gain some good understanding of how such an environment
is experienced, and also how it affects the sense of self. For this reason, I had to undergo the process of obtaining ethical clearance from the HRA for the NHS. It was universally deemed that my participant group was ‘high risk’ and so the process was quite rigorous. Whilst I was fully cooperative with this, I was also aware of a feeling of increasing irritation. Fundamentally, my frustration was (is) with this notion of participants being (in this particular instance) ‘high risk’. I had, and still have, quite a strong feeling that this ‘risk’ element likely pertains more to the institutions involved than it does to the research or participants. Having spent many months in such a Unit myself, I am aware that conversations akin to the ones I was proposing to instigate are common in this environment – daily even. I felt that the direction I was hoping to guide my interviews in was one that would probably happen naturally, and that (generally) there would be no more distress felt or created by having these conversations than there would by not having them – after all, the experience of the implications of SCI (which is what I was interested in) are embodied by each participant in every moment of every day.

In my clinical practice, I have experience of working on a one-to-one basis with individuals affected by neurological conditions (through a charitable organisation), and also with patients and their families in a dedicated cancer hospital. In this role I am acutely aware of the need to be respectful of each individual’s experiences, beliefs and values, as well as their idiosyncratic potential vulnerabilities, pain and challenges. Consequently, it felt that to be cautious, respectful and attentive was indeed a necessary prerequisite for this particular study, but that this perhaps might not be as ‘high risk’ as it initially appeared. The ‘high risk’ classification potentially posed many logistical issues that I felt were unnecessary ‘barriers’ for me to be able to (even theoretically) access this group of people (which I had once been assigned to). Instead, I felt that it might be exactly because there is currently no significant in-depth investigation into what the psychological challenges might be post-SCI that this sort of research becomes labeled as ‘high risk’.

According to both the bulk of the existing literature and common societal
views, to be suddenly significantly physically disabled is apparently an experience typified by unbearable loss and potential for suicidal tendencies. Perhaps (understandably) it is this that may induce potentially prohibitively cautious anxiety in those who have some responsibility, which then translates to the ‘high risk’ classification. This is, however, generally the view of the able-bodied and is, I feel, ultimately simplistic. Additionally, the ‘othering’ (Joffe, 2011) that occurs when an individual gets labelled (as disabled/high-risk), doesn’t allow recognition that the person with a new SCI was, until very recently, just another person…and actually still is. Ironically, this transpired to be one of the challenges (identified in the analysis) for participants in the study; they expressed a noticeable feeling of suddenly being viewed differently as ‘less than’ they had previously been, and in such a way as to feel disempowered in their ability to engage in life. I have been very aware of my desire for the endeavors of this study to go some way towards enabling individuals with SCI to be understood primarily as people, and less as somehow challenging ‘others’ at the mercy of historical and societal misconceptions. It was partly for this reason (as already mentioned) that I chose the method of analysis that I did.

3.4.4 Access To Participants

In order to be able to conduct the first interviews within a SIU setting, I needed to have an honorary contract with an in-house dedicated NHS psychological service for ethical approval. I initially approached the Unit I had myself been a patient in as I had some personal links. When I had casually mooted the idea for the research to some of the staff there, it had been met with enthusiasm. However, I also felt apprehension and misgivings about being in an environment so close to my own experience as I wanted to be able to be sure I could be focused primarily on the experiences of participants and felt this might be more difficult for me there. Consequently, whilst I was engaged in the HRA process I tried to find alternative opportunities, although the options were limited; there are only twelve SIUs across the UK, nine of which are in England.
Serendipitously, at roughly the same time, I received a letter from NHS England that contained a questionnaire asking about my experiences of health services for individuals with SCI. I found the questions particularly interesting as I was still going through the ethical process for my own study and was very aware that I was viewing them more from a researcher's perspective than as the researched. I felt very frustrated by the lack of space the questionnaire gave for answering questions, and also that, when I did think of my personal experience, that there was no space at all to put down some things that I had felt important and relevant. I contacted the source of the questionnaire to see if they were at all interested in my perspective, or even my research proposal, and was met with active interest. It was through this timely and fortuitous connection that I was able to establish a relationship with a SIU that could (willingly) facilitate my proposed study.

According to the ethical approval stipulations, it was necessary for any access to participants to be given via the in-house psychological team. I had initially thought that I would be able to distribute information about the study across the Unit and that people could choose to 'opt in', rather than it being an 'offered opportunity'. What happened in reality was that all information about the research was given to the psychologists and they chose whom to approach as potential participants, dependent on who they thought would be 'good' or 'safely' able to take part. Whilst I felt ultimately grateful for their facilitation, I was also aware of a degree of frustration that there was possibly some participant selection happening (out of my control), which was perhaps both unnecessary and unhelpful. I felt, maybe wrongly, that people might have been more likely to talk and engage with me, as someone who had experience of SCI, as opposed to yet another practitioner/member of staff, and, in fact, this was expressed by the Dentist a few times:

‘you know yourself, nobody can know what it’s like unless you’ve been there, and you’ve been there’
‘I think you’re ideally placed to do this’

There was also more than one instance where participants said that they had not spoken about certain (significant and impactful) things with psychologists/nurses/consultants because they had felt that there was no way they could understand or help them:

‘I didn’t particularly open up too much to the psychologists at the hospital because I didn’t feel they did any good’

This saddened me and made me wonder who/what else I might have missed by participants having been selected for me. Only being given restricted access to certain people on the Unit felt particularly peculiar and redundant as there were regular visits to the ward from ex-patients and volunteers, and it appeared that they had access to any/everyone and were at liberty to talk about anything. I too am an ex-SCI inpatient and I did wonder whether had I been there in a volunteer role, I might have had far more (uncensored?) access to potential participants. Additionally, as a trainee counselling psychologist, I am used to having sensitive and difficult personal conversations and keeping them within boundaries of safety. I did begin to consider what it was that I might be missing that was so particularly threatening about what I was doing, as well as for whom.

3.5 Insider/Outsider/Somewhere In The Middle

According to Berger (2015), researcher positioning can affect research in three significant ways; gaining initial access to the area of research, the relationship between the researcher and the researched (which can, in turn,
affect information shared), and the way the researcher constructs and makes meaning of information gathered (according to their own background/understanding of the world). A common way of clarifying this positioning is to identify researchers as either ‘insiders’ or ‘outsiders’ (Bonner & Tolhurst, 2002); either belonging to the group to be researched, or not. It has been attested that this dichotomy is simplistic (Breen, 2007), and that the role of researcher could be better understood as on a continuum between ‘complete participant researcher’ and ‘complete observer’ (Ellis & Bochner, 2000; Kearns, 2000). Breen (2007) describes her positioning for her research as ‘in the middle’ of this continuum, which has some resonance with my experience of ‘having a foot in both camps’. However, I would like to take the idea even further and suggest that this continuum is also potentially subject to constant, contextually dependent flux, so that at times I have identified more or less as both the researcher and as one of the researched. I hope there is evidence of reflexive awareness of my experience of the slippery, perpetually-shifting subject positionings and relationships throughout the entire study, as the effects of issues of power and positioning are something that I feel is central to this research.

For the majority of the study I feel I am likely to be (appropriately) viewed as an insider-researcher; the conceptualisation, design and epistemological underpinnings of the research are all from a position of ‘research with’ rather than ‘research on’ (Denzin & Lincoln, 2000: Patton, 2002). When I have felt most like an outsider to the research group it has been because I have been positioned as such by another agency/institution. The ethics process, as discussed previously, forced me to ‘other’ the individuals I wanted to interview by creating access barriers to a group of people that I felt I had some kinship with. The experience of ‘gatekeeping’ (Lavrekas, 2008) by the SIU psychology team also positioned me as an outsider to their community within the SIU, which affected recruitment, perhaps significantly. The psychology team (as outsiders themselves?) were also concerned that I would not be able to get participants who were willing to engage in the first interview to carry out the second interview in their
homes after they had been discharged. In fact, all participants who were physically able to conduct a second study did so with eagerness and committed enthusiasm, perhaps illustrating (as also outlined above) that, when viewed by participants as an insider, the researcher may be allowed a privileged, increased capacity to facilitate and engage in research (Berger, 2015). It also potentially illustrates the notion that it might be easier to establish trust and rapport with participants when/if they feel the researcher is an insider (Pitman, 2002). It was in conducting and analysing the interviews that I experienced the fluctuating ‘somewhere in the middle’ positioning, and I hope that this is apparent throughout the analysis. A more focused inspection of how/why this might be so is looked at a little more closely in the immediately following section.

3.5.1 Researched-Researcher

I am, of course, grateful to the participants in the study, for everything they have contributed. There were times during the interviews where I felt the tension between my identification both as researcher and the researched, and sometimes this can be seen in the interviews; often I was asked specifically what it was that I was doing, and to what end. At the time, I was acutely aware of my positioning as researcher, however I also felt it was of even more importance to the individuals who were enabling the research that I was firstly human in my responses, secondly with some personal understanding of some of their experiences, and only finally as someone researching a phenomenon:

David (during 2nd interview): ‘So what exactly will you be doing with all your job? Is this to help other people?’

Me: ‘So, yeah. This research now is to do with - the reason I’m doing this research is because - I told you before – you know I had a spinal cord injury myself… but I don’t want it to be all my assumptions – I
I felt that to be human and ‘with them’ was more important than my role as researcher as I did not want to perpetuate any potential power imbalance that participants might have been feeling as a result of their injury/disability. This will, no doubt, have affected what participants said to me during their interviews, but then so would anything I might have done (Berger, 2015). Any researcher conducting qualitative research will be in some way co-constructing reality with their participants (Finlay, 2002), and will necessarily affect and influence what might be said and/or focused on. To be outside the participant group brings the benefit of ignorance and openness, which can shed new light on phenomenon, being free of pre-existing beliefs, perceptions and biases (Drake, 2010). However, it can also mean that significant issues can be missed, or not seen for what they are and given far less/more importance than they may actually have (Berger, 2015). Conversely, to be an insider-researcher means there is likely to be some prior awareness of what is being researched (Kacen & Chaitin, 2006; Padgett, 2008), which can be facilitative and progressive. It can also direct too much, and can create a situation whereby everything in the research exists in order to reinforce personal prior convictions (Bonner & Tolhurst, 2002).

I can identify with all participants to some degree, and absolutely with none. Six out of seven individuals involved in the study were male. As a female, I do feel there were some particular challenges that I experienced during rehabilitation that were specifically to do with gender. Actually, the Dentist asked about this during his second interview:
‘Is there much difference in the responses you get from female patients?’

I had hoped to have a fairly broad representation of participant groups in terms of gender orientation to try to address questions such as this, however it was not to be. The only female participant in the study expressed nothing of any issue that I had thought might be more specifically a female concern (e.g. menstruation/mothering [for example, pregnancy and breastfeeding]/catheterisation). It is something worthy of investigation in the future.

Overall, I felt any awareness of a tendency to identify with participants was patchy and inconsistent as there was no-one who had similar enough circumstances to me to remind me enough of myself/my own experience. Three had school-age children like me, however none of them were full-time single parents. Three participants had strong professional identities, as I had, however none were self-employed as I had been. Only one participant had regained his ability to walk, as I had done - all others were permanent wheelchair users, and some had significant enduring impairment in their arms also. I regained all movement, strength and control in my upper body. All participants still had bowel/bladder issues, unlike me. All except one participant were white, with English as their first language, yet nobody came from/lives in the same part of the country as me - and the list goes on. Like the experience of disability itself, my awareness of being able to identify with participants fluctuated, depending on both our environment and the issues in question. Even when someone spoke of something I felt I knew about, often I was acutely aware that the experience they were describing was very different to mine. In short, other than the fact we had all incurred SCI, there was very little to suggest that we might all ‘belong to the same group’. This has felt significant for me throughout the study; from an able-bodied perspective, perhaps a group of people who have suffered SCI appear to be cohesive – yet in reality there is very little that can be assumed
from this. It was always the intention of this study to try to illustrate this notion, as well as find out what might be potential common issues and ways to address them.

3.6 Interview Locations

I visited the SIU a few times before I was able to conduct any interviews. On my initial visit, I was aware that I was very curious to see how it might be different to the Unit I myself had spent many months in. I was told that the SIU I was visiting for research purposes was the best in the country...I had also been told only a few years previously that I was lucky because the Unit I had been in was the best in the country. Consequently, I was aware that, in my mind, I doing an absolute 'compare and contrast' analysis of the two. During these first few visits, I allowed myself to indulge in this comparative exercise between what I was seeing and what I myself had experienced, and noted my reflections. This meant that by the time I got to meeting and interviewing participants, I was able to focus on their experiences of the Unit they were in without fear of being distracted by my own (Kanuha, 2000). It also enabled me to offer some understanding and sense of familiarity to the participants with less risk of imposing my own experiences and biases on the interview (Pillow, 2003). Of course, the fact that I had presented myself as someone who had experienced SCI and a prolonged stay in a dedicated SIU made it imperative that I remained alert to the almost inevitability of some drive to compare experiences by both participants and myself. Accordingly, it was a constant fine judgement for me to make as to whether or not to engage in some self-disclosure of my experience in order to potentially facilitate some sense of understanding between us (De Tona, 2006), or even to share potentially helpful knowledge (Berger, 2015).
Court & Abbas (2013) encourage consideration of the location of research material collection and how it might impact the researcher-researched dynamic. The effect of location is an integral part of the design of this study, and so has been considered/analysed throughout the process. However, there is additional benefit to be had from considering location as having effect on the generation of knowledge itself. My initial meeting with participants was in the SIU, where I had the peculiar-feeling role of ‘visiting psychological researcher’, which accorded me with some kind of curious power to interrupt routine on the ward in order to conduct interviews. Whilst I welcomed this on one level (to facilitate research), it felt unnatural and uncomfortable when I was talking with participants as I was far more used to feeling the sense of disempowerment created by the environment that many of them were describing. Consequently, I was very aware of wanting to make sure that my positioning at that moment was clearly that of insider – someone with personal experience of SCI – rather than as outsider able-bodied therapist-researcher. This was, I know, an attempt to address my own concerns regarding any potentially negatively felt effects of power in both the researcher-researched relationship, and also the inferred expert-patient one. I would like to think that this was primarily out of compassion for the participants (Pillow, 2003), albeit informed by my own experience.

All but three of the primary interviews were conducted in a meeting room that was not commonly used. This had the effect of increasing the potential for me to be seen as someone sympathetic to the challenges of SCI rather than as a professional clinician. We sat across a table and so, for the duration of the interview, there was no significant difference between our physical capacity to engage with each other/the environment. The other interviews were subtly affected, I am sure, by the participants being restricted to their beds and, for two of them, lying down. I was very aware of the physical vulnerability of these participants, particularly so for the one whom I helped have lunch. It is potentially significant that these two interviews are also the shortest, where I ask fewest questions –I was so aware of the magnitude of all these individuals were experiencing, I didn't want to challenge them
further by asking them to engage in something for my benefit (they were also two interviews dominated by the experience/expression of intense pain).

The second time I met with participants was after they had been discharged from the SIU. All but two were back in their homes and I found myself readily and generously invited into their personal lives. One individual who had not moved back home had moved into adapted accommodation as his new home. The only one who was not ‘at home’ was at a military rehabilitation unit, which created a particularly unique environmental dynamic dominated by institutional rule and regulation, however it was also one of generous and facilitative personal invitation.

It was apparent that the power dynamic between participants and myself was dramatically different in the various second environments. All participants offered me food, drink and even accommodation, and appeared pleased to be able to do so. This was a stark contrast from our meeting in the Unit where two had apologised for having to end the interviews prematurely in order to get their food at the allotted time, and one not even knowing what/when lunch was. The second interviews were also all more relaxed in nature, and were consequently longer and with more depth and discussion of potentially difficult subject matter (e.g. sexual expression, bowel/bladder function and medical oppression). Additionally, participants’ wives were present for three of these interviews, and during the transcription process it became apparent that they were, at times, catalysts for extra perspective and meaning created by/through their presence. It must also be recognised that their presence may have prohibited some topics of conversation, but I had felt unable to even consider requesting them to leave the interview space when it was in their own home (illustrating further the different power dynamic in the second interviews).
3.7 Broader Political Dimensions

As discussed in detail in the analysis, the sense of personal agency is challenged by SCI, and can have huge negative impact on an individual’s feeling of self-worth and capacity for hope/purpose. To be in a home environment that could create any sense of enablement was clearly beneficial to participants, and, for some, created a perspective of how difficult they had found it in the SIU. However, this was not the case for all participants. Two individual’s experiences had become worse, and I found myself compelled to adopt a position of advocate for social justice, both through the research and also in action. It is recognised that insider-researchers are often intimately engaged with their areas of research, and that this can mean they may choose to conceptualise themselves as advocates rather than researchers (Bonner & Tolhurst, 2002). Whilst I acknowledge that I always hoped/intended for this research to be in some way revealing and emancipatory, I did not expect it for it to create the sense of urgency for activism in me that it did. Since my own experience of SCI, I have been painfully aware of the ignorance and inequity of the society we currently live in when it comes to issues of physicality and disability, and this has been the major driving force for this research. As identified by participants and discussed in the main body of analysis, there is no guarantee of comprehensive, good, or even adequate aftercare post-discharge currently in the UK, however I have been truly horrified by the absolute absence of some basic requirements for functioning. When I visited one participant who had been confined to his bed for weeks apparently for no reason other than he had not yet been issued a wheelchair, I felt (after some reflection and discussion in supervision) that I had no option other than to act as advocate (with his permission, of course) to try to make sure that he got one as a matter of urgency. Guidelines about researcher roles and permissible ways of ethical contextual interaction are not clearly specified (Jain, 2017), yet are significant questions when standard psychological research historically tends to favour research that presents itself as independent, detached, unbiased and objective (Breen, 2007; Jain,
2017). Apparently in conflict with this is the justice-oriented ethical basis of counselling psychology that professes to have an obligation to identify, acknowledge and address experiences of oppression (BACP, 2015; BPS, 2018), and this is the dilemma I faced. Participatory action research is a methodological approach developed in attempt to integrate participation (in society), research (the growth of knowledge) and action (the engagement with experience and context) (Chevalier & Buckles, 2013), and whilst it is not what I set out to do, I feel that there is an element of this that has emerged during the process. I am not sure how useful it would be to label this research as such however, as tensions between disciplines with diverse and sometimes conflicting ideologies and contexts can overshadow the common intention to overcome the repressive elitism of conventional science and the negative effect this has on institutions and the communities we live in (Phillips, Kristiansen, Vehvilainen & Gunnarsson, 2012). There is not space enough in this thesis to address the implications, benefits and drawbacks of such an approach, and nor is it necessary for its purpose, however I do feel it pertinent to identify this element within the study in order to illustrate how vital I feel it is for strong links to be made between research and action.

3.8 Awareness Of Own Reactions

It is not possible to be fully aware of my impact on the production of analysis material, however much I might engage in reflexive practice. Self-reflective consciousness (Sartre, 1956), where the self-in-relation-to-others becomes aim and object of focus, cannot ever make one aware of all forces affecting our embodied being (Bishop & Shepherd, 2011). Whilst conducting an interview, we are necessarily active participants ourselves in the construction of analysis material, and so cannot simultaneously deconstruct our impact on what it is we are endeavouring to co-create. In fact, reflexive accounts (including this one) are written from a perspective of hindsight,
and it is perhaps only really possible to identify (some of) the impact one has on their research after it has been left in the past (Mauthner & Doucet, 2003).

In order to have the best possible degree of self-reflective consciousness I could, I listened to interviews immediately after I had completed the long drive home from conducting them. I found the journeys useful to reflect on my visceral reactions and thoughts, and, combined with my observations from listening back, I was able to journal much peripheral detail. This was helpful during the analysis process to increase understanding by contextualising the content of the transcriptions. Also, during the transcription process, I found myself engaging with the data again, in a different way; this time I was much more aware of myself in the process, particularly in places where I sounded very much like I was an ‘insider’ due to my involved interactions. Finlay (2002) suggests scrutinising where we appear to behave unusually in material generation and reflecting on possible causes. By using reflexive awareness during the transcription process, I was better able to monitor the tensions between my involvement and detachment as researcher-researched, and consequently enhance the rigour of the study (Gemignani, 2011). I have endeavoured to incorporate all this into the main analysis, but also to inform this reflexive analysis.

Finally, in presenting the main analysis, I have drawn on regular group research sessions and supervision to try to maintain full engagement with the material and avoid (as much as possible) any ‘unconscious editing’ (Berger, 2015. pg. 221). I have tried to use quotes in such a way as to let them ‘speak for themselves’, and, to that end, have not edited them to be ‘clean’ or without extra, grammatically unnecessary words. Nonetheless, I have to acknowledge that however aware I am of the impact of myself on the construction, deconstruction and dissemination of material, and despite all attempts to minimise/reveal any biases and agenda, I can only produce work that is fundamentally my own, and will be necessarily partial,
emergent, and bound to social context and rhetorical genres (Etherington, 2007; Finlay, 2002).

3.9 Limitations

A reflexive chapter would be incomplete without some reflection on the limitations of reflexive practice itself. It has become commonplace for qualitative research to include examination of the researcher’s positioning in relation to the phenomena to be investigated (Willig, 2001), particularly if the epistemological standpoint of the study is one that necessarily implicates the researcher as significant contributor to the process. However, the reasons for conducting reflexivity and the way in which it is done, are not unanimously agreed upon. One conceptualisation of reflexive practice suggests it should be an exercise that attempts to explain/justify decisions (and excuse mistakes?) made during the research process, and therefore enhance the trustworthiness of a study (Boyle, 1994; Muecke, 1994). An alternative approach links reflexivity with bracketing as a methodological attempt to achieve a position of neutrality in order to be more scientific (Ahern, 1999). Either way, the purpose of such endeavours is to enhance the credibility of the study by accountability (Cutcliffe, 2003), and yet reflexive efforts will always be incomplete or only partial processes and so cannot account for everything. Qualitative research is over-archingly messy and inconclusive, and cannot ever be comprehensive. Cutcliffe (2003) illustrates how even the most thorough engagement with reflexive awareness practices cannot fully describe all I may ‘know’, as there are things I do not consciously know that I know (Luft, 1969). Further, May (1994) identifies immeasurable and unobservable factors involved in qualitative analytic method, such as creativity and intuition. Consequently, I cannot say that because I have engaged in reflexivity that my research is now more authoritative, credible or valid. I also cannot say with any degree of certainty how much I have had effect on
the analysis or, for that matter, it has had on me. I can say that I have rigorously attended to methodologically analysing from more than one perspective, and have tried to discover and explain all I can in an attempt to add to the truthfulness of what has been, and is produced as analysis. Ultimately, I do this in order for the reader to evaluate for themselves (with all they bring to their reading of the study) the extent to which I have been able to identify and explicate my involvement in the creation of the presented knowledge, and the impact it may have had (Horsburgh, 2003).
4 ANALYSIS

Previous research has already demonstrated many of the Foucauldian dimensions of discourses concerned with disability and rehabilitation (e.g. Tremain, 2005). Mobilizing Phenomenological and Existential frameworks with such discourses is less common. Consequently, the primary focus of this thesis is in articulating these lesser-used dimensions – which can then be synthesised with the Foucauldian framework to create a more holistic and possibly new understanding of both disability and SCI.

Whilst transcribing the interview data it became apparent that there were clear common issues and experiences (that were managed in different ways), but also that the effects of these often seemed to affect individuals’ responses to other felt experiences and issues. I outline how I have identified and organised these dominant themes and sub-themes before exploring them further in the main body of the chapter.

4.1 Identification and Organisation of Dominant Themes and Sub-themes

The analysis was equally informed by the works of Foucault and Merleau-Ponty and was intentionally divided into two distinct parts. The first, dominated by the ideas of Foucault, is concerned with describing and analysing the roles of power relationships, institutions and culture through language and behaviour in order to identify and illustrate the potential implications of these for the affected individual. This section I have called The Ecological as it aims to encompass some of the complex relations of beings with one another and their environments. Subsections of this involve investigation into the many manifestations and repercussions for the individual of the medical and social models of disability.
The second part of the analysis is concerned more with the experiences of the individuals. This I have divided into two sections; The Phenomenological (informed by the work of Merleau-Ponty), and The Existential. Despite them being significantly connected by their concern with the nature of existence, I felt that to separate them made for more clarity for the purpose of this particular study.

The Phenomenological is used to acknowledge the challenges people face post-SCI in constructing new personal meaning and understanding of their physical selves. It is based on Merleau-Ponty's assertion that the body is the primary site of 'knowing-the-world' (consciousness) and thus the self is located in time and space, and personal meaning is constructed through the individual interpretation of bodily experience and expression. This area is broken into two parts; embodiment and directedness. The notion of embodiment relates to the fundamental experience of a new physicality post-SCI. What was previously an unconscious, easy and assumed knowledge of physical self commonly (understandably) becomes a challenging preoccupation as parts of the body become unresponsive or dysfunctional, and the physical self becomes demanding; either through the experience of having to manage/repair functionality or the experience of pain. Directedness refers to the experience of physical expression. Self affects action and vice versa, so when it is no longer possible to participate in activities previously used to define self, what, or who, is left? Similarly, a person’s character is partially realised through behavior/action, yet if an individual’s ability to act is compromised, then can they never express that part of their character? Or does it cease to exist and a new character is created? An inability to participate in activities in the same way as others (including expression) can also lead to an enduring sensation of being a spectator of life rather than a participator.

The Existential is used to describe the exploration of some of the potential challenges faced by participants as the consequences of their injury force a reconsideration of the significance or purpose to be found in living and
existing. Various common ‘answers’ to the meaning of life in the context (and as a result) of experiences of the implications of a newly altered physicality are identified. The acknowledgement of some of the struggles involved in how to find personal meaning illustrates fundamental existential challenges to be significant and common concerns of individuals post-injury.

It is pertinent to acknowledge that I have deliberately only superficially addressed one ‘theme’ - Trauma - in the analysis. This is because I feel it is a significant and huge subject of research that has already received much attention in both psychological and counselling literatures, and (more pertinently) is an area I do not have space to address sufficiently alongside other, less attended-to themes in this particular study. In order to comprehensively understand the potential therapeutic needs of individuals post-SCI however, it’s presence and relevance cannot be ignored and shall be more equally weighted in the discussion chapter.

Additionally, running throughout all these sections is a significant temporal element. I have not acknowledged it as a specific ‘theme’ in the analysis, as I feel it is addressed variously and sufficiently for this study in both the constructed and the existential analyses, however I do feel it is worthy of some specific and particular mention. The study was purposefully designed with a longitudinal element in recognition of the fluidity of the potential challenges posed by SCI, and their influence/affect at different times. This is most clearly illustrated in the Ecological part of the analysis. However, what I had not expected was that a third temporal positioning would be identified (unknowingly) by the participants, and that it would be embodied by myself. The temporal element will be picked up in the discussion chapter where I shall address the potential impact of this third positioning, which, for the participants, currently constitutes their future. It will also form part of discussing the inter-relatedness of identified dominant themes.
4.2 The Ecological

According to Foucault, ‘Power is everywhere’ (1998: 63) and this section of the analysis is primarily concerned with identifying some of the Foucauldian concepts that create and perpetuate power relationships. Discipline, as mentioned in chapter 1, is a mechanism of (social) power that regulates thought and behavior by organizing space, time and everyday activities. Foucault argues in ‘Discipline and Punish’ (1977) that power in everyday society is largely exercised through disciplinary means in institutions such as, and including, hospitals. Surveillance is also integral to disciplinary practices. Throughout this section, institutional power can be seen to be asserted regularly; the organization of space to create an ‘air prison’ (pg 104) is particularly punitive, and the way participants (specifically Denis and The Soldier) struggled with bowel/bladder management issues (apparent in various sections of the analysis, but particularly section 4.2.1.1) illustrates clearly how power can control subjects by processes of regulation of the body in its parts to keep it docile. In this way, Foucault’s assertion can be seen to be more than just political, permeating the individual everyday embodied experience.

Dividing practices (Foucault, 1982), also mentioned in chapter 1, are evident throughout the analysis (but particularly in the Ecological dimensions) as further, related mechanisms of asserting and maintaining power via institutions and society. Dividing practices separate people who are viewed as a threat to the wider community both socially and spatially. The notion of ‘rehabilitation units’ (4.2.2.1) illustrates participants’ experiences of such practices, and the consequent objectification of the subject (the practice of making the body a finalized, decontextualized and pathologised ‘thing’) is addressed in section 4.2.1.2; depersonalization/dehumanization.
4.2.1 Medical Model

The way a phenomenon such as SCI is understood and explained constitutes the rational basis for practical interventions designed to reduce the potential difficulties of subsequent living. All participants of this study were first interviewed whilst in a specialist SIU that is dedicated to the management and rehabilitation of SCI. The focus of such an environment is on improving the ability of an individual, and is understood specifically in terms of medical knowledge. As such, it employs and asserts the medical model of disability through discourse and action. For all participants except one, this constituted a new and difficult experience as they found themselves viewed, treated and spoken to in ways in which they were not accustomed and did not feel comfortable. The effects of medicalisation continued even after discharge from the Unit through engagement with District Nurses, Carers, Physiotherapy etc. The following section aims to illustrate and understand some examples of how this was manifested.

4.2.1.1 Paternalism

In an ‘expert’ system that consists of a hierarchy of a specific form of knowledge, the authorities of such knowledge determine how the phenomenon should be understood (constructed) and treated (dealt with). Within a medical institution, the hierarchy is clear; the individual needing care is at the bottom, consultants at the top, and nursing staff and doctors at various points in between. On a practical intervention level this organisational system is often entirely appropriate and appreciated, yet it can also create tensions when the person needing care and help with coming to terms with a new physicality feels that decisions are being made on their behalf, apparently for their own good, and sometimes even contrary to their wishes – serving to potentially diminish their sense of self. One participant, the Soldier, expressed his anger at his experience of this in the SIU:
‘So...I moved from suppositories onto Pirastine...It’s a massive difference...I can get up now and make quarter past eight parade here. I only have to get up at seven – so an hour fifteen to have - get showered, do my bowels, do my bladder, dressed, breakfast and over for parade...so it’s like a normal person...but...I wasn’t allowed to go on it in hospital... ‘ah, no, you’re just -you’re just on suppositories’, ‘but I want to try this’, ‘well.’

(2.855)

‘It’s all very easy for someone who is able-bodied to sit there and go ‘you’ll have to shove a tube down your penis every day, a couple of times a day’. Brilliant. You do it – ‘well I don’t have to’ – well...stop judging me...and I’ll tell you what's good for me’

(2.898)

There is much within this scenario that illustrates the disempowering effect of a paternalistic attitude, although this is also potentially compounded and reinforced by the subject matter (bowel/bladder management) being one that is commonly subjected to a discourse of infantilisation. ‘I want to try this’ and ‘I wasn’t allowed...’ both suggest an appeal for a particular approach to an issue that was ultimately at the mercy and judgement of a greater power – one that was clearly felt to have no actual understanding of the effect of the prescribed course of action and prohibited the suggested alternative. To have disallowed the alternative treatment maintains the impaired individual as ‘abnormal’ and thus also the power imbalance, as well as the potentially unnecessary practical challenges and hardship. There is an expressed awareness and emotive reaction to the oppressive effects of this power imbalance; ‘stop judging me...and I’ll tell you what’s good for me’, yet nothing actually changed for the individual until he changed environment and was freed from such a dominant paternalistic attitude.

Another participant, Denis, had a similar experience concerning significant decisions being made about him that disregarded him entirely, however his
was with the District Nurses behaving as authorities once he was back at home:

‘What I’ve found terrible, I don’t know if you did, was District Nurses. ...I mean, I’m supposed to have, as you know, a suppository every morning...but ‘can’t maintain that! We’re not coming out every morning - nine miles every morning to put suppositories in. No way!’

(2.227)

‘...with respect, who are they? To decide what the priority is for me?’

(2.1025)

Denis was having significant and on-going issues trying to get help with establishing a consistent bowel/bladder routine and he too felt angry that others were openly making decisions on his behalf without consultation. This created for Denis a sense of powerlessness over the functionality of his own body, and also his daily routine and therefore lifestyle. It also placed stress and challenge on his relationship with his wife as they both had to find ways of managing the situation. One result of this was his wife had adopted the language of the healthcare professionals and thus (subconsciously) also a position of dominance that infantilised and medicalised her husband:

‘well, it says you’ll do an action between six and eight hours...so we had the same performance like we’ve just had – had to hose him down, clean him up, off in the shower-room, and then I just left him (laughs) wrapped up in a towel, gave him a cup of tea and had to wait for the carer’

(2.391)

The potential impact of this on Denis in terms of the dynamics of his relationship with his wife, but also on his sense of self-worth and pride is significant.
Both Denis and the Soldier implied that there were other factors they suspected made it easier for external agencies to ignore their wishes – the Soldier felt it came down to cost, and Denis felt it was due to inconvenient travelling distance. Denis also expressed his feeling that even his discharge from the Unit had been a decision made by his consultant on his behalf that was not perhaps in his best interest:

‘So the consultant basically said to me, erm, you know, ‘you won’t be going home until your home is ready for you. But that was the biggest load of rubbish he had coming out, because as soon as they decided, you know, he wanted me out – for whatever reason - I was transferred to another hospital’

(2. 186)

Whether there were additional factors in decisions made or not does not diminish the effect of paternalism; whatever the reasoning behind the decisions, both men were reduced to have little more capacity other than to be passive recipients of the benevolence (or otherwise) and judgement of professionals and other adherents to the medical discourse.

The Roofer felt that, under the guise of ‘care’, he was being restricted in his own recovery by medical staff, and that it was causing him extra frustration and distress:

The Roofer: ‘they won’t let us do nothing...in the bed like – weights, for my top half, and not let us do anything’

Me: ‘so you feel like you could be doing stuff to help yourself?’

The Roofer: ‘yeah, yeah, yeah...they wouldn’t even, like, let us do little weights in the bed or nothing...so I feel as though I’ve just been – I feel
as though I've been wasting time with us. I know I'd an injury…but I could have been doing something’

In this instance, the individual was keen to participate actively in his recovery and rehabilitation, yet for reasons unfathomable and, perhaps more significantly, un-discussed with him, he was unable to take charge of his own physical progression. This is a transparent example of agency being taken away from an individual as a result of decisions and judgement of others. Even if there is good medical reason for such action, to not discuss and explain it with the individual is to adopt an assumptive paternalistic position that serves to disempower the individual, and potentially cause negative affect.

The Roofer also expressed distress at his experience of consultants apparently withholding knowledge about his own injuries from him:

‘Dr XXX, the neurologist, came round the other day and said I've got damage to my rectum…and that's, like, the first I've ever known. So this morning I was saying to Mr XXX that Dr XXX said I had damage to my rectum like, and - “well, one thing at a time” - and I was like – Hell! I need to know!...like, I don’t know what’s happening down there, you know? And when I mention it, he's like – “well, let the dust settle” ....so…’

He and his partner felt that nobody had sat with them and told them either what his injuries really were or what the consequences of them might be, let alone any kind of rehabilitation or recovery plan. As a result, they felt they were totally at the mercy of judgements of the medical staff, and were living with a lot of fear, worry and confusion about both their present and the future. The Roofer expressed how, when they had asked direct questions which they felt would be helpful for them to know the answers to,
consultants were making decisions on their behalf even about what knowledge they would be able to deal with:

‘he’s not really speaking to us about it, and when we asked, he’s like – “oh, woah, woah, woah! One thing at a time”- which I understand, but I need to know, like, something’

(1.470)

This illustrates the well-documented phenomenon that having a physical issue/limitation can create confusion about the individual’s cognitive capacity. In this instance, the medical consultants seem to be making judgements about what the individual needs to know about his own physical condition based (apparently) solely on the fact that he is a patient and therefore ‘less than’. As a result of this, the participant and his wife could only guess fearfully about their current situation and their potential future.

The immediate future for individuals was often a cause of fear or distress, and the effects of paternalism had capacity to compound this by reinforcing a sense of powerlessness. Mohammed relayed what he had been told:

‘well, that’s what the doctor said – “if you want to go home we must send somebody round to your house to see if you’ve got enough room, or not” …you know what I mean?…“if you don’t have enough room then you have to go to a home”… and I say I really don’t want to go to a home. He said – “we’ll send somebody round and we’ll check”

(1.218)

The tone of this exchange carries an explicit assertion of power in decision-making regarding what is best for the patient, despite Mohammed voicing his concerns. Whilst it is perfectly appropriate and necessary for some investigation into whether current living quarters can accommodate living with a SCI (or whether modification/adaptations are needed), it does not
necessitate outside agencies making decisions about how or where the individual lives. Rather, it should be the beginning of discussion with the individual and their family (where appropriate) about how to enable living well once discharged from the Unit. Even when it was decided that Mohammed could live at home, he was still expected to defer to the judgement of others as to what room would turn into his bedroom:

‘They say they want to put it (the bed) in the other room, you know what I mean?..And – wife and me – we don’t…and then when the bed come, they say – “oh no, no, no, put it in this room”

‘Why?’

‘it’s easier for them…I say use the other room, but they said the bed will not go in here. They will fix it in there, but I said no. It’s not their choice. Do you know what I mean?...and they still say – “oh, no, no, no. we go in the other room. But I’m in here…”’

(2.55)

Mohammed and his wife had their reasons for wanting him to be based in a particular room, which were concerned with the way their family life centred round their kitchen. They both felt that if Mohammed could be based in the smaller room adjoining the kitchen, it would be easier for him to feel involved with his family and friends. The external agency connected to the SIU that was assessing his accommodation preferred the larger living room to house the hospital bed, but this was not based on Mohammed’s needs or best interests – indeed, he himself suggests that the decision was made with the interests of others as primary motivation (‘it’s easier for them’), rather than to enable him to live well and thrive. Again, the individual is not expected (allowed?) to make decisions regarding their own existence, and is instead expected to defer to paternalistic authority.
The only individual who did not express any discomfort or distress at the effects of medicalisation in the rehabilitation environment was Luci. Prior to her SCI, she was already living with diabetes, epilepsy and schizophrenia, which meant she was well used to medical and institutional interventions. She seemed already very accustomed/adjusted to passivity and deference to medical staff:

‘I don’t really do anything – the nurses are good. They come and clean me up and everything…and everything they have to – what...I can’t do anything. I just have to lay here’

(1.128)

It seemed clear to her what her ‘role’ was within the medical environment, and that she was accepting of it and apparently able to hand over all responsibility and control for her experience within the unit to the medical staff without any sense of distress or loss of agency.

It would be wrong to suggest that the patronising infantilisation of participants was restricted to the attitudes and behaviours of medical staff towards individuals with SCI. A medicalised formulation will have some subtle impact on how everyone within Western society understands disability. This is also true for the participants of the study who, until recently, were fully physically able. The Dentist realised he had expressed something of this attitude when describing a volunteer at the SIU who was also a wheelchair user:

‘there’s a little helper – a little helper...terrible thing to say...’

(1.913)

This same individual expressed how he had always had a negative attitude towards disability since childhood, and that this was now causing him to experience a degree of distress and self-loathing. To address this, he
referred to himself as ‘crippled’ in order to distance himself from his understanding of disability. He expressed it this way:

‘I’m a cripple – I’ve been injured...I almost think a disabled person is someone who’s born with a condition – you know, can’t really do a lot about it... whereas with an injury, you’re at the very bottom to start with and you become more able if you work harder; you push yourself really hard... and that’s the difference between being crippled and being disabled, in my book’

(1.898)

This differentiation has fundamentally embedded within it the notion of disability as hopeless as the disabled individual is (according to the medical model it is based on) neither fully functioning nor curable, with the ‘problem’ of disability located firmly within the individual as pathological abnormality. Conversely, to be ‘crippled’ (in this case meaning injured) is to evoke a sense of hope (and therefore purpose) that the individual can be ‘fixed’ or ‘rehabilitated’. However, even this carries an assertion of bio-power and the need for ‘patient’ co-operation, effort and subordination.

4.2.1.2 Depersonalisation/Dehumanisation

The effect of a paternalistic attitude is to disempower and infantilise the individual by denying (overriding) their maturity in experience, age and cognitive capacity. In a SIU medical environment that focuses all attention on restructuring, managing and controlling the body, it becomes easy for the individual to become objectified and thus depersonalised. Combined, this can have such a strong effect as to even become adopted by the affected individual themselves, potentially illustrating how self-identity can become eroded. Denis illustrated this starkly at the very start of his first interview:

‘Shall I tell you a little about what I am?’

(1.17)
In the environment we were in, he seemed to feel objectified to such a degree as to have altered even his own language regarding himself, denying his own subjectivity. For Denis, the sense of having become depersonalised through a combination of medicalisation and paternalistic infantilisation seemed to be the single biggest cause of distress in either environment since his initial hospitalisation, and was a constant theme throughout both of his interviews. He felt that practitioners did not consult or inform him of anything, instead keeping him in the dark about his future:

‘at the moment I feel as though, erm, I feel confused. I’m not sure what is happening. I’m not sure what the doctors have got planned, what the nursing staff have got planned, and what anybody’s got planned for me’

(2.1061)

Worse, he also felt that some practitioners didn’t care at all about him, instead seeing him only in terms of his physical needs, and attending to them as little more than means to a financial end:

‘she doesn’t really want to know, you know? – “I’ve come out here to do a job...bonk, job is done, fill in the ticket and off I go”

(2.1046)

Denis summed up his feeling of having become depersonalised at the very end of our second meeting:

‘the big difficulty I have had from last July until now, is people treating me as a human being and talking to me – as opposed to talking about me, you know? The number of times they’ve come to the end of the bed – there’s a couple of registrars and a consultant – they’re nattering away there and you’re thinking...so you say to them ‘can you tell me what that means? – “oh no, it’s alright” – as if to say, what’s it got to do with you? You know, they don’t want to discuss your case with
David expressed a similar experience of feeling unimportant and barely present, let alone human, although for him it was to illustrate what felt like an unusually positive encounter:

‘I’ve had a few problems with some of me doctors when they don’t listen to you – I saw Dr XXX, a lady in her late 40’s – first time I’ve had her, and she’s smashing…and I said to her afterwards, you know, I said – “I’ve enjoyed this. Not once have you looked at that computer or switched it on” – you know, a lot of them are like that as soon as you walk in’

(2.150)

The combination of discourses of medicalisation, infantilisation and depersonalisation can lead ultimately to the dehumanisation of an individual. Denis expressed his experience of this when he was in the SIU. He described how, at best, he felt he had been seen as an irritant:

‘he just - how can I put it...he just as though – “while I’m here, I’ve got to put up with you. You’re a patient”

(2.677)

...and at times he had felt treated as less than human:

‘you were just a bloody number, you know?’

(2.656)

This was also the experience of the Soldier when he tried to take some control of his circumstance and contact social care regarding the adaptation of his house:
‘I was like, so how do I shower? – “well, you’ve been trained to do it in your bed, so bed-bath. And you can do your toilet in your, erm, bed – and you can – you’ve been trained to do that. Yes, you can do that” – brilliant. So I have to have a bed in my living room and I’ve got to crap in my bed every day basically? That’s not me living – because I don’t need to crap in me bed. Because I’ve got function that I can get onto a toilet...So I said. How do I shower? They said – “well, a shower’s a privilege” – what have you just said to me? And then she said – “you can go to the swimming-pool, pay to go in the swimming-pool and have a shower at the swimming-pool” – what are you on? I said, I’ve been to Afghanistan four times. I’ve never been treated like that in my life’

(1.717)

The ‘solutions’ offered were apparently with no consideration, awareness or even understanding of the potential challenges of the original issues for the individual, and served merely to compound distress as they utterly disregarded the implications of such suggestions for pride, dignity and self-worth, let alone practicality and functionality. The Solider went on to say:

‘that’s not people living...and that’s what I think you feel – and that’s coming back to the worthlessness, that you’re like, well, my life means absolutely nothing to you. You’ve got figures and facts and figures and blah, blah, blah to achieve...means nothing...’

(1.757)

Fielding the negative impact of being seen to be barely human and little more than a statistic, combined with managing all his new physical challenges was significant and difficult for the Soldier:

‘at the same time, to find that strength in your head, in this situation, is really fucking hard’
yet dealing with situations and attitudes such as these are rarely openly recognised as a significant contributing factor in potential distress expressed by people who have recently sustained a SCI.

Mohammed described his experience of the nursing staff within the Unit, and how he felt that not only did they not attend to his pleas for help with pain, but also the way they treated him seemed cruel:

‘I saw them standing talking and you’re not blind – you see them and you’re shouting for them. They don’t, you know, you shouting quite a few times and she comes in after a few times and she say (in a raised voice) – “what do you want Mohammed?” – you know? I say, ‘my pain’, and you see them all moving and doing their other things and they say – “oh, five minutes and we do it” – five minutes. They stood there in the corridor talking, laughing, carrying on – do you know what I mean? I mean, the nurses were all there for the patients – to look after the patients....they don’t bother with it’

What he is describing here cannot be put down to staffing issues, or even potential clashes in personality. Rather, it is illustration of the combination of a hierarchical environment and discourses of medicalisation and depersonalisation that led to patients losing their humanity and becoming instead objectified by the medical staff.

David expressed a similar felt experience of being treated as less than human:

‘the nurses can toss you around like a piece of meat’
The Dentist realised the extent of the dehumanisation he had felt from the medical staff once he was living in adapted accommodation with 24hr care. He had expressed a fear during his initial interview about the standard of care he might receive outside of the hospital environment, however during his second interview he expressed how he latterly realised that in the Unit his needs had been viewed as purely functional, and disallowed for any human preference or variation:

‘I asked a carer to hold a drink to me, with a straw...I downed it in one. They go – “God! You don’t have to drink it all the way down!” – I’d say, ‘well, at the hospital you have to do that otherwise...the rest of it – you won’t get it’

(2.290)

Even if it was impossible for Mohammed to have any further medication for five minutes this could have been explained to him, and his struggle with pain could have been dealt with empathically rather than as an unreasonable irritant for the nursing staff to have to address. Turning a patient, I know from personal experience, can be done sensitively and gently, or in a manner that feels brusque and harsh, and can cause extra distress. And, whilst how and when one is enabled to have a drink may seem fairly inconsequential, it is these little things that become the big things when one is so suddenly reliant on others. As Denis said:

‘you know, these are only little things, but they help...the way of understanding....that make a really big difference, so it might be a little thing, but actually it’s a big impact’

(1.575)

It must be acknowledged that SCI patient needs are regularly intensive and frequent, and that the ratio of staff to patients is far from an ideal 1:1. This apparent dehumanising behaviour is then perhaps a (somewhat necessary)
coping mechanism of medical staff to dissociate patients from their humanness in order to protect themselves. However, I would argue that the cost of this for the affected individual is far too great for this to become overtly commonly accepted practice.

4.2.2 Social Model

Once discharged from the SIU, most of the participants who were able to engage in both parts of the study were able to move back home. There were two exceptions to this; the Dentist, who moved into adapted accommodation owned by Aspire (a charity supporting people with spinal injury) that was close to his family home as his wife did not want carers living in her home and she was not willing/able to take full responsibility for his 24hr care herself, and the Soldier, who went to an MOD dedicated Trauma Rehabilitation Centre for an indefinite period until he was able to make the double transition into both an able-bodied and civilian world. For all participants, this was their first experience of an environment other than a medical one, post-injury, and it illustrated for most of them the potential enduring impacts on their lives of an environment(society) that fails to accommodate impairment (Oliver & Barnes, 2012). The social model of disability offers an alternative paradigm for understanding disability as an experience dependent on the political and social organisation and structure of society, with the focus therefore on discriminatory barriers and issues of accessibility that disallow certain individuals the ability to participate in life. Surprisingly, this was also identified as an issue within the SIU, expressed by the Dentist:

instance, the television remote control, you can’t press because it’s a very stiff button...erm, you can’t get into the computer room because it’s a spring-loaded door which has to be kept shut for fire regs. You can’t log onto a computer because you have to press control/alt/delete and you can’t do it without fingers...’

(1.166)
It seems extraordinary that a Unit dedicated to the care and rehabilitation of individuals with SCI should not address (or possibly even notice) these small but significant issues, and yet it provides clear illustration of the embedded marginalisation throughout society of those who are not ‘fully able’. It appears that the experiences of the very individuals that the Unit is designed for and dedicated to are not imagined/recognised/heard enough for an inclusive environment to become the norm, even here.

4.2.2.1 Rehabilitation

The Soldier described how/why he was sceptical of the notion of ‘rehabilitation’ in the SIU:

‘one of the frustrating things here is that they train you in certain ways – a basic way, but if you want to develop something else, it takes more time.’

(1.477)

According to the NHS Commissioning Guidance for Rehabilitation (2016), the WHO asserts that ‘rehabilitation interventions should be aimed at achieving broad objectives – including improving or restoring function, compensating for lost function, maintaining current function’ (pg. 4). However, from a Foucauldian perspective the concept of rehabilitation is less benign. Understood as being based on a principle of reform not unlike that of the penitentiary system (Foucault, 1977), rehabilitation marginalises the constitutive population in such a way as to leave them no alternative than to behave in ways prescribed by their classification – in this case, disabled from full participation in society. This resonates eerily absolutely with the Soldier’s experience:

‘I’m in what is an “air prison”. They’ve moved my wheelchair out there (to the corridor), which means I’m stuck in this bed. So...I’m a prisoner of this circumstance’
'You just leave me here – take my wheelchair away if you want…it is literally as if they’ve just slammed the door in a scene from Porridge…what do I do? Do I shout down the corridor at you and upset everyone else? No, that’s not my style, so I’ll just lie here and look out of the window and think…and that’s the worst thing about a spinal cord injury…’

Mohammed also referred to the Unit as ‘a prison’ (1.536).

The feeling of becoming ‘institutionalised’ was a common one amongst participants, and generally was a cause of confusion and frustration. Being in an environment where the participants were subject to biomedical dominance meant that they were encouraged on some level to relinquish their sense of independence and responsibility for their own wellbeing (be ‘patient’), yet simultaneously the rehabilitative nature of the Unit constantly focussed on notions of improvement and restoration. This created a feeling of conflict for some individuals, such as the Dentist:

‘I’ve built up to be, erm, well, in some ways stronger…and in other ways weaker in that I’m becoming institutionalised here. I’m quite happy to be looked after and cared for 24 hours a day, and at the moment I’m sort of looking to move out into the real world but I’m quite daunted by the prospect of doing so’

He was very aware of the rehabilitation environment potentially unhelpfully protecting him from the realities and demands of life:

‘…I think just getting back into a situation where you’re not in that little cocoon. You know, we’re protected so much, and yeah, I’ve become institutionalised to some degree’
'I think going out in the big wide world’s going to be a massive challenge...it’s scary'

The Soldier frequently expressed a similar awareness of how he felt the rehabilitation environment wasn’t always facilitative and conducive to learning independent living:

‘I don’t get the practice here’

‘it’s only when you get out that you start to learn how to live’

‘you either get on with it and try and work it out as best you can, or you just – you just sit there and wait for them to help you, but then you can wait a bloody long time’

The Soldier had a particularly enlightening experience of what rehabilitation could be as after he left the SIU, he went to an Armed Forces trauma rehabilitation centre. This environment was clearly very focussed on enabling individuals to be the best they could be in order for them to thrive in an able-bodied civilian environment. He felt that there was attention paid to individual needs, and the focus really was on independence - in contrast to his experience of the SIU:

‘here it’s no, we’re going to help you live – not survive – live’
'I think, from the NHS point of view, when they’ve released you, you can feed yourself - that’s as good as you’re going to get – out you go! You’re kind of stuck because a) you haven’t been taught how to train yourself to get stronger, erm, to get better at stuff unless you’re physically minded. You, erm, it would be a very – you could definitely dip, I mean I reckon I’d severely dip because a) you probably haven’t got a bloody wheelchair sorted by that point – because of the disconnect between infrastructure…'

\[2.469\]

4.2.2.2 Societal Attitudes

The Soldier didn’t know it, but his prediction (above) was exactly Mohammed’s experience. The second interview I conducted with Mohammed was at his house, where I was shown into a room with a hospital bed, sofa and TV. He had been discharged two months previously and was very happy to be back with his wife and children, however it quickly transpired that he had no way of getting out of bed, and consequently had lain there for the entire time. He said he had asked for a wheelchair on many occasions:

‘every time I’m asking, they say “oh, the chair will soon be here”, you know what I mean? And next week comes, and the next week I’m asking and they say “next week, next week, next week” – that’s all they say…and I’ve got no wheelchair. Every time I ask them about it, the nurse comes and she says “oh, I asked them again and they said oh, we’re making it especially”…and I’m still in the bed. I’ve still not got it’

\[2.105\]

This was a major problem for Mohammed. Without any sort of wheelchair, he was unable to leave his room, let alone his house. His daily experience was one of total disablement, and it was impacting significantly on his ability to interact with his children:
'most days I'm lying in the bed and it's getting really boring, you know – nothing to do, just lie on one side, you know what I mean? When the nurses come round they just turn me round the other side – that's all they do'

(2.199)

'they want their daddy to go in a wheelchair. They really do want to go out with us'

(2.212)

'she said Dad!...you spend your whole lifetime sleeping...all that time sleeping...you never go out. You sleep in bed like bedtime all the day...you know what I mean? I feel terrible, honestly'

(2.222)

In his first interview, Mohammed had been struggling significantly with trying to manage pain and the distress caused by being apart from his family as the most difficult parts of his experience. The use of a baclofen pump meant that he was now pain-free. He was clearly also very glad to be back with his family, and appreciated their dedicated care, love and attention. Consequently, when I asked Mohammed in his second interview if he felt his situation was better, he replied ‘oh, a hundred times!’ Whilst with some significant limitations caused by SCI, he nevertheless had movement and function in both his arms, and had experienced using a wheelchair whilst in the SIU. However, without access to a wheelchair to use at home, it was clear that Mohammed was significantly compromised; he was absolutely dependent on others for everything, and was dis-abled from participating in life. As a result of this, his experience of the world post-injury was ‘Awful. Terrible, man’. Mohammed’s plight cannot be solely attributed to his experience of SCI. Concurrent with any particular issues that might arise from living with disability, all individuals who are not identified as able-bodied suffer, to some degree, the effects of living in an ableist society that views disability as negative and discriminates against it. The organisation
and structure of society in Britain in relation to disability and social care is such that there are (too often) occasions where specific needs related to functional impairment are not always recognised as necessary and/or urgent, with the consequence of the already disempowered individual being further disallowed an equitable chance to engage fully in life.

The experience of living in a society that is apparently unaware of, and insensitive to issues of disability is made stark to individuals who acquire their disability, especially if it is in an instant. It is the experience of many individuals with SCI that suddenly their own home environments become hostile to their physical needs, and prohibit re-entry into their lives. The Roofer expressed concern about his home:

‘three steps going into the house. I don't think I’m going to be able to get up them, you know – in a chair. So, just stairs – there’s no chance I’m going to sleep downstairs….I feel as though – not yet – I’m 38. I want to sleep upstairs in me bed’

(1.915)

‘the bathroom door’s a bit tight so we’d have to take the door off – can’t have no door, that’s rubbish for the girls’

(1.958)

Denis had had similar issues, and had spent a lot of money on adapting his home:

‘We had carpet down, and as you know, carpet is useless with a wheelchair...so that came up and we laid floorboards down. We had a cloakroom – in the same way as we had a dining room – the dining room is now a bedroom, the cloakroom is now a wet-room and XXX did that, didn’t you? Sorted all that out’

(2.838)
Whilst he had been in the SIU, Denis’ wife had spent a lot of time and money restructuring their home to enable his return, but there were still significant things that had not happened many weeks after his discharge. Because they did not qualify for any assistance in adapting their environment, they had no permanent ramp that could allow him to be able to get independently in and out of his house - instead they had a heavy plinth borrowed from a neighbour that needed two people to lift, and when in place was balanced on bricks/wood. It was dissatisfactory at best, yet the company that had been recommended (by the Council) to do the job had left them waiting with no apparent consideration of the implications for Denis and his wife. Having to make such major alterations to your home and having to find the means to do so are both potential causes of immense stress/pressure on individuals who already have a lot of challenges to find their way through. In addition to everything else, it was clear that this was a significant contributing factor to Denis’ low mood.

The Dentist had a rather different experience. It was not possible for him to return to his family home, so he was renting a fully-adapted flat from Aspire, complete with lift and wet-room. He found this to be a preferable environment to the SIU, and one that he appreciated as he could shower and be independent as a result of his environment and dedicated care; an experience that felt new to him:

‘God, it’s great! You know, you just - funny thing is, you look back at the hospital and I thought the care in hospital was good. I was reluctant to leave, or apprehensive about leaving. I look back now and it was just absolute shite’

(2.273)

For the Dentist, it was when he experienced society at large that he found himself discriminated against and disabled by his environment:
‘The worst thing is getting the bloody buses...there’s some dodgy drivers recently...Yeah, like they say you can’t get on ‘cos it’s busy. There’s twice I’ve been refused actually because there’s a pushchair in the wheelchair slot’

(2.165)

It is apparent from these examples that disability is created by more than just physical injury/impairment. Most of the participants of the study found themselves more or less disabled as a result of particular environments/organisational structures, and that this was as adversely affective of mood as the SCI itself.

4.2.2.3 Camaraderie

The affirmation model of disability (see introduction) acknowledges the potential for unity, camaraderie and collective identity amongst disabled people which prioritises the capacity for positive reframing and the power of expression of shared experience (Eisenhauer, 2007; Swain & French, 2008). For some participants in the study, the experience of being in a rehabilitation/hospital environment surrounded by others with similar injuries and challenges was felt to be just such a positive one; the atmosphere of the SIU was positively described as one of safety, acceptance and shared knowledge regarding their experiences and challenges:

‘the morale here is generally very good...even as patients you support the person who’s feeling down’

(The Dentist. 1. 125)

‘you can hear when someone’s had an accident ...the mood changes...because we’ve seen what’s happened to our friends on the ward and we know it’s possibly us next’

(The Dentist. 1. 464)
‗xxx had one of those big luxury electric wheelchairs and sometimes he’d say to me – are you feeling a bit weary this morning? – yep – grab hold! And he’d tow me along the corridor, into the lift, out of the lift, tow along to physio, you know and nobody cared. We had a good laugh. The nurses turned a blind eye – because they’re supposed to tell you not to be silly, erm, xxx would go bananas if she saw, but doctors would just ignore you – they’d just laugh!‘

(Denis. 2. 500)

The Unit staff were included in this by some of the participants, who also felt that by virtue of their professional experience/knowledge, they were able to contribute something important to the atmosphere of safety and acceptance:

‗Now if I’d been at home on my own, I wouldn’t have felt any different, but that condition (autonomic dysreflexia) can rapidly cause deterioration and can even be fatal in certain circumstances and I didn’t recognise it and that scared me. If it hadn’t been for the nurse that was used to that sort of thing saying – you look a bit peaky – goodness knows what would have happened‘

(The Dentist. 1. 713)

The Soldier, however, felt quite the opposite way -expressing his surprise that there were not more (any) individuals who had personal experience of SCI on the staff:

‗what I find strange here is the occupational therapy team, although very competent – they’ve been trained – got degrees and whatever else – there’s no-one up there that’s disabled…so how can you tell me how to do this when you’ve – all you still work?‘

(1. 1130)

For him, the practice of ex-patients coming and chatting with current patients as ‘peer-support’ was a useful way of creating this sense of affirmation and positively-framed unity:
'they are very good here with trying to get patients that come back in for their check-ups to come and speak to people – so I had a man come in last week who’s sort of put a lot of little issues in my head to rest – of how do you do that?'

(1.347)

Both elements of this were variously apparent in the participants’ interactions with me as both ‘professional’ and a fellow individual with SCI. There were many references to my ‘knowing’ about experiences, and possibly understanding them in a ‘different way’, whilst participants also took the opportunity to ask me how I had done things or got through them – effectively appealing for the sharing of knowledge.

The feeling of equality and shared knowledge is not a simple and inevitable phenomenon. The Dentist was able to recognise that he himself had held prejudiced, misguided views of disability pre-injury that he was struggling to re-adjust:

‘...you see someone in a power-chair and you think, you know, you think they’re a vegetable almost’

(1.882)

This had significant consequences for him once he was living in the community, as he was reluctant to participate in activities he enjoyed and benefitted from, purely because he didn’t want to be associated with disabled people and become part of a collective identity:

’so we went out for a coffee...and he was really helpful, gave me a few clues as to what to do, but he had one of these all-singing, all-dancing chairs and I just looked at him and thought – yeah, you look, like, really special in that chair – and then we sat in the pub together...and I just thought – this is really horrible. I don’t want to be sat with anybody
else in a wheelchair...you’ve got a couple of spazzers in, you know, in your wheelchairs’

(2.980)

The Soldier was less clear about his own attitudes pre-injury, but he was acutely aware of negative attitudes regarding physical disability, and acknowledged that it was likely the result of ignorance:

‘can anyone look past a wheelchair?..I know there’s nice people out there, because obviously there’s nurses and there’s HCAs and there’s people who care about other people and they can look past...but when you feel like the rest of – when you watch tv and social medial and everything’s very vain at the moment...are people developed mentally enough when they are very vain about looking past someone’s....?’

(1.895)

Paralleling this notion, the Dentist expressed frustration at the able-bodied community for their insistence that to be able to walk and ‘be normal’ must be everyone’s primary focus/goal; as though living in a wheelchair can only be defined by all it reveals to be absent:

‘I say to people - you know, you can’t walk, you’re in a wheelchair – having no legs is absolutely the least of my worries. I couldn’t give a shit. You know, I can survive life very well thank you, and be happy without legs’

(2.2125)

This acute awareness and frustration surrounding the lack of knowledge of the experience of acquired disability such as SCI was a significant element contributing to the sense of camaraderie expressed by the participants, and was perhaps, for some, the most surprising phenomenon to emerge from the aftermath of SCI.
4.3 The Phenomenological

4.3.1 Embodiment

Merleau-Ponty (1962) makes an important distinction between the 'objective body' (as physiological entity) and the 'phenomenal body' (as experienced by the individual). This allows for the notion that the body is not only object, but is also permanently 'experiencing', and therefore can be understood as part of conscious awareness. In this light, thought and sensation occur against a backdrop of perceptual activity that we understand in bodily terms. However, this constitutive role of the body is peripheral to our perceptual awareness. Consequently, through 'being-in-the-world', the individual tacitly experiences and understands both their environment and him/herself in active relation to each other. If intentionality is (or becomes) ambivalent or inhibited, then the world becomes experienced in terms of 'I cannot' rather than 'I can'. This is central to understanding the concept of embodiment as related to and affected by the body, and our awareness of it. After SCI, the body can suddenly become a challenging and demanding preoccupation, and the previously unconscious assumed knowledge of physical self and ability to interact with the world is significantly altered.

4.3.1.1 Pain

Pain is a complex psychological phenomenon and one that is extensively documented. This study does not attempt to produce anything new in this respect, but does seek to acknowledge, locate and embed the potential phenomenological experience of pain and consequences of its presence within the challenges faced after SCI. It might be assumed that pain is inevitable after such an injury, however medical advances are such that it can now be extremely effectively well-managed. Perhaps surprisingly, only three participants expressed an experience of pain, and one of these reported in his second interview that his 'terrible pain' was no longer
present after the intervention of a baclofen pump. Prior to this however, Mohammed’s pain had been overwhelming, both physically and mentally:

‘when I’m lying there, is like the pain coming out – just shake, all my body is shaking with pain’

(1.105)

‘when the really sharp pain is coming, you can’t put it behind your head’

(1.628)

At its worst, the experience of pain as a result of SCI can feel all-consuming and totally dis-abling.

David had a difficult experience of pain. Despite taking an imposing daily concoction of gabapentin, tramadol, amitriptyline, paracetamol and codeine, he still found pain had significant effect on his daily life which was perpetually challenging. During his second interview he described his experience:

‘It’s like I’m in a boxing match and - ‘you’re not going to beat me. As old as I am, I will get – I will beat you. I will get past it. You’re not going to stop me’ – sounds silly, but in my mind – ‘you’re not going to stop me from walking from A to B. you’re not going to stop me from, erm, going to the pub, or, erm, enjoying my activities’. You know, I talk to myself. I’m fighting and, I’ll be honest, most times I’ll win because I know if I don’t I will end up, erm, and it will get into me and destroy me’

(2.590)

For him, pain was a constant and significant threat that he felt he had no choice other than to meet and overcome, otherwise it would ‘chew you up and kill you’. He therefore felt that he had no choice but to ‘learn to live with
pain’, but was also very aware that the never-ending battle and attempt to be ‘positive’ and ‘strong’ was exhausting and overwhelming:

‘The other day I was quiet. I was just tired with the pain. Pain can make you tired’

(2.821)

‘You do get those moments where I’m – I’d say – I’ve had enough. No more – and it’s ...it’s not that you want to end your life or ‘owt like that – although sometimes you can get so low that you think, well, what do I do? How will I get out of it? How long have I got to suffer this?’

(2.793)

It is this experience of managing constant (chronic) pain that has the potential for enduring impact on the individual who must adjust to new physicality post-SCI. This persistent and relentless demand challenges personal resilience and, because pain is not visible or even measurable, is easily underestimated, forgotten or not considered by others.

4.3.1.2 Bowel/Bladder Issues

SCI usually results in some degree of bladder/bowel dysfunction. It is not commonly a life-threatening issue, but it is increasingly recognised that the impact it can have on daily life has the potential for major psychosocial consequences (Coggrave & Norton, 2013). The most frequently expressed phenomenological experience from participants in this study regarding bowel/bladder control was one of fear of accident, and the corresponding experience of mistrust of the body. The Roofer expressed how this had significantly inhibited his behaviour initially, and was constantly an issue:

‘I wouldn’t feel comfortable going anywhere, or anything with it...I’ve always got it on my mind...it’s what’s messing me up, you know?’

(1.604)
Both the Soldier and the Dentist were affected in a similar way, and all three had missed significant family gatherings/celebrations purely for this reason. More consequentially from the perspective of phenomenological embodiment however, was the constant unsettling mistrust of what their (previously assuredly trustworthy) bodies might do. For the Soldier, it was something he felt he had to try to ignore in order to engage with living:

‘If I had to go to the toilet every time I thought I’d passed wind, I just might as well sit on the toilet for the rest of my life’

(1.1675)

However, this was understandably almost impossible, and he had become apparently angry with his body as a result of feeling helpless:

‘No matter what you say, there’s no way anyone could ever stop me feeling like a two year old after I’ve done that – or a bad dog.... like a puppy sat there going - and watching some poor nurse had to come in with a mat and clean it up like, cos I couldn’t get on the floor and help her out – or I couldn’t get on the floor and hide it before she got in there’

(1.1053)

‘I’m laying here...just filling piss bags up...that’s all I’m doing. I’m turning water into - I might as well just pour it into the bag’

(1.555)

The Dentist expressed how he could only rely on his senses of hearing/smell to be aware of his undependable bodily functions, and the consequent sense of unease this created:

‘you’ll find us in a quiet corner, sniffing - to make sure that it was wind and not faeces. We can’t feel anything down below, so if you pass wind you have a minute or two of dread thinking – ‘oh my god, I’ve pooed
myself’ – then when you can’t smell anything, you think – ‘thank god for that’

(1.409)

For him, this new sense of unreliability had a direct effect on his mood and sense of self:

‘having an accident decreases your self-confidence...you end up having an accident and they have to scrape faeces off you – off your bum, off your trousers. Erm, it makes you feel quite low’

(1.430)

The Dentist found the whole issue of bowel dysfunction very difficult to come to terms with, as he felt it was ‘undignified and disgusting’ (1.348) having to engage in any kind of bowel-care routine. Consequently, he elected to have a colostomy. Whilst this hadn’t resolved his feelings of disgust, it did help him with bowel management:

‘It’s really horrible having your shit coming out your stomach, but it’s a million times better than having shit in your bed. But it’s still horrible. I don’t want anyone in my circle of friends and family to ever see it, you know?’

(2.2071)

His feelings about his physical self were very much negatively affected by this intervention however, and as well as not wanting others to see him, he found it impossible to even look at himself:

The Dentist: ‘I won’t let xxx see me without clothes on – because I’ve got this colostomy bag and a tube out my tummy and all this shit…’

Me: ‘so it sounds like you’re not feeling comfortable with your own physicality?’
The Dentist: ‘Oh my god! (laughs) Massive understatement! You know, I don’t – there’s no mirrors in here. I absolutely hate my physical shape’

(2. 689)

The Roofer expressed a similar feeling of finding himself fundamentally unable to engage with his new physicality necessarily involving a colostomy bag:

‘I couldn’t get me head around it – I couldn’t even look at it...I hate it’

(1. 189)

Alongside the practical challenges of bowel management, and perhaps making it harder to come to terms with, was an awareness of such issues being taboo subjects, even in the SIU. The Roofer hadn’t been able to express his constant ‘worry about it leaking and – just everything’ with anybody (including ward nurses) other than the stoma nurse he’d seen a couple of times. The Dentist also hadn’t discussed it with anyone other than consultants and a support worker who had initially suggested it. The combination of potential negative and difficult feelings about self, combined with social taboo appeared to make the experience of bowel dysfunction and management akin to a weighty, embarrassing secret. As the Soldier put it:

‘you don’t want to go into everything and go – ’I’ll tell you what, I shit myself today’ they don’t need to know that. I still feel quite embarrassed that I did – do that’

(1. 1497)

4.3.1.3 Altered Bodily Experiences
After SCI, an enhanced awareness of the body is a common phenomenon that is apparently keenly felt. One such manifestation of this, illustrated in the transcribed interviews, is as a new, demanding sense of having to ‘pay attention’ to physical movements/activities that had previously been
performed subconsciously with ease. As the Soldier identified, the instant nature of SCI makes this particularly apparent:

‘It’s all happened (snaps fingers) like that. You’ve gone from there to there like that, and lost all that in between....this hasn’t developed over time’

(1.1642)

There has been no chance to become gradually adjusted to altered physical sensation (or lack of) or functionality, and so the task of learning to adapt is two-pronged. For some participants in the study, a sense of cautious apprehension was evident as they learnt to respond to what consequently felt like a different, or alien (‘they’re not my legs any more’) body. David described how it felt for him, and how he appeared to be in constant conscious dialogue with his body – responding to pain:

‘You’ve got to move your body accordingly – to suit the pain’

(2.874)

He had also learnt (from unfortunate experience) that he had to pay more attention to the outside environment as a consequence of his new limitations:

‘I’ve got to be very careful. I walk a lot slower, and smaller steps, erm, it’s no good rushing and I’m watching the ground all the time, because if I trip, you know? Some of these kerbs – or sometimes me foot will just go over...’

(2.337)

‘It’s like when I fell in the club. There were only like three steps that I were going down, and someone shouted, and I looked, you know, but...’

(2.344)
What had been previously easy and unconscious interaction between his physical self and the world had become constant awareness of engagement with an environment full of potential peril and pain. However, David also illustrated that this need not necessarily be an insurmountable challenge:

‘You do learn to adapt different ways with the problems you have, you know? Walking a certain way, getting out of bed a certain way, move in a certain way’

(2.1431)

For the Roofer, his awareness to his new physicality had been awoken when he had his first interaction with an environment outside of the SIU. He had apparently been almost ambushed by the reality of his current limitations, and it created a sense of vulnerability:

‘...it just hit us today when I went to get a coffee and, like, I was getting my drink, like, and putting it between us legs and (laughs) – as I say, it’s the first time I’ve been out to the shop on me own really, today. So I went to the café and I didn’t think – I didn’t think about it so I had a coffee and I was like...? And I was just like – ‘I don’t care what anybody thinks’ – and I put it between my legs...I was rolling along thinking I got to be careful, I don’t want this spilling...’

(1.731)

This set off a sequence of anxious thoughts for the Roofer identifying other potential new and difficult experiences yet to come. Whilst he acknowledged that this was now playing heavily on his mind, he also felt that, perhaps because previously they had been inconsequential moments for him from a phenomenological perspective, they somehow shouldn’t feel so insurmountable:
'daft stuff, like – just being in a queue, you know?...and how to talk to strangers, stuff I really shouldn’t have to be thinking about....'

(1.717)

The Soldier felt a sense of frustration at the challenge of having to relearn everything:

‘It’s like you have to tick every – what you don’t consider a major task – you have to re-tick it when you’ve had an injury like this’

(1.1978)

He also felt that it was a lonely experience that no-one was truly aware of, either practically or psychologically:

‘when you start telling people...all of this (gesturing towards lower half of his body) shuts down, and they’re like – ‘what?!?...the first time I sat up – so when I sat up, I said it felt weird...like I’m on a tennis ball... all I can feel is I’m sat on the bottom of my spine. I’m not, but all I can feel is I’m sat like that – so I’m perched, and my balance point now is my head, because when my head moves – but normally, by the time your head’s gone over it’s too late. You can’t recover that. So I said – me sitting up is just a massive struggle right now’

(1.1506)

‘you don’t want to keep telling people how hard you’re finding your life, but they don’t understand’

(1.1545)

For him, the sense of being understood in the experience of this perpetual struggle was very important to his sense of wellbeing, and could be addressed by support and practical advice. Without the acknowledgement that ‘everything is harder’ (1.1933) – even ‘what looks simple for an able-
bodied person’ (1.1934), the Soldier felt that he was susceptible to ‘shutting down’ (1.1919) and that a feeling of ‘worthlessness comes in’ (1.1921).

4.3.2 Directedness

The notion of phenomenological directedness encompasses and draws attention to some of the challenges faced in having to acknowledge and understand a new physicality in relation to both the sense of self and also the world, post-SCI. It refers to the experience of physical expression/engagement as action that both defines and is defined by an individual’s understanding of self. If this ability is compromised, then the individual may become unable to participate in activities ‘as themselves’ and so must either find an alternative means of expression, or compromise/adjust their sense of whom they are. There are many potential examples of how an individual’s sense of their self can become challenged by an injury that creates paralysis and an inevitable degree of compromised expression/participation in life. The nature of SCI also means this is an instant altered experience, and consequently potentially more starkly felt than if there were a process of gradual adjustment. In the interviews for this study, the challenges posed by an altered capacity for physical expression caused intense distress in two particularly affected aspects of life/self. These are further explored in the following section.

4.3.2.1 Parenting

All of the participants involved in this study were parents/grandparents. There does not appear to be much existing literature on how SCI affects parent/child relationships in particular, although there is some acknowledgement of how familial roles can change. Historically, people who incurred SCI have been predominantly male, and so perhaps an assumption that parenting is a more engaged female role has caused this oversight of attention. However, during the interviews for this study, it was very apparent that for some participants (all male), their (in)ability to carry out
their parental role was of significant concern and a potential cause of distress.

The Dentist’s children had grown up and left home, and he was not overtly concerned by his newly limited capacity in a parenting role. However, he was sympathetically aware of how younger fathers on the ward (like the Soldier and Mohammed) might be impacted by the enduring affects of their injuries, and what they might potentially lose by becoming more spectators than active participants in familial life:

'It’s still difficult sometimes, but not as difficult maybe as it is for other people. Erm, the other aspect of being injured at my age - I’m fifty – and my two boys are grown up and are at university. I was there every day when they were growing up...

(1.645)

'When I look at other people on my ward who are younger...they won’t be able to do the things I did, you know, going skiing, scuba diving, all our little trips that we’ve had away with my boys. I’ve done all that stuff…'

(1.658)

The Soldier was acutely concerned about exactly this potential inability to actively engage in life with his children (‘a fear that I can’t take the kids on holiday ever again’ [1.368]), but also how the impact of his newly compromised physicality might stop him from being a good role model for them - as both a father who could provide for his offspring, and as a contributing member of society:

'How do I support my kids? ‘Cos at the moment I give quite a bit of money as maintenance. If I’m on benefits, I can’t do that. So am I less of a man ‘cos I’m not benef – looking after my children?'

(1.680)
'That's why I do want a job as well – so they can say – 'oh, he still works. He still does this’

(1.993)

The Roofer had similar concerns about being able to be the father he wanted to be due to restricted physical capacity, although his focus was on his perceived (in)ability to protect his family as he had done:

'Thinking about the kids. Just, bullying, or anything else – like, I dunno, what can I do? Just sat in this room, like.... Just, like, taking me girls out and protecting them’

(1.708)

Mohammed had expressed in his first interview how badly he had missed his children, who he had barely seen whilst he was in the SIU due to practical issues of distance, travel and resources. It was clear that some sense of ‘normality’ had been restored for their family just by his return home (despite him having no wheelchair and being unable to leave his bed for weeks). His wife expressed this very clearly when she said to me:

'Now he’s a better Daddy. For five or six months he wasn’t there’

(2.22)

Mohammed himself also felt that he was (glad to be) able to fulfil part of his role as father just by being present, and that his children similarly felt the benefit of this:

'when the kids come – you know what I mean? They laughing and – 'Daddy, Daddy – hello Dad! Are you alright?’ and they sit here and put the TV on and all that. You can’t be in a bad mood when the kids come’

(2.473)
However, he was also upset by the impact of his new, significantly altered physicality, and the effect it was having on his relationship with his children, who couldn’t understand why he wasn’t able to interact with them in the way they had all been used to:

“The kids and, like – ‘Dad! Come on! We’re going to Morrisons” and I’m like – ‘Son. I cannot walk’. He say – ‘come on! ...they want their daddy to go in a wheelchair – they really do want to go out with us’

(2.208)

‘She say – ‘Dad, Dad. It’s like you’re three years old’. She said – ‘Dad!’ I said – ‘what?’ she said – ‘you spend your whole lifetime sleeping – all that time sleeping. You don’t, you never - never go out. You sleep in bed like bedtime all the day’. I said – ‘oh, dad’s poorly now’

(2.221)

Mohammed’s awareness of his inability to participate in activities with his children was something that clearly affected his general mood and caused him frustration and distress. Additionally, without a strong physical presence, or more pertinently, the capacity to assert it, he commonly was finding that his children were struggling to accept his authority over behavioural issues:

‘they straight put the telly on – very loud. I really shout at the little one. I say – ‘put the level down, man. It is too high’ you know what I mean? And they will look and then put it high again. I say – ‘it’s too loud, man!’...all day they do it. I say – ‘now you do it, I’ll turn the telly off and – and the kids aren’t daft. They say – ‘how are you turn the telly off, Dad?’ I say – ‘I’ll rip the telly down’. They say – ‘but you can’t get up!’. I tell them I can, but the laddie – he’s five – he puts it on and he knows it. He say – ‘Dad. He can’t get off the bed to turn the telly off’. You know what I mean? ‘You can’t make a cup of tea. Mum make you a cup of tea’. I say – ‘I will get up and turn it off’. He say – ‘you can’t turn it off.
Mohammed’s ability to act in the way he had previously done pre-SCI was fundamentally compromised, and as a result, his assertive paternal self was no longer available to him in the same way it had been. Worse, this was clear to his children, and they were challenging how he was now going to be able to manifest this side of himself for them. Mohammed described how he was learning to parent in a new way through discussion and reasoning, yet it was clear that the physical immediacy required for parenting small children was exacerbating and bringing into relief for him some of the difficulties of his experience of a new, more limited, capacity for physical engagement and expression.

For all the participants who spoke of themselves as parents, the challenges of their (altered) ability to express themselves physically clearly impacted on how they felt they could engage in that role, and consequently how they felt about themselves.

4.3.2.2 Sexual Self
Sexual function is often dramatically compromised as a result of SCI, and there is some awareness that, combined with potential restricted capacity to move, bowel/bladder dysfunction, and loss of sensation, SCI can be experienced as ‘sexual death’ (Tepper, 1997). However, almost three quarters of individuals with SCI maintain an interest in sex post-SCI (Singh & Sharma, 2005), and, of course, the enduring effects of the injury do not necessarily or even definitively mean that sexual expression is no longer possible. Nevertheless, the sexuality of people with disabilities is rarely openly discussed (Brodwin & Frederick, 2010), and (probably because of social prejudices and stereotypes of disability) has become almost invisible as a potentially important psychological and physical challenge in adjusting to the experience of living post-SCI.
For the Dentist, his sexual self, and capacity to physically express it, was a big cause of distress and yet he felt he had not experienced any forum where he had been able to disclose/address this:

‘it’s a huge, huge thing - and yet a big taboo really, you know?’

(2.1379)

He was not alone in feeling unable to broach the subject with professionals, but it was perhaps surprising that ‘not one of them mentioned it’ either. He did suggest that the biological function of sexual organs was superficially addressed in the SIU; ‘they sometime offer you a Viagra – ‘go and try this if you want’, but he suggested that this was worse than no mention whatsoever, as it didn’t begin to acknowledge the potential challenges involved in physical sexual expression:

‘Why the hell would I want to go and get Viagra? You know, are you having a laugh?’

(2.1352)

Not all participants in the study mentioned sexuality as an issue post-SCI and this can perhaps be partially ascribed to other potentially contributing factors such as age, relationship status and the generally private nature of the subject. However, it is hard to know how much this feeling of sexual expression being a taboo subject may have also hindered conversation, both in interviews for this study and possibly also with medical professionals.

Sexuality encompasses more than merely physical function, and is closely associated with/dependent on body-image. The Roofer, the Soldier and the Dentist all found their physicality hard to accept in terms of perceived attractiveness, and all expressed frustration that they felt unable to do much to alter/improve it. The Soldier was used to being able to positively address
his body shape with intensive exercise – an option he was all too aware was no longer available to him for parts of his body that no longer had function:

‘Physically I think – I hate the way my body looks. I can’t get away from that because I can’t work the middle’

(2. 293)

This challenged his sense of agency to affect his capacity for feeling physically attractive, and consequently left him with low self-esteem:

‘Sitting in a wheelchair when you’re not feeling great about yourself because of your body image – that’s a massive thing to overcome’

(2. 362)

The Dentist was also unable to accept his new physical presentation:

‘I haven’t really looked in the mirror for the past five months because I don’t really like what I see. I lost about four stone – all muscle...I’m quite slim, skinny, or skeletal, as I would call it now – and that doesn’t sit well with me’

(1. 326)

It was a particularly big issue for him as he identified that prior to his injury he ‘was pretty vain’ (1. 325) and ‘used to look after myself’ (1. 323). The Dentist expressed how his physical manifestation no longer reflected who he felt he was:

‘the sexual side of me’s the same and yet you can’t really do anything so...’

(2. 1281)

‘what I was then, was what I am now – with a different physicality’

(2. 1776)
At the point of interview, he felt this personal discontent as a great loss that he couldn’t see a way of overcoming:

‘I used to think I was alright…and then you could strut round, and be happy with yourself. Whereas I’m not ever going to get that again’

(2.1033)

A person’s character is partially realised through behaviour and action, so when the ability to act is compromised, as can happen post-SCI, then so too can the ability to express that part of their character. When sexual thought is in conflict with capacity for sexual action it has the potential to cause intense frustration and discomfort, as expressed by the Dentist:

‘Occasionally I’ll see a post on Facebook – of someone I know wearing a bikini or something and, you know, you look at it and think – ‘oh God’ and you feel a stirring somewhere and you think – ‘quick! Flick over – stop looking’...because I’ve got exactly the same drive and the same thoughts and the same reactions, you know, there’s still things can happen – things happen down there, which I can’t do anything about, so, you know, it’s frustrating’

(2.711)

On both a mental and physical (hormonal) level, he still felt ‘that element of like a sexual thrill, spark, or whatever’, yet he wasn’t able to act on it in the way he previously might have done. Instead, in these moments, the Dentist found that he was acutely aware of his lack of physical agency and expression, which impacted negatively on his sense of physical self:

‘I’m feeling, you know, the same feelings because it’s the same me, and then I’m like – shit. I look like a piece of crap in a wheelchair....and then you’ve still got the sexual frustration on top of that’

(2.1327)
The Soldier was also keenly aware of his newly altered physical functionality and how it would potentially affect both his capacity to express his sexual self, and also his ability to be spontaneous and responsive to situations:

‘I can’t perform as that man does, in that sense, because I can’t move my legs and hold myself up. You cut yourself down – just in that sexual part – the positions that you can achieve are going to be minimal’

(1. 925)

‘I can’t be spontaneous, realistically – with bedroom stuff. Whether that bedroom stuff works properly is still to be…’

(2. 373)

He could only see his capacity for physical sexual expression in relation to his own past experience of his physical sexual self, and thus could only feel it as now being somehow less than he was:

‘I can’t offer what I used to be able to offer’

(2. 392)

The Dentist was having a similar personal struggle, however his was illustrated through his changed relationship with his wife. He had chosen not to return home post-discharge from the SIU because of his need for 24hr care, and was living alone in adapted accommodation. He felt this was a preferable situation, not least because of what he felt to be the painful impact of his physicality on his capacity for sexual expression:

‘I’d probably rather it that way, erm, I don’t know why. I think part of it is because she’s a big reminder of my physical condition and, you know, things I can’t do any more – and that’s quite a big one, in the back of
my mind pretty much always, that I'm not going to have a physical relationship with any woman, ever again’

(2.678)

For him, not only did this mean that his sexual self was compromised by his physical lack of agency and expression, but also his ability to fulfill what he understood to be his role as a husband:

‘I'm quite conscious of the fact that she deserves more from a husband than having someone that she sees just during the day and can't be there at night’

(1.1031)

The Dentist saw this as an unacceptable compromise for his wife, which he felt unable to ask her to make. Instead, he found it easier to offer her the option of divorce:

‘I've asked her to consider what she wants from life, ‘cos she’s young, you know, she's only coming up to fifty, and I wouldn't want to – her to be lumbered with someone who can’t be a full, proper husband’

(1.1025)

This action was clearly affected by the way he was feeling about himself due to the impact of significantly restricted physical sexual expression as a result of SCI.

4.4 The Existential

4.4.1 Meaning Of Life

This section explores some of the possible challenges to an individual’s understanding of the meaning of life, posed by an injury that inevitably
alters the experience of existence. Various identified existential considerations outlined below all help to contextualise and enable some understanding of the potential preoccupation with finding meaning in life, or at least some sense of purpose and reason amidst what might feel like chaos and meaninglessness, post-SCI.

4.4.1.1 Why?
Unsurprisingly, SCI are often catalysts for deep, intensive, and sometimes urgent searching for meaning in life. For some of the participants this began with consideration of their injury as they tried to find ways of understanding and coming to terms with what had happened. The Roofer expressed a sense of injustice at what had happened to him:

‘It’s not as if it’s my fault, like. It was just these pipes falling on us, you know?’

(1.510)

The Soldier felt similarly (‘I’m laying there going – ‘I’ve not caused this’), but was also aware of a concurrent unpleasant feeling of judgemental bitterness towards others who appeared to treat their health with a lackadaisical disregard:

‘These people are throwing their life away, literally. There’s nothing – you can’t judge...I’m just sort of going – ‘why aren’t you laying in this position, and I can live a full life? Because you’ve thrown yours away’

(1.1765)

For him, the idea that his plight could merely have been an (impersonal) act of chaos/chance felt like an almost unbearable impossibility:

‘All you can think of is – ‘why me?’, and someone said it the other day. They put it into maths...I am more unlucky than someone winning the lottery, because there’s only 250,000 people in the UK with a SCI. Less
people have won the lottery...I'm more likely to win the lottery than I am to have a SCI, so how have I been – I can’t win that, but I've been picked for this one?'

(1. 1809)

The Dentist, on the other hand, had a sense that his accident might have been both meaningful and personal:

‘I was very vain. I used to work out every day. I used to love myself – so probably been struck down as a lesson. Vanity.’

(2. 698)

Of course, not all participants had such a retrospective focus when trying to determine a meaning to life and existence - indeed some did not express any experience of existential challenge or consideration at any point. However, for those who did, it is apparent that there was possibly some subtle influence of historical attitudes to disability - particularly that of the moral model (Olkin, 2012; Smart & Smart, 2006). This bias is based on the notion that disability is the embodiment of badness, failure of faith or some sort of moral absence, and that the presence of impairment is the result of immoral or sinful behaviour (Rosenberg, 2009). This is perhaps what the sense of injustice felt by the Roofer and the Soldier is likely to have been a reaction to – they did not feel they deserved such a ‘punishment’. For the Dentist, who had engaged in a lot of self-destructive behaviour prior to his incurring a SCI, the notion of his accident being some kind of punishment felt comfortable for him, and coherent with his own sense of (and attitude towards) himself. It thus appeared to be a potentially satisfactory (for him, at that moment) resolution to the ultimately unanswerable question ‘Why?’

4.4.1.2 Religion/Faith
For many, the search for meaning in life can feel deeply destabilising, frightening and even incomprehensible without some sort of religious belief in a transcendent being/realm. There is, in religious belief, an attempt to
find meaning (essence) in existence, albeit involving a ‘leap of faith’. For some participants in the study, a belief in some sort of transcendental power felt comforting and as though they had been/were being ‘looked after’ David felt sure that ‘someone’s looking after me – I should be dead’ (1. 33). Luci expressed a similar understanding that her life was in the hands of a higher power:

‘I was knocking and they wouldn’t let me in. Said it wasn’t my time, go back downstairs’

(1. 488)

For both Luci and David, this feeling seemed to bring with it some sense of strength/purpose/ability to face some of the challenges posed each day post-SCI. It also engendered a sense of personal responsibility for David, who felt he must ‘fight as long as I can’ (1. 32) in return. This was perhaps because he and his wife believed his experiences of transcendental interventions were very personally intended; they felt he had ‘a guardian angel, and by God, it’s a good one!’ (2. 1106) and that this angel was his (deceased) parents.

For the Soldier however, the idea (or even suggestion) of a God who could allow an experience as life-threatening, disruptive and irreversible as SCI was an insult of a notion that he would not even entertain:

‘I’m not a God-believer, and when they come in saying God’s got a picture for you – get out! Get out of here now. I’m not listening to you rabbit on about this because if I believe that, then I believe in Karma, and I deserve to be like this, apparently. No. Get away from me. In God’s world - piss off’

(1. 1822)
He felt that, according to his understanding of religion and God, his experience of SCI could only be interpreted an act of punishment or malevolence, and that he was deserving of neither:

‘Piss off with your God because he’s – clearly he doesn’t like me. ’No, it’s not about you. He has a picture’ No. Not listening. God wants to see me struggle? Well, tick – tick for that one, well done. Well done, big man – high five you’

(1. 1837)

For him, religion/God made no better sense of his experience of existence than anything else, and in fact seemed more absurd than the notions of chance or chaos:

‘I’ve gone beyond the belief of that now, because – so I’ve got to wait years in this body, to go up there in the hope that I might walk again? That’s what your book is saying. No, I’m not listening to that. So, spiritually, you can’t justify this with anything’

(1. 1854)

Other participants did not mention faith/religion or any kind of higher power, although this, of course, does not mean they had not considered or were engaged with/affected by it. As an example, Mohammed did not mention faith during either interview, yet he told me before his second interview that he and his family were practising Muslims, and he had some scripture from the Qur’an on the wall directly opposite his bed. As an existential consideration for understanding and making meaning of life post-SCI, the particularities of any religion/faith or belief are less important than what it does for the individual, along with the awareness that it too is not necessarily something people feel they have any control over. In the end, perhaps it is as the Soldier said:
‘The only thing I can believe in is what I need to move forward’

(1. 1863)

4.4.1.3 Meaning/Purpose

Searching for a sense of purpose was a common experience for many of the participants, however where they looked for it and how it manifested differed between individuals. As already touched upon in the Phenomenological analysis, previously embodied roles (such as parent) that formed significant elements of self-schemas brought with them a strong sense of purpose for individuals such as Mohammed, the Roofer and the Soldier. Family, in more general terms, seemed also to create purpose for Denis, who had recently become a grandfather and had been intent (and successful) on becoming rehabilitated enough to be able to physically engage with the role:

‘When I was in hospital knowing I was expecting my first grandchild, and I wanted to push the pram. So that was – oh, really come on! You’ve got to keep going, you need to push the pram’

(2. 894)

David had found his family, particularly his relationship with his wife, had provided a great sense of meaning and purpose for him. They also gave him a feeling of strength and perseverance when times had felt hard:

‘You think of your family and – you’ve got to have something to fight for. Not only for your self, but it’s for other people – other loved ones as well’

(2. 1318)

‘She (wife) keeps saying – ‘you’re a little miracle man’. But yes, you’ve got to have someone. Those thoughts are very important and I treasure them because that’s what’s pulled me through. I had something to live for – something to fight for’

(2.1376)
Additionally, David’s SCI had instigated behaviours in the extended family that served to strengthen their relationships (‘it’s brought us all closer’ [2.1209]) and provide them with a new sense of perspective that they appeared to value and appreciate:

‘All problems are not problems, if you know – they’re all silly things aren’t they?’

(2.1222)

(David’s) Wife – ‘there’s something more important’

(2.1235)

David was fortunate also in that he appeared to have an innate personal drive (purpose) to ‘try your best, give your best, do your best’ (2. 1420) and was constantly striving ‘to be good – I want to be the best I can’ (2. 1556)

Incurring a SCI had offered the Dentist a ‘second chance’ (1. 1015) in life that he was keenly aware of. Unlike other participants, he described his experience of life immediately prior to his accident as a very dark and turbulent time:

‘My behaviour before the accident was going to lead to my erm, well, to my death. It was, erm, pretty much suicidal the things I used to do, and there was a question mark about whether this accident was a suicide attempt ...because I was under the care of a psychiatrist, various psychologists – and due to my alcoholism/depression, and there was quite a high risk of suicide’

(1.570)
He was very candid in his expression of how he felt he had been, how different it was for him now, and that his SCI ‘probably saved my life’. The phenomenon of post-traumatic growth is documented in positive psychological literature, but is perhaps more difficult for an able-bodied person to believe/accept than the idea of inevitable tragedy and loss. The Dentist was compelling in his assertion that ‘life is much better than it was five months ago’ and that ‘I now realise that I do want to live’. He found an ironic humour in the fact that his alcoholism had been comprehensively addressed by disability resulting from his injury: ‘I can’t drink – because I can’t physically’, and was aware that as a direct consequence of his inability to drink alcohol excessively, he was feeling happier and no longer experiencing depression or suicidal thoughts. For the Dentist, incurring SCI had been, in some ways, a positive thing that he felt had given him another chance to engage in life in a meaningful way:

‘It’s a new life. It started from when I got injured and, for me, I, you know, I should have been dead. I fell 30ft and landed on my face on a solid wooden table. So, you know, I was very lucky to survive it. Erm, and I was grateful I got a second chance. And I feel actually better now, as I said, than before. So, yeah, this is my second life now, and hopefully, I go back to being, you know, the proper Dad I was’

(1.1011)

Additionally, he was also able to envisage new personal growth from his experiences. He was ‘planning to lecture...dentists on like, mental health and mental situations and elements of addiction and all that side of it’ – creating meaningful activity and personal sense of purpose in his life.

Of course, this extremely positive experience of the impact of SCI is not everyone’s, and there are individuals who can find it (either periodically or enduringly) understandably unbearable, and struggle to feel any sense of hope. Luci expressed this when she said:
‘I’ve had enough. I would never do it – I wouldn’t do that to my XXX, but you just feel like – knowing that I’m not going to have a life anymore really….thinking about ending my life’

(1.462)

David had also expressed how he had moments when ending his life had crossed his mind as a way of ending the pain he was experiencing when he had been particularly struggling. However, he was keen to clarify that it was about wanting pain to stop, rather than for life to end:

‘you do get those moments where I’m – I’d say – ‘I’ve had enough. No more’ – and it’s – it’s not that you want to end your life, or ‘owt like that, although sometimes you can get so low that you think, well, what do I do? How will I get out of it? How long have I got to suffer this?’

(2.793)

The Soldier, at the time of his first interview, had been struggling with feeling bleak and defeated because he couldn’t imagine any kind of purposeful/meaningful existence post-SCI. He felt he had lost his ability to be a soldier (‘I can’t go to war. I can’t go back to the desert in a wheelchair...I’d just be a burden to the rest of the unit’ [1.272]), which had been such a huge part of what had previously created meaning in his life that there was very little left:

‘I’m laying here just filling piss bags up...and that’s all I’m doing’

(1.555)

‘At the moment...one of my biggest hurdles is that I can’t foresee a new life’

(1.54)

The Soldier had been battling with the fundamentally existential conflict between needing to find meaning in life and the apparent meaningless/chaos of the universe. Without religious belief or the capacity
for acceptance (at that moment), he acknowledged he had contemplated suicide as a way of resolving such an unbearable dilemma. However, as a man who was ‘used to adjusting my life from my job’ (1. 1160), and as a father with a strong sense of purpose in the role, he was able to reject that course of action and ‘turn (him)self around and go – this is who you are now. You need to live with that’ (1. 965). For everyone in the study who spoke of their various existential challenges, there was some degree of acknowledgement for a need to, as David put it, ‘ride the storm and accept it’ (1. 31) – a notion not dissimilar from Camus’ proposed resolution to the disharmony between the need to search for meaning and the apparent meaninglessness of the universe; embrace, accept and live ‘in spite of’ (Camus, 1942).

### 4.5 Trauma

Trauma is a broad-reaching area of concern that is well researched in both psychological and counselling literatures. Whilst evidence of trauma being part of the experience of SCI is clear and present enough in the material for it to be classed here as a theme, it will not be addressed in depth in this study as there is not space enough to be anything more than superficial. However, in attempting to understand the therapeutic needs of individuals post-SCI, it also cannot be ignored – particularly when looking at the inter-relatedness of the themes and how they potentially can affect each individual in different ways at different times. The Oxford English Dictionary defines trauma as ‘a deeply distressing or disturbing experience’, an ‘emotional shock following a stressful event or a physical injury’, or, in medicine as ‘a physical injury’. From these definitions it seems inevitable that there would be some kind discourse of trauma for any individual who has incurred SCI, and yet this does not seem to be particularly acknowledged or addressed by anyone (individuals themselves or professionals) in the interviews conducted for this study.
All participants apart from Denis incurred what is termed a ‘traumatic SCI’, which means they are caused by physical trauma. The initial cause of injury was not the only traumatic element for the participants however; realising the extent of their physical injuries, their need for prolonged care in a high dependency unit/SIU and the potential implications of their injuries were also described as traumatic times.

Denis experienced the onset of a condition (transverse myelitis) that caused paralysis which subsequently he partially recovered from. This brought its own set of problems that he felt were not understood or attended to well enough, perhaps precisely because it was not as common as a traumatic injury. Both Luci and Mohammed fell down flights of stairs in their homes. Neither of them chose to speak of their accidents during the course of their interviews, so it is impossible to know in what way it might have affected them. This, of course, does not mean that there was/is no traumatic impact as a result of events.

David did not mention how he incurred his injury, but he did talk of the initial trauma it caused him and his family. He also showed me photos his son took of him whilst he was in the ambulance to illustrate the depth of his pain and the intensity of his experience. Pain can be a difficult thing to manage after a traumatic experience as it can act as a reminder of trauma (Wicksell et al. 2010) and serve to keep it very much part of present experience. David illustrated the effort it takes for him to manage this:

‘It’s like I’m in a boxing match and “you’re not going to beat me”...you know, I talk to myself. I’m fighting and, I’ll be honest, most times I’ll win – because I know if I don’t, I will end up, erm...and it’ll get into me and destroy me’

(2.590)

The Soldier, the Roofer and the Dentist were the most overtly affected by their traumatic experiences. The Dentist had fallen from a height face-first
onto a table, however he felt that it was the period immediately after his accident that was the most traumatic for him:

‘it was tough initially...I was sedated heavily and had dreadful hallucinations...it was a very unpleasant time when I became lucid - I for some reason knew that I was paralysed, I don’t know how. I had a tracheostomy and ventilator and couldn’t eat, speak, and couldn’t move...I kept asking how long I’m going to be in for. If, at that stage, someone had mentioned that I’d be in for six or seven months, I’d have probably tried to kill myself”

(1. 60)

An awareness of his physical state and the degree of medical intervention he needed was shocking and difficult to comprehend. The Roofer expressed a similar experience of trauma as a result of what had happened medically (in terms of interventions) after his accident, when he said ‘I’ve been mutilated’ (1. 501). He had experienced a freak accident at work on a building site where some unsecured pipes had fallen and crushed him whilst he was alone, and had to wait around fifteen minutes for someone to find/help him. Alongside SCI, he had sustained multiple other injuries and significant complications. When I asked if he had received any help or guidance with navigating his way through his intense experience, the Roofer said he had spoken to nobody, and that if he had wanted help or to talk about anything, he felt he would have to go and specifically ask for it – a difficult challenge for a man who described himself as someone who was ‘not good at speaking to people’ (1. 435) and easily flustered. Instead, he had stayed quiet, ruminating and worrying about everything.

The Soldier had fallen over a wall into a building yard when he was being mugged on holiday and found it hard to comprehend how, in just a moment, his whole life had been turned upside down:
'so, the day before this I was round the pool with my friends, swimming, doing normal things...and the next day I wake up and I’m in hospital with – on a board like this (gesturing at his own body) going what’s happened here?...why can’t I move my toes? Why’s all this not working? Well, hang on, this is what’s happened. What? Woah – hang on!'

(1.1296)

For him, the trauma was in the sudden and absolute nature of the injury that instantaneously challenged and affected every part of his life:

‘it’s not something that you might be able to get rid of. If you injure your spinal cord, that’s it...it’s instant. You’ve got to adjust your life instantly, but it’s not an instant thing to get out of here...it’s a long process to change your life’

(1.1270)

Both the Soldier and the Dentist mentioned some interaction with psychiatrists and psychologists, but that the focus was more on their low mood than listening to and helping understand and contextualise their experiences. As such, it was felt (by both men) to have been unhelpful:

‘there was nothing that he could offer...they can’t cure your physicality...but at the time when you’re dealing with the rehab side of spinal injury, you can’t put that to rest ‘cos its fresh and it’s still active’

(The Soldier. 1.1037)

4.6 The Temporal

The purpose of this study having two meeting points to interview participants was to try to capture some of the fluidity and fluctuating nature of the experience of SCI and disability. It was anticipated that there could be
significantly different challenges faced and expressed in different settings, and that this would be partially due to the passing of time and inevitable change (in circumstance/perception/understanding), yet it was not expected that time itself would feature as a structural part of the experience of SCI. Three distinct time periods were identified:

4.6.1 First Time Period

Participants felt that time was initially defined by how long they had been in hospital and the SIU, and how long before they could hope to get out. This period tended to focus on physical progress and physiotherapeutic goals as measures:

‘I was speaking to the physios and generally it’s about three months...in my head it’s like the home strait, once I start the physio.’

(The Roofer. 1. 338)

4.6.2 Second Time Period

Once out of the SIU, a newly defined time period was created by some participants that was focussed on the ‘2 years post-injury’ point as the point by which it is commonly felt (amongst the medical profession) that pretty much what recovery can be achieved will have been achieved. In other words, it is at this point that the individual can see more firmly what their enduring physical limitations might be:

‘it’s going to be long way to get to the best I can, anyway...two year...I’ve just got to keep at it, that’s all, and hope that I can at least restore some of me strength and me energy’

(David. 2. 1520)
For all participants who engaged in a second interview, this period was clearly one consisting mainly of fluctuation and adjustment – to their respective environments, their inter-personal relations, their social positioning and their metaphysical adjustment to themselves.

4.6.3 Third Time Period

A third temporal position became apparent, occupied by myself. I had introduced myself as a researcher with personal experience of SCI, and for many of the interviews I was using a stick for walking so some of the consequences of my injury were ‘visible’. A lot of the participants expressed interest in what had happened to me, what my experience was, and, more significantly, what my experience is now – living with SCI years later. Most of the participants expressed a feeling that my having incurred SCI was significant in that they felt that I might have some better understanding of their circumstance, experience and struggles. Because of this sense of kinship, I was cautious in my responses to their questions about my current experience as it was clear that, aside from needing to satisfy their curiosity, their queries were really about a time in their future and how the injury might impact them enduringly. David and his wife were keen to know more about how his experience of neuropathic pain might affect him in the future. His wife asked me if it ever goes, after I had acknowledged I had an awareness and a personal experience of it:

Me: ‘...you can find your own way of dealing with it. It might go, it might not. Some days it might not be there and some days it might be...but they can’t.’

Wife: ‘so you’re saying it’ll maybe never go?’

Me: ‘maybe not, or maybe it will, or maybe it will go partly’
Wife: ‘yes, yes. Well that’s what I said to him – this might be the best you’re ever going to be’

(2.40)

I could not, as no one could, tell anyone with any certainty how they would feel or cope, or even how things would change for them, but it was nonetheless apparent that they were looking to me - as someone like David but further along the line - for some sort of hope that things could feel ok again.

Whilst apparently perhaps obvious, the knowledge that the experience of SCI is both fluctuating and enduring, and passes through ‘phases’ that potentially have different focuses is significant in the attempt to understand the complexity of the psychological impact of such an injury. Each stage experienced post-injury is likely to focus attention on differing aspects of the enduring injury/disability, and throw up challenges specific to time and location in relation to the individual and their experience of their injury thus far. It would therefore be impossible to make absolute statements about what psychological challenges an individual might face without having some idea of their history and context.
5 DISCUSSION

This chapter begins by taking up emerging issues and reflections from the analysis. It first looks at the interrelatedness of the identified dominant themes before extending and developing these issues using other existing, related literature in order to advance understanding of disability and the psychological experience of SCI. Limitations, omissions and implications of the research are then identified before the thesis is brought to conclusion.

5.1 Time And SCI: Past, Present, Future

I had not expected there to be such a temporal element to the experience of SCI, yet it has become an important feature of the study in terms of structure, experience and positioning. On a broad and structural level, the three distinct time periods identified in the analysis as First, Second and Third could also be formulated as the Past, Present and Future for the participants in their experience of life right now, today. However, it is not really this neat as the first interviews were conducted in their present, and only became their past with the experience of the second environment as their present and the presence of me as symbolic of something in their future. Moreover, this conceptualisation ignores an even broader perspective, wherein the Past was pre-SCI, the Present is post-SCI(!) and there is no discernibly different Future state as there can (currently) be no post-SCI experience without the existence of enduring effects of the injury, however small. For a while I grappled with this as a metaphysical issue to do with the philosophy of time (for more, see McTaggart [1908]), yet, whilst I acknowledge that this is an important and complicated area of thought, these philosophical deliberations don’t feel particularly relevant to the felt difficulties and challenges commonly expressed in this study as a result of SCI. Instead, I turn towards understanding more of the subjective perception of time as inextricably bound with the experience of self and emotion,
particularly in relation to issues of health. The noticeably different nature of the experience of the three time periods seems to affect (direct?) the focus of attention of the individual on aspects of their enduring injury to create specific challenges. The following section explores how and why.

5.1.1 Perception Of Time

The perception of time is part of human experience, yet it is not something that exists as a distinct physical entity in the empirical world (Lakoff & Johnson, 1980). Rather than perceiving time itself, we each ‘feel’ time by experiencing constant flux and changes at a subjective level. We conceptualise and understand time as a metaphor for the constant motion of events through space (Evans, 2004; 2015), however it is complicated by the fact that the measurement of time is apparently influenced by our own individual drive, emotions, and mood states (Wittmann et al, 2006; Droit-Volet & Meck, 2007; Noulhiane et al, 2007). This seems to reflect Heidegger’s assertion that time is a construct of the self (1972), and that perceived time represents something of the mental status of the perceiver (Wittmann, 2009). Generally, time distortions are caused by emotionally arousing events (Droit-Volet, Brunot, & Niedenthal, 2004; Effron, Niedenthal, Gil, & Droit-Volet, 2006; Gil, Niedenthal & Droit-Volet, 2007), and the experience of the protracted duration of time is often related to dangerous/life-threatening situations (Hancock & Weaver, 2005), physiological arousal due to stress, and/or an increased attention to time (such as when waiting) (Wittmann, 2009). This understanding of time, self and emotion being subjective and inextricably bound together, juxtaposed with the overarching temporal experience of change as constant motion of events through space, feels significant in understanding SCI as a complicated, fluctuating and enduring existential experience.
5.1.2 Provisional Existence

The first temporal positioning identified in analysis was one that focused on time being ‘kept’ in rehabilitation before release. Frankl (1959) talks of the effect of a ‘provisional existence’ on prisoners in concentration camps, and there is something of this in the first positioning. As previously outlined, the nature of SCI is such that it is impossible to predict what recovery may be made (if any), and so medical staff manage expectations by offering no definitive prognosis statements. SCI is, in the acute period at least, a dangerous/life-threatening situation filled with stress, and the amount of time spent consciously waiting when one can do nothing unaided cannot be underestimated. The experience of time spent in a SIU (as described in the analysis) has echoes of a feeling of incarceration and a peculiar inability to live for the future or aim at a goal as a result. Frankl suggests that in this situation a person ‘cease(s) living for the future, in contrast to a man in normal life. Therefore, the whole structure of his inner life (is) changed; signs of decay set in…’ (Pg. 79). Unlike the experiences Frankl describes however, at some point there is a goal to aim for in this first temporal positioning – one dependent on physical progress and physiotherapeutic goals as measures.

5.1.3 Provisional Existence Of Unknown Limit

The second positioning identified in the study – being discharged from the SIU but still within the two year ‘best chance’ recovery potential period – does not have the captive (circumstantially, if not necessarily embodied) challenges of the first, however it is also not necessarily easy by any means. It is during this period of time that there is potential for individuals with SCI to experience what Frankl identified as a ‘provisional existence of unknown limit’ (1959). It is only after discharge from the SIU into everyday circumstances/life that the individual can see more clearly what the impact of their physical limitations may be….and that they will indeed be enduring
as there is no potential for a ‘date for release’ – no end to the experience of their injury. As stated in the reflexive chapter, I myself experienced this; whilst in the SIU I had felt/imagined that I was injured more than I had become disabled, and that after a period of time that was indeed a ‘provisional existence’, I could go back to a ‘normal life’. It was only when I left the rehabilitation environment for my home that I realised that my life would be forever different. This feeling was reflected with great clarity throughout much of the phenomenological analysis of people’s experiences of their altered embodiment.

5.1.4 Everything Changes

The third positioning is one that perhaps does not really exist other than in this thesis. For me personally, it is another perspective (coming from the participants) of my personal ongoing experience of the second positioning – this is my provisional existence of unknown limit. For the participants in the study, I, as someone who has lived with SCI for longer than they, represent something of a potential future existence that is both the same and different to their own current experience. To fully understand the importance of recognising and acknowledging this third positioning involves the consideration of Heraclitus’ notion that ever-present change is the fundamental essence of the universe; the panta rhei - ‘everything changes and nothing remains still…you cannot step twice into the same stream’ (Sedley, 2003). This leads into the next section, which discusses the relatedness of the dominant themes.

5.2 Relatedness Of Dominant Themes

In attempting to understand the complexities of the challenges faced by individuals post-SCI, it became clear through this study that issues do not ever stand alone, unaffected by anything else. Rather, it is apparent that
particular experiences have had significant effect on how individuals have met, understood and managed other experiences/issues, and that whilst obviously a particular moment/challenge could not be returned to, it could be understood differently or given different significance when considered in relation to something else. Conversely, in the light of particular experiences, subsequent challenges were sometimes apparently met in particular ways related to/because of that previous experience. In terms of potential therapeutic needs, this seems significant, as the inter-relatedness of these themes serves to affect an individual’s understanding and sense of self – here acknowledged as the Subject.

In order to try to illustrate how the identified themes can impact upon an individual, I have tried to create an overarching illustration of how they can be understood as inter-related and vulnerable to affect from each other to varying degrees. In my view, this may be best illustrated initially through simple diagrams. Firstly, the subjective experience of Time, as already discussed, must be recognised as a metaphor for the experience of constant flux and change, and as such, necessarily all themes are impacted by their temporal context in some way:

![Diagram](image)

**Figure 3:** illustration of the inter-relatedness and mutual affect of identified themes in relation to Time
The next diagram, developed through the processes of analysis and interpretation as a way of making sense of the affect(s) of the various themes, attempts to develop this notional relatedness as the ever-present affective backdrop for other concurrent complex inter-relatedness between the identified themes (abbreviations remain the same), as illustrated by the arrows:

Figure 4: Diagram of the inter-relatedness of identified affective and affected themes resulting from synthesising conceptual frameworks

The following sections will explore the relative nature each of these themes, as outlined above, before attempting to understand and illustrate their contextual inter-relatedness. This is initially achieved diagrammatically by determining whether the theme is more affective (blue arrows) or affected (red arrows). Each theme is then elaborated upon and discussed further in order to illustrate some of its potential affect and affectedness on the experience of SCI and physical disability.
5.3 Trauma

In terms of inter-relatedness, the initial trauma (T) that constitutes the beginning of the experience of SCI (either by causation or experience) is clearly an affective theme which has potential impact on the Subject, the Phenomenological and the Existential, but does not have any bearing on the Ecological – rather attributes of the Ecological (e.g. medical interventions/negative power imbalances/discrimination) can constitute traumatic experiences themselves.

5.3.1 Definition

‘Trauma’ is an elastic concept that is used across many disciplines to represent a variety of conditions or states (Joseph 2012). Originally, it was/is a medical term used to refer to bodily injury, and indeed most SCI are termed ‘traumatic’ (to differentiate them from those occurring as a result of infection/disease). The meaning of ‘trauma’ has become extended in psychology as metaphor to acknowledge the idea that the experience of some events can be so powerful as to leave an emotional/cognitive ‘scar’. However, the boundaries of what is accepted as trauma are continually disputed, as illustrated by the constant redefinitions in DSM in relation to PTSD diagnoses. For the purposes of this study, I have used the term in
relation to SCI as illustrative of something distressing that overwhelms the inner resources of an individual, and thus ‘causes injury’ to their emotional wellbeing.

5.3.2 Traumatic Injury Or Trauma From Injury?

The experience of SCI results in a set of circumstances that significantly challenges both the adaptive capabilities of the affected individual (the Phenomenological), as well as their place in the world (the Ecological), and their understanding of it (the Existential). According to some trauma research (e.g., Janoff-Bulman, 1992), this alone constitutes trauma. Participants in this study expressed all these elements when they described their realisation of the extent and full implications of their physical injuries, as well as the potential trauma of how (and how suddenly) they had come about. It was noticeable, therefore, that apparently none of the participants had spoken about their traumatic experiences with any professional – particularly those individuals who had had specific contact with psychological/psychiatric care. Perhaps it is the historic medical focus on the (necessary) adaptation to physical disability as a consequence of SCI that has meant that attention to psychological trauma has apparently been routinely marginalised as part of post-injury care. The experience of acquired physical disability is certainly not routinely present in trauma literature (although it is admittedly more apparent in some arenas such as traumatic brain injury and positive psychology [for example, Collicutt McGrath & Linley, 2006; Elliott, Kurylo & Rivera, 2000]).

5.3.3 The Negative Effect Of Trauma

Emotional responses to the experience of trauma are typical (Wortman & Silver, 2001), but (like all other responses to SCI) there are none that can be safely identified as universal. The consequences of suddenly acquired disability can be frightening as well as confusing; fundamental assumptions
about the world, life and self-identity can be challenged and may result in significant levels of psychological distress. Depending on the intensity, duration and severity of physical threat/suffering as a result of trauma, highly emotional psychological responses can persist for prolonged duration (Tedeschi & Calhoun, 2004). The experience of trauma can significantly (sometimes enduringly) change an individual’s perspective and understanding of existing relationships, meaning in life, and personality schemas (Joseph & Linley, 2008). As is well documented in the literature, cognitive distress is common after trauma, and reactions such as intrusive thoughts/images, high levels of stress, anxiety and psychological 'numbness' are also often regularly experienced (Tedeschi & Calhoun, 2004). Some of these reactions have been identified throughout various parts of the analysis as part of the experience of SCI, however it is impossible (and also not the aim of the present study) to know whether these experiences expressed by participants are as a direct result of the trauma that caused their injury, or their resulting experience of disability. It is enough to recognise and acknowledge that the likelihood of some traumatic expression after SCI is high, and that it appears not to be so routinely catered for/to.

5.3.4 Post-Traumatic Growth

Individual responses to the challenges of SCI are various, as can be seen throughout the analysis, and it is important not to assume certain reactions are inevitable. One participant (the Dentist) seemed to exemplify post-traumatic growth (PTG) in his positive psychological approach and change of perspective post-injury. Others, perhaps more usually, did not. PTG has been well documented within literature generated by positive psychology (Coyne & Tennen, 2010; Tennen & Affleck, 2002; 2009), yet there is currently no agreed definition of what this complex phenomenon actually constitutes. It has, however, been widely (self)reported following various different traumatic life events (Affleck et al., 1987; Joseph & Linley, 2004; McMillen et al., 1997; Sears et al., 2003), including (particularly pertinently
to this study) people with chronic health conditions (Tennen, Affleck, Urrows, Higgins, & Mendola, 1992), and those with lower reported levels of ‘quality-of-life’ (Tomich & Helgson, 2004). Four major theories dominate PTG discourse (Jayawickreme & Blackie, 2014), all of which focus in some way on the possibilities of positive psychological change arising from the challenge of traumatic circumstance. Psychological growth is, of course, not a direct or necessary result of trauma, and is not achieved consciously (Tedeschi & Calhoun 2004). It is most likely to be an outcome of the struggle to survive (or decision that survival is worthwhile) (Davis & Nolen-Hoeksema, 2001), and is separate to the experience of distress and the notion of ‘wellbeing’. Indeed, growth, distress and wellbeing may all coexist (Yalom & Lieberman, 1991).

The notion that psychological growth can come from suffering is historically less readily acknowledged in disciplines that tend to pathologise (such as psychology and medicine) than it is in philosophical or theological thought (Jayawickreme & Blackie, 2014; Tedeshi & Calhoun, 2004). Nietzsche (1889) asserted ‘that which doesn’t kill me makes me stronger’ which illustrates the experience of personal post-traumatic growth beyond survival that can be fundamentally life-changing and profound. Joseph & Linley’s (2005) conceptualisation of PTG relies on acknowledging the difference between hedonic and eudaimonic wellbeing as fundamental to this experience of growth. They suggest that considering eudaimonic wellbeing takes into account constructs such as autonomy, purpose and meaning as significant indicators of functioning (Jayawickreme, Forgeard & Seligman, 2012), and that there is more to human existence than pure pleasure/happiness (Boniwell, 2008). This then allows for the possibility that traumatic experience may leave an individual perhaps sadder, and even with a level of enduring distress, but also with an enhanced appreciation of (and commitment to) what is important and of value to them. This can result, as expressed by the Dentist, in new-found meaning, priorities and clarity to their sense of purpose in life.
PTG may also be conceptualised as the expression of a redemptive narrative generated by the experience of trauma (Jayawickreme & Blackie, 2014). Trauma narratives tend to adopt a universal formulation; before trauma, after trauma and the turning point (McAdams, 1993; McAdams, Reynolds, Lewis, Patttern & Bowman, 2001). A redemptive narrative constructs these periods as personal low, personal high, and trauma as the turning point (catalyst) that redirects the flow of the lifecourse (Jayawickreme & Blackie, 2014). This revision of a life story based on how a person has changed is one way in which individuals can make sense of the world (and themselves) post-trauma in order to accept an enforced disengagement from past goals/meaning and reformulate more appropriate ones. Both David and, more overtly, the Dentist expressed something of redemptive narratives, with positive affect.

More simply, PTG has been identified as the process of finding meaning and learning lessons in the aftermath of trauma (Park, Chmielewski & Blank, 2010; Roepke, Jayawickreme & Riffle, 2013; Wong, Reker & Peacock, 2006). It has been acknowledged that there is often need to relinquish certain goals, assumptions and even identities as a result of trauma, whilst simultaneously striving to build new ones. Dwelling on fundamental questions such as ‘who am I?’ or ‘why?’ (as some participants did) may appear to be negative ruminative cognitive processes, but can also illustrate an orientation towards the future (as with the Soldier) and the revision of schemas and goals (Tedeschi & Calhoun 2004). This active engagement with the consequences of trauma can generate healthy processing of emotional responses and promote psychological growth (Calhoun, Cann, Tedeschi & McMillan, 2000; Ulrich & Lutgendorf, 2000). With this in mind, it may be that the facilitation of cognitive processing is key, and that the role of peer support (such as from past in-patients visiting the SIU) may be crucial in determining the degree of willingness to incorporate new perspectives (Tedeschi & Calhoun, 1993).
5.4 The Ecological

The Ecological (Eco) (relations to/with others and the environment) impacts on the Phenomenological and the Existential experiences of the individual, and therefore inevitably also on the Subject. The Ecological bears no direct relation to Trauma (although it can have a traumatising effect on the subject via the phenomenological or existential experiences of the individual).

5.4.1 Critical Disability Theory

In an endeavour to further the identification and analysis of power relationships between individuals, institutions and culture through language and behaviour, I now return to Critical Disability Theory (Hosking, 2008). As introduced earlier, this conceptual framework is a useful deconstructive tool with which to broaden out the current analysis. The following methodical application of CDT illustrates how the Ecological (as formulated in this study) affects the felt experiences of the individual living with SCI, and goes on to challenge the status quo by seeking essential transformation in the social construction of disability.

5.4.2 Bio-power

It is perhaps to be expected that the full force of bio-power be exerted/felt within a medical institution as it is necessarily structured according to an
'expert' system consisting of a hierarchy of specific knowledge. Such a system inevitably involves dividing practices which are justified and tolerated by society through the power it gives to science and scientific claims (Foucault, 1982). On a practical level this is vital and effective, and many of us are the grateful beneficiaries of such systematic care. However, how these knowledge-based interventions are carried out, can(should) be critically analysed in order to ascertain the full implications for the individual at the bottom of this hierarchy as they experience their bodies becoming scientifically classified as labelled and categorized ‘things’. It is of no surprise perhaps that participants in this study found themselves subject to a paternalistic attitude that maintained this subordinate positioning in a number of ways. The predominant manifestations of this in participants’ experience involved the withholding of medical knowledge regarding the nature/extent, potential treatment and implications of injuries, as well as through employing particular language, and the apparently regular imposition of decisions made ‘on behalf of’ the individual with SCI without allowing them capacity to voice their own preferences/desires/interests.

5.4.3 Language

The combined effect of medicalisation and institutionalisation as a result of SCI lead to participants reporting feeling they had become depersonalised and even dehumanised. Through language adopted by professionals, family members and even participants themselves, participants described how they experienced themselves post-injury as ceasing to be individuals. Instead, they described how they had become subjected to a reformulation of themselves (permeating beyond the medical environment) as an objectified invalid body that needs restructuring, managing and controlling by more ‘valid’ dominant others.
5.4.4 Voice

The able-bodied dominant construction of disability as something that is inherently lacking contributes to negative and discriminatory societal attitudes by denying the capacity for challenge from those affected. By privileging the expression of an able-bodied perspective, the assertion of what contributes to disability by those living with it has been historically marginalised and suppressed by the argument that it can be simply dismissed as inappropriate, unfounded, and due to an unhealthy relationship to issues of disability (Titchkosky, 2003). This leaves disabled people utterly unable to assert their needs, or even voice their experience if it challenges or disagrees with what the able-bodied want to hear. Participants in the study expressed frustration towards the able-bodied community for their expectation of a passive (and sometimes even grateful) attitude towards their benevolent application of judgement in the name of attending to their needs. They also described how it had a significant impact on their sense of self and worth, and denied their capacity for agency.

5.4.5 Valuing Diversity

Illustrating the fluidity of disability caused by SCI is something that was identified in the Introduction as central to it's reformulation. As well as identifying and illustrating (the effect of) flux within the individual experience, it is necessary to emphasise that ‘disabled people’ in general constitute an extremely varied and diverse population, and so understanding disability as something simply categorical is fundamentally problematic. From an able-bodied perspective, there might be some-thing(s) that make a group of people who have incurred SCI appear cohesive, yet there is nothing that can be safely assumed from this other than they have all experienced a biologically defined injury that itself has no absolute or inevitable enduring consequence. Moving towards understanding disability from a human rights perspective necessarily rejects the privileging of
‘normal’ over ‘abnormal’, but more importantly, also means acknowledging and engaging with the ‘dilemma of difference’ (Minow, 1990). There is no singular experience of the impact of disability as its significance is contingent to each and every contextual experience, therefore the ‘dilemma’ arises out of knowing when it is necessary to acknowledge and respond to physical difference, and when it is not. In the SIU, the treatment of personal rehabilitation needs as purely functional requirements according to a uniform standard routine potentially ignored the impact on each individual of their specific physical difference. In the attempt to be inclusionary, differences can be overlooked by the dominant group (the able-bodied), with the effect of significantly risking the marginalisation of disabled individuals, and disallowing their participation in society. This was most evident in this study during the second set of interviews, where individuals were trying to integrate themselves back into their lives. The experience of fundamental needs being overlooked by social services and other external agencies was expressed by a number of participants, and it would be all too easy to frame these experiences as illustration of irritating problems caused by an individual’s SCI. Instead, these accounts indicate how such experiences can (should be) identified as societal issues of equality and inclusion, with the intention to seek solutions that enable full participation in life.

5.4.6 Rights And Transformative Politics

In terms of rights, the individual needs and interests of people with (acquired) disabilities must be recognised as issues of autonomy, whilst as a (socially constructed) group the assertion of the right to full participation in society must be upheld. All individuals who are not identified as able-bodied suffer (to varying degree) the effects of living in an ableist society that views disability as negative and discriminates against it. When the medical model is adopted economically, a disabled person becomes conceptualised as a potentially ‘in-valid’ member of society. The current organisation/structure of British society, especially during this period of austerity, has not invested
either financially or socially in social care resources (rather, has withdrawn from them by reducing entitlements to PIP [Disabled People Against Cuts, 2018]), leaving them depleted and regularly unable to satisfactorily meet needs arising from living with disability. All too frequently, as described by participants in this study, attention to these needs is often treated as neither urgent nor even necessary, with the consequence of the already disempowered individual being granted no respect or equitable chance to engage fully in society. This potentially affects family relations, personal agency and, perhaps most damagingly, the fundamental sense of self and worth.

5.5 The Phenomenological

The Phenomenological (Ph) (meaning/understanding and experience of physical self) necessarily and inevitably directly affects the Existential, and the overall experience of the Subject. It is affected by Trauma and the Ecological. Whilst this (and the following) section is primarily informed by and concerned with Phenomenology and embodied experience, it can only be communicated through language which is necessarily a construct of the society we live in. As such, it is all within a wider, socially constructed framework that involves the assertion and perpetuation of power, as previously discussed. It is the recognition and synthesised articulation of
these two dimensions that enables a more holistic and inter-relationally aware formulation and understanding of the identified challenges presented by SCI and sudden acquired disability.

5.5.1 Lived Body

As outlined in the Introduction, the notion of the lived body (‘being-in-the-world’) provides a useful non-dualistic conceptualisation of the relationship between mind/body that takes into account the psychological, physical and social dimensions of being human. It is not possible to express any kind of universal SCI experience, however I think it is useful to illustrate something of the peculiarities of the phenomenological effect of enduring disability as a result of SCI. Predictably, when discussing issues of disability the medical model dominates discourse, so it is of particular import to acknowledge that the body is more than merely a biological organism – it is also the individual’s embodied perspective of the world (Merleau-Ponty, 1962). Despite the fact that we most commonly talk of ‘having’ bodies, in actuality we ‘are’ our bodies and, as such, the body is both the subject which we are, and the object that we have. An acquired disability as the result of SCI defamiliarises our experience of our ‘body-in-the-world’, and in doing so, brings it to attention. All the participants of the study articulated this fact variously and to differing degrees. By turning to Feminist literature and Disability Studies in conjunction with the phenomenological philosophy of Merleau-Ponty, I hope to be able to further explore some of the implications of this for the individual who has recently incurred SCI.

5.5.2 Unfamiliar Body

Prior to injury the body is ‘inconspicuous, unobtrusive and non-obstinate; (it) is absent from our experience – which comes through it’ (Diedrich, 2001). Heidegger (Being/Time, 1927) describes this instrumentality of the body through the notion of ‘zuhandenheit’, which translates as ‘readiness-
to-hand'; as long as the body is working, it is the intention that the body is working towards that is the focus. When the instrumentality of the body breaks down however, it fully discloses the world but also the body as tool (Leder, 1990). Murphy (1987) acknowledges the impact of an acquired disability on an individual when he states: 'not only are their bodies altered, but their ways of thinking about themselves and about the persons and objects of the external world have become profoundly transformed' (Pg 87). The experience of pain expressed by participants forced them to become aware of their bodies as objects, standing between their intentions and the world. The sense of self and body is potentially divided as the object-body becomes something obtrusive and the demanding focus of attention. The painful body becomes dominant, and the articulation of self and world can become diminished (Bullington, 2009) Because this focussed experience of/on the body is both a new experience and new perspective, the body becomes, to some degree, alien to the individual, and exists as both other and owned (mine).

5.5.3 Objectified Body

Disability, as already discussed, is defined as ‘other’ in our society; the inessential correlate to the able-bodied. As Young (1980) identifies, this means the individual living that embodied, subjective otherness is living a contradiction; as a human, the disabled individual is a free subject with agency and intention, yet their positioning as disabled serves to deny that very subjectivity. The inclination to think of our bodies as something we have rather than what we are is reinforced by the natural sciences and medicine, which teach and encourage us to objectify our own bodies. In a medical environment this is particularly concentrated and was reflected in the way participants talked about their injuries, and even described themselves. Bowel/bladder issues compound this objectification of the body – losing bowel/bladder function necessarily requires some kind of alternative routine intervention, yet this separation of the (dys)functionality of the excretory system from the entirety of the individual constitutes a
mechanistic, technological dehumanisation (Montague & Matson, 1983) that reduces the objective body even further to that of machine (Haslam, 2006). This (re)conceptualisation of the body is very far removed from the pre-SCI primordial, lived experience, and is understandably for some participants a cause for distress.

5.5.4 Intentional Body

Husserl (1900) asserted that it is intentionality that distinguishes conscious beings from the being of entities. The subjective body is the primary locus of this intentionality as it is the dynamic point of presence and openness to experiencing the world. Consciousness (being-in-the-world) consists in projecting purposes and goals, directing itself outwards, and forming an ‘intentional arc’ (Merleau-Ponty, 1962). Disability (especially acquired) causes a shift or disturbance in the character and nature of this intentionality, but it does not mean it disappears. Instead, the experience of the lived body moves into the foreground of awareness and (interaction with) the world shrinks into the distance. The struggles with embodiment and directedness that participants expressed can be perhaps understood as (resistance to) the visceral consequences of this disturbance to their phenomenological intentionality and a need to find a way of accommodating a more passive being-in-the-world. Whilst it is not at all in original context, there is something about this struggle that brings to mind a quote from Frankl (1959); ‘it did not really matter what we expected from life, but rather what life expected from us’ (pg.85) – it is perhaps only when there is some sort of understanding and acceptance of the new, physical limitations that affect the intentional arc, that adaptation to a new way of being-in-the-world can enable individuals post-SCI to find ways of leading and living meaningful lives.
5.5.5 Pain-Full Body

As well as being physiological, it is increasingly understood that pain is an emotional, psychological, existential and socio-political phenomenon (Bullington, 2009). When persistent and/or severe, it alters the way we are-in-the-world, dominating our experience and affecting our every sensibility (Svenaeus, 2015). As described by the participants in the study, acute pain can hinder ability for interaction in the world, both in terms of inhibiting movement, but also through distraction as the body becomes increasingly hard to tolerate. In this sense, the experience of pain is potentially comprehensively alienating; the body displays itself as uncontrollable and even unmanageable – estranged from its pre-pain self, but also from others who do not and cannot experience the pain.

Pain is intrusive and forces focus on the pain-full body (Bullington, 2009). Consequently, it is demanding, challenging and isolating, and yet if the individual is to engage with the world and live, pain must be negotiated. It is perhaps this that caused the sense of vulnerability and mistrust expressed by some of the participants; the body, in its intentional being-in-the-world, moves outwards towards a task, but simultaneously remains immobile due to the fear of getting hurt. Attention (and perhaps desire) becomes divided between the body’s accomplishment of the aim to be realised, and saving it from harm. It is possibly in this way that the experience of the disabled body post-SCI can become both a burden and something to protect.

5.5.6 Disallowed Body

Whilst the nature, and possibly importance, of the physical aspects of sex may change after SCI, for many individuals sexual identity remains important to their sense of self (Wilder, 2011) as well as their potential need for sexual expression (Kreuter et al., 1996). Sexuality encompasses more than just (objective) physical functioning, and is closely associated with self-
esteem, body image, identity and self-worth (Singh, Rohilla, Siwach, Dhankar & Kaur, 2012; Steins, Westheimer & Young, 1997). The sexuality of people with disabilities is rarely openly discussed (Brodwin & Frederick, 2010) which contributes to a subconscious, tacit understanding of physically impaired people as asexual (Maia & Ribeiro, 2010). Social prejudices and stereotypes of disability conceptualise the injured individual as ‘damaged goods’ and therefore no longer of any sexual value (Brodwin & Fredrick, 2010). Media portrayal of women with physical impairments is almost entirely asexual (Hwang, 1997), and sex between someone with SCI and a non-disabled partner is seen to be at best dysfunctional (Stiles, Clark & Labeff, 1997), and even as objectionable as to be considered perverted (Cole, Chilgren & Rosenberg, 1973) or social taboo (Lamb & Layzell, 1994). By culturally objectifying the sexual body as defined by the ability to complete the sexual response cycle (Masters & Johnson, 1966), the disabled body becomes sexually neutral. Of course, this doesn’t acknowledge the very real possibility for subjective sexual pleasure or feeling obtained from other activity (Barnes, 1996; Tepper, 2000). An experience of the loss of capacity for sexual expression and identity was a significant emergent theme in the analysis, and one that caused particular distress for some. If the body is to be understood holistically as the primary site of consciousness for being-in-the-world, then the acknowledgement of capacity for (and attention to) potential need for sexual intention to be expressed cannot be ignored.

5.6 The Existential
The **Existential (Ex)** (concerned with the meaning of life and a sense of agency) affects the experiences of the **Subject**, but is vulnerable to affect from the experience of **Trauma**, the **Ecological** and also the individual **Phenomenological** experience.

### 5.6.1 Spirituality

It is fairly consistently documented that searching for (and finding) meaning through spiritual practice is common amongst individuals with significant health disabilities (Matheis, Tulsky & Matheis, 2006; Patterson & Staton, 2009). Spirituality is often divided into that which is religious – related to a God or higher power (Colon, 1996), and that which is existential – exploring the meaning and value of life (Brady, Peterman, Fitchett, Mo & Cella, 1999). Spiritual consideration post-SCI is possibly connected to an active search for meaning as part of a coping mechanism through which individuals can attempt to understand, accept and adjust to the consequences of their injury (Matheis, Tulsky & Matheis, 2006). It has been asserted by McColl et al (2000) that spirituality (of either sort) can enhance awareness of self, increase perception of independence and give a sense of purpose in life, thus enabling the individual to be able to interpret their injury positively. This can be established through feeling a sense of cosmic meaning to injury and a connection to something greater than biological existence (Patterson & Staton, 2009), as reported by David and Luci. However, it is also possible to make sense of injury as punishment for moral wrongdoing - potentially the interpretation of the Roofer, and the cause of his sense of injustice. This also appeared to be the understanding expressed by the Dentist, although for him it was apparently not uncomfortable. For others (such as the Soldier), the experience of significant injury/acquired disability may constitute proof to them that there is no higher power, fairness or justice, and this can be a source of intense distress and despair. Paradoxically, it can also eventually
lead to spiritual and existential freedom that reportedly enables the greatest personal sense of wellbeing (Patterson & Staton, 2009). Consequently, it has been asserted that engaging with spirituality is an important part of processing the impact and effects of SCI (Matheis, Tulsky & Matheis, 2006). Specifically, an existential perspective might (eventually) significantly contribute to a feeling of optimism and hope about life and the future post-SCI.

5.6.2 Meaning And Purpose

Frankl (1959) developed existential thought by identifying three different courses of action that can aid the pursuit of meaning and purpose of life; through deed/experience, through engagement, or through suffering:

‘What man actually needs is not a tensionless state, but rather the striving and struggling for some goal worthy of him’ (Pg. 110)

The purposeful effect of suffering has been addressed in the section on PTG above, and will also be touched upon later in the chapter. It cannot be ignored in this discussion that unbearable suffering can result in a loss of hope and the desire to end life, and that the presence of such dark thoughts were expressed in this analysis, and are perhaps common post-SCI. It is, however, a conscious decision to not dwell on this here, as I feel issues of suicidality as a result of both psychological suffering and SCI are well enough documented elsewhere. Additionally, as previously asserted, I feel there has been a dangerously common assumptive and simplistic causal link made between SCI acquired disability, suffering and suicide that I wholeheartedly wish to challenge as it contributes to the pathologising and objectification of individuals who are striving to find a new way of living and thriving post-injury. Consequently, I shall focus on reframing and developing better understanding of the challenging drive to pursue purpose post-SCI.
5.6.3 Eudaimonia

The notion of ‘wellbeing’ in psychology has historically been closely aligned with the hedonistic tradition (Deci & Ryan, 2008). Hedonic wellbeing has focused on happiness defined as striving for the maximisation of pleasure (positive affect) and the minimisation of pain (negative affect). Eudaimonic wellbeing, in contrast, is concerned with living life in a way that feels rich and satisfying (purposeful), in accordance with Aristotle’s notion that happiness is found by leading a virtuous life and doing only what is worth doing (Boniwell, 2008). Thus, eudaimonic wellbeing is a term developed and used to challenge psychology’s prevailing conceptions of ‘subjective wellbeing’ and ‘satisfaction with life’ being measured by feeling good/content, and instead replace them with something akin to the notion of ‘psychological wellbeing’ (Ryff, 1989), or the ‘fully functioning person’ (Ryan & Deci, 2000). In this sense, the search for purpose, post-SCI, can be understood within the framework of humanistic psychology and the belief in the innate ‘actualising tendency’ (Rogers, 1959) of the individual; the directional trend to constantly develop, mature and realise self. The challenge then becomes how to experience this potential growth and fulfilment when it has become profoundly influenced or compromised by the context of the individual’s life (in this case, SCI). Attention and efforts must perhaps necessarily turn (as indeed participants experienced and expressed in their various challenges) to striving for subjective congruence between the ideal and the present experience in order for there to be a feeling of purposeful meaning and satisfaction in life. According to Self-Determination Theory (Ryan & Deci, 2000), there are three inherent elements for fulfilment and purpose to be felt; autonomy, competence and relatedness. Without these, personal motivation and wellbeing are hard to find, and purpose can be lost. Across the themes identified through this study, all participants (to various extents) expressed their frustrations and struggles with these elements. Perhaps in this context, hedonic aims and measures can be allowed to fade, and the individual post-SCI can be
acknowledged and encouraged to be able to achieve a sense of eudaimonic wellbeing (meaning) in their life.

### 5.7 The Subject

Questioning identity and meaning regarding self is addressed in this study as part of the possible existential (and phenomenological) challenges that might be faced post-SCI. This is within a socially constructed, Foucault-informed framework that, when combined, potentially amalgamate to form a pathologised, decontextualized (from society and historical understanding of self) view and understanding of self-identity. This research does not intend to investigate in abstract form either identity or self, but without an acknowledgement of the affected human as subject in relation to both context and experience, there is no way of understanding the complex interrelatedness and fluidity of the consequences of SCI. It is possible that by identifying and centrally locating the Subject within the context of many potential forces acting upon/within an individual, there can be recognition of the potentially destabilising underlying awareness of ‘who I was verses who I am verses who I can and/or will be’. Consequently, the Subject is understood in this study as being directly affected by the initial Trauma, the effects of the Ecological, the Phenomenological experience and the Existential challenges.
5.8 Everything Flows

There is possibly some irony to be found in the awareness of the presence of constant motion relating to the experience of SCI (which, after all, causes paralysis). Consistently, throughout the research process, I have attempted to illustrate the fluctuating nature of disability, as well as the fluidity of inter-personal relations (and positioning) and the ever-changing inter-relatedness of identified themes. Paradoxically, as I have not been searching for any universal truths, this ‘truth’ found in the consistency of change is not a notion limited to Western philosophical thought; it can also be found in classic Japanese literature (Chomei, 1998) as depiction of the Buddhist concept of impermanence (anicca). This is one of three foundational premises of Buddhist thought, and is closely linked to the other two; anatta (there is no essential, absolute self) and dukkha (suffering). It feels striking that these are elements identified in the present analysis (and discussion) as so pertinent to the experience of SCI, but which have perhaps hitherto been predominantly pathologised or disregarded on a psychological level. Engagement with spiritual understanding and acceptance of these Buddhist premises leads to enlightenment, which again shares something with growing existential awareness and the concept of eudaimonic wellbeing, post-SCI. Further, and fundamentally challenging the medical model of disability, is the extended Buddhist concept of ‘Wabi-sabi’ originating from Japan (Lawrence, 2011). This focuses on and values all that is considered to be authentic in the world by identifying three simple realities; nothing lasts, nothing is finished, and nothing is perfect (Powell, 2004). Cherished characteristics of wabi-sabi art are asymmetry and the appreciation of the integrity of natural objects and processes (Koren, 1994). The classic Greek ideal of beauty in the Western world prizes smooth symmetry and perfection, and this extends to the desire for perfection in the human body. Anything less than ideal is therefore rejected medically (and morally), as well as aesthetically. However, by adopting a wabi-sabi standpoint, the body with acquired disability as a result of SCI is neither hopeless nor in-valid.
Instead, it merely constitutes embodied evidence of change, and thus is worthy of considerable thought/attention.

5.9 Limitations And Omissions

It is impossible to be comprehensive in the investigation of a phenomenon. By engaging in conversation with individuals who have recently sustained SCI about what their experiences have been at two different points within the first year of injury, I have attempted to identify, extract, illuminate and explore individual yet also common expressions of some of the challenges faced when the concepts of being, knowing, identity and the fundamental reality of existence are so abruptly and dramatically altered. Individuals who have sustained SCI form a markedly heterogeneous group, although there are statistical trends (as outlined in the Introduction) that were mirrored by characteristics of participants of this study. The already small sample group was reduced for the second round of interviews. After consideration of various consequences, I chose to include the initial interviews of the two participants who could not complete their engagement with the study as I felt the experiences they had expressed during their initial interview were no less relevant without the second one. Perhaps, however, there is something significant lost to the study without their second contributions.

Certain specific experiences relating to SCI were not addressed at all in this study, partly because opportunities did not arise through participant engagement (gatekeeper selection), expression or design choice. There was only one female participant, and consequently there is remarkable little exploration of anything concerned with gender difference; no mention of childbearing/birth, menstruation, female catheterisation, trans-gender issues, specific sexual function, or gender-based societal expectations. There was also no expression of any experience other than that of the heterosexual male. Additionally, there was only one participant who was not white British
and with English as his primary language. By design, I had chosen to exclude participants who had concurrent head injuries or traumatic brain injuries, as their apparent needs made the necessary ethical processes too complex. One participant expressed something of significant pre-existing mental health issues, yet any potential difficulties arising from these alongside the experience of SCI are not properly explored here. As a consequence, many issues of intersectionality are not particularly acknowledged or even present throughout this study, and would be pertinent foci for future research.

I purposefully chose to interview participants in two locations in order to gain better understanding of some of the environmental issues arising from acquired disability caused by SCI. I had not expected to be able to visit a military rehabilitation centre during the study, and found the experience quite particular. Unfortunately, the confines and practical limitations of this study have not allowed for me to explore this. Again, this could be useful and informative work for the future.

Whilst I endeavoured to illustrate something of the constantly fluctuating experience of SCI, further longitudinal study of a similarly intimate yet generalised nature could shed more light on how the enduring experience of SCI is felt and managed. It was only during the analysis that I realised that this life-long enduring experience has a potentially different character to experiences boundaried by time and expectation. As life expectancy post-SCI is increasing, it would be pertinent to know something of the common experiences and challenges faced years down the line.

The analysis is based on personal lived experiences of individuals who have incurred SCI, yet I did not involve participants again after their interviews. This was due to the adopted method of analysis not requiring further input/co-production for the purposes of validity (Willig, 2003; 2013). However, as already intimated in the reflexive chapter, this does mean that the final analysis is fundamentally only mine. Perhaps to involve
participants in the design, co-creation and production of research might create even more insightful work that would be pertinent to clinical understanding and practice. It would certainly do more to address the historical absence of disabled researchers, although in my defence, I feel I might be able to adopt this position myself.

5.10 Implications For Counselling Psychology

It is my hope that this thesis will give counselling psychologists (and other practitioners involved in SCI care) knowledge and confidence to approach supporting each individual with SCI in a mature and pluralistic way. Concepts of humanistic psychology are well established in many areas of human services (Muramoto, 2011) and have particular relevance to issues of physical health and disability (Altmaier, 1991). The definition of counselling psychology (BPS, 2017) firmly emphasises the core importance of humanistic values in professional practice. The relationship between humanism, phenomenology and existentialism in counselling psychology philosophy converge to provide a perspective on the human condition that is constantly seeking to delve deeper into the essence of humanness and relational being (Cooper, 2007; 2009; Joseph, 2008). The essential commitment of the counselling psychologist is to recognise and give value to their client's (inter)subjective experiencing of the world in order to help facilitate their empowerment and actualisation of potential, whilst also appreciating and recognising the forces of their social context (Cooper, 2009; Strawbridge & Woolfe, 2014). To this end, an emphasis on change and development is recognised/encouraged; humans are in a constant process of essential, natural growth, which requires shedding both self-imposed and societal limitations in order to actualise into fully functioning persons (Rogers, 1965; Rowan, 1992).
5.10.1 Education And Reflexive Awareness

The counselling psychologist (or other therapist) engaging in therapeutic work with the newly disabled individual post-SCI is likely to encounter common challenges of disability experience such as living/coping with pain, adjusting to physical limitations and managing medical interventions. However, potential issues of discrimination, prejudice and the internalised oppression of the self can be equally present and devastating/disabling (Reeve, 2000). It was my intention for this study to fundamentally challenge the apparently routinely pathological conceptualisation of living with SCI or acquired disability. By approaching the research from a particular standpoint (insider/outsider/somewhere in the middle), I hope to have avoided most/all of the oppressive biomedical assumptions of the dominant able-bodied community regarding what issues may arise as a result of SCI and acquired disability, whilst simultaneously illustrating what these negative and disabling attitudes can do to exacerbate potential struggles for the affected individual. Hopefully, this has highlighted the clear need for counselling psychologists to be properly informed of prevailing stereotypes and dominant discourses of disability, and how they are perpetuated. As practitioners closely aligned with an agenda for social justice, it is important (even ethically necessary) for us all to be aware of the machinations of such widespread and embedded application of institutional power relations, as well as their consequences for the subjected, objectivised individual.

To my mind, change can most comprehensively be effected through education. Whilst other issues of ‘difference and diversity’ have been thoroughly explored through engagement with research, textbooks, seminars and reflexive exercise, disability has consistently been noticeably absent from virtually all areas of training, certainly routinely (McLeod & Machlin, 1998; Parkinson, 2006), and this risks unconscious assumptions being left unchallenged. The counselling psychologist has an obligation to be aware of issues pertaining to social justice, and consequently must develop their capacity for reflexive awareness and sensitivity to negative
constructions and attitudes towards disability in order not to perpetuate them in therapy and/or research. Within organisational settings, practitioners who are well informed can perhaps also feel more confident to challenge institutional discriminatory cultural practices that maintain power imbalances.

5.10.2 Clinical Practice

Counselling psychology focuses on facilitating holistic wellbeing through the therapeutic relationship by paying ‘particular attention to the meanings, beliefs, context and process that are constructed both within and between people’ (BPS, 2017). By establishing a relationship that is equal and collaborative (rather than expert-patient), the counselling psychologist can hand control and power to the disabled individual; thus also acknowledging that they have responsibility and choice. In acknowledging their client’s subjective experience of both life and disability, the humanistic counselling practitioner recognises that their client cannot be reduced to their disability, or any other singular component part. Also, that their client’s emotional reactions to circumstance are all valid and to be respected.

Positive psychology (Seligman, 2002) stems from the traditions of CBT and clinical psychology, yet is driven by humanistic philosophy; instead of a pathological focus, it aims to optimise human functioning whilst still being defined by an empirically oriented approach (Orlans & Van Scoyoc, 2008). Szasz (1961) described psychological distress as ‘problems-in-living’; a notion that recognises the processes active within an individual, but also the significance of the dynamic interaction between the individual and environmental/social factors. This awareness of the relational interplay of inner and outer worlds in psychological issues demands attention to phenomenological experience and a holistic approach to therapy (Polkinghorn, 2001). ‘Third wave’ therapies (e.g. Mindfulness-Based Cognitive Therapy, Dialectical Behavioural Therapy) are values, mindfulness and acceptance based methods which deal holistically with topics
traditionally embraced by humanistic psychology, and align themselves with the philosophy of counselling psychology even more exactly. Of these, ACT adheres to a health model (Hayes, Strosahl & Wilson 1999), and also acknowledges the historical (as well as situational) context of the individual and their distress, making therapy in this vein an absolutely holistic and contextual task (Biglan & Hayes, 1996).

To focus on the subjective experience of living with physical disability is perhaps unlikely to enable the formulation of theories and models from which to base clinical practice. However, to have some knowledge and understanding of some of the potential contextual phenomenological and existential experiences of individuals with SCI (as illustrated through this study) can enable the counselling psychologist to relate to them as ‘beings who have capacity to grow; and understand them in terms of the social, economic and cultural limitations that they might face’ (Cooper, 2009. p. 121). This is a more attuned positioning for a discipline fundamentally built upon humanistic and existential philosophy (Cooper & McLeod, 2011). In terms of therapeutic approaches then, a ‘bespoke’ integrative application of therapeutic formulations co-constructed with the client would be the most privileged, and ideally preferring those that take a holistic and values-based approach.

### 5.10.3 Social Action

Finally, in January 2018, the BPS Division of Clinical Psychology published a conceptual alternative to the (medically-based) diagnostic model of distress, unusual experiences and troubled behavior – the Power Threat Meaning Framework (Johnstone & Boyle, 2018). In its infancy, and currently purely theoretical, this meta-framework encompasses sociological, psychological, biological and philosophical considerations to make important links between meaning-based threats (physical danger/betrayal etc.), meaning-based threat responses (e.g. coping strategies/symptoms of distress), and the wider contexts of power and social/ideological meaning. A particular
consequence of this holistic reformulation of distress is the central focus given to that which has been previously obscured by pathology: the operation and consequence of power, the wider social, political and cultural contexts, and the attempts at meaning-making and agency of those who are struggling to survive/live/thrive within their embodied environments. In a direction that is possibly counter-cultural to current British societal attitudes, the framework acknowledges the significant connection between social injustice and distress, and promotes progressive social action. It became apparent through the experiences of participants in the present study that the effects of power differences, inequality and discrimination in social context have the potential to cause distress no less significant than that immediately caused by the individual physical implications of SCI. Identifying the need for equality and diversity in society addresses the reality that issues of disability affect all areas of personal experience, not just the physicality of a person (Bryant-Jefferies, 2004; Higgins, 1992). Consequently, this framework is potentially useful in reinforcing the ethical obligation of counselling psychologists to embrace issues of inequality and discrimination in both practice and research (British Association of Counselling and Psychotherapy (BACP), 2015; British Psychological Society (BPS), 2018), as a constitutive part of their responsibility and obligation to society (BPS, 2017).

5.11 Conclusion

Living with a chronic condition such as SCI has been described as a continually shifting process in which individuals experience a complex interaction between their condition and their life context (Paterson, 2001). This thesis has endeavoured to capture something of that constant fluidity of personal experience, whilst also illustrating the felt implications of far less fluid discriminatory and oppressive attitudes and constructions of disability in society. In engaging intimately (through interpersonal interaction and discursive analysis) with the experiences of seven
individuals with SCI, I have identified common thematic challenges, and some of the potential variety of individual responses to meeting them. Using the work of Merleau-Ponty and Foucault to inform the analysis, I have explored some existential considerations arising from the experiences of acquired disability as a result of SCI, and broken down for scrutiny some of the implications of social constructions of disability, as well as some Foucauldian concepts such as discipline, bio-power and dividing practices. I have then turned to critical disability theory, feminist literature, disability studies, positive psychology and Buddhist thought to discuss and elaborate identified themes, and embed them in broader knowledge. I have also briefly explored the experiences of time and trauma in relation to SCI. Throughout the research, I have been acutely aware (and made use of) my own positioning as (dis)abled and insider/outsider/somewhere in the middle to inform all aspects of the study as usefully as possible. On considering the implications of this research for the counselling psychologist, I have suggested reflexive awareness, education and social action as necessary responses to identified issues (to varying degree), and acknowledged that therapeutically, there can be no simple model or ‘easy answer’. Rather, the competent and effective therapist can only meet any individual as exactly that, but with awareness of (their own and the client’s) self and context…and with a degree of education.

To end, I would like to return to the concept of wabi-sabi. Often, research seems to aim for answers and solid conclusions. I can produce none, and never intended to. My primary purpose for this thesis was merely to begin to illustrate just how complex and various the psychological challenges resulting from SCI can be, in contrast to the simplistic assessments and formulations found in much of the existing literature. I suggest that it is only with such a holistic, in-depth awareness of forces acting both upon and within an individual who has incurred SCI and has a suddenly acquired disability, that therapeutic practitioners can satisfactorily meet their needs (or those of others with similarly acquired disability), and potentially avoid ignorantly perpetuating oppressive and prejudiced attitudes and
behaviours. It is perhaps easier, appealing and (apparently) more satisfactory to want to use established theories, practices and subject discourses in both research and practice in order for the counselling psychologist to feel knowledgeable, and with some sense of control and potential for achievement. Yet, I feel that by doing this, we may risk entirely missing our fundamental goal of welcoming, respecting and validating the Other (Cooper, 2009).
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APPENDIX 1

Papers identified in preparatory systematic review exploring what 'being-in-the-world' entails as an individual with SCI:


APPENDIX 2

Participant Information Sheet

Therapeutic needs of individuals who have recently sustained a spinal cord injury: an interview study

You are being invited to take part in a research study as part of a Doctorate Thesis in Counselling Psychology. Before you decide to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?

Researcher: Esther Ingham, Counselling Psychologist in Training

School of Education
Ellen Wilkinson Building
The University of Manchester
Oxford Road, Manchester M13 9PL

Title of the Research
Therapeutic needs of individuals who have recently sustained a spinal cord injury: an interview study

What is the aim of the research?

The aim of this research is to enable individuals who have recently sustained a spinal cord injury to have a voice with which to express their specific therapeutic needs in relation to some of the psychological issues they face in the months immediately after injury. By listening to individual experiences of adjustment and rehabilitation, the research will explore the emotional and psychological impact of a SCI as equally important as the physical effects. The purpose of the study is to enable Counselling Psychologists and other Counsellors to understand and address these dominant issues with the most appropriate therapeutic interventions. The results of the study will contribute to disability and rehabilitation literature for Counselling Psychologists, and also the broader literature on psychological issues of identity and disability for those with a SCI.

Why have I been chosen?

You have been invited to participate because you have experience of the impact of a SCI and also a rehabilitation environment. There will be approximately five other individuals with similar experiences who will be involved in the research alongside yourself, should you choose to take part.

This study is conducted independently to the NHS and has no connection with the hospital or staff. As such, your decision whether or not to participate in the research will have no effect on your future treatment in the unit.

What would I be asked to do if I took part?
If you choose to take part in the research, you will initially be asked to participate in an interview with the researcher lasting no longer than one hour. You will be asked open-ended questions about your experience of being in a rehabilitation environment, your understanding of disability and spinal cord injury, and also more generally about how you are feeling within yourself. This interview will be held in a private space in the rehabilitation unit and will be audio recorded to collect data.

Once you leave the rehabilitation unit and are comfortably settled outside hospital, you will be asked to contact the researcher when you are ready to set up a repeat interview within 12 weeks of having been discharged. This second meeting will take place in a location that suits your physical needs and can be discussed/arranged closer to the time. The interview will be conducted again by the researcher, and will follow the same form as the first one with many of the same open-ended questions, although this time will focus on external environments rather than the hospital one. Again, the interview will be audio recorded to gather data.

**What happens to the data collected?**

The data collected will be immediately stored on an encrypted memory stick for confidentiality. All interviews will be transcribed by the researcher and then analysed using qualitative discourse methods to identify dominant psychological themes, understanding and constructions of disability, and what therapeutic interventions might be most helpful.

**How is confidentiality maintained?**

Confidentiality will be maintained through data encryption and secure storage procedures in accordance with governing ethical bodies. All collected data will be immediately encrypted and stored securely in a password-protected file that only the researcher will be
able to access. Transcribed data and analysis documents will be stored in the same way, and with the same restricted access. Participant anonymity will be ensured at all times throughout data collection, analysis, and dissemination; each participating individual will be only identifiable to the researcher by an allocated ID number. Quotes will be anonymised in report writing and no identifiable information of participants will be used at any point in the research process. All gathered data will be destroyed five years after dissemination of the findings.

What happens if I do not want to take part or if I change my mind?

It is entirely up to you to choose whether or not you will participate in the research. If you do decide to take part, your next step will be to read and sign the enclosed consent form and post it in the return box. My email address is esther.ingham@postgrad.manchester.ac.uk if you prefer to electronically communicate your interest in participating, however you will still be required to sign and return to me the enclosed consent form. After I have receipt of consent, we will be able to negotiate a time for your first interview that will be convenient to you.

If you express an interest in taking part but then change your mind at any point during the research, you are always free to withdraw at any time without giving a reason. If, for any reason, you lose the capacity to consent during the study, you will be withdrawn from any further participation. Data already collected will continue to be used anonymously unless specifically requested otherwise, however no further requirements would be made.

Will I be paid for participating in the research?

There is no payment for taking part in this research.
What is the duration of the research?

The duration of the research will be one hour whilst you are in the rehabilitation unit, and one hour within twelve weeks of discharge.

Where will the research be conducted?

The research data will be collected initially in the rehabilitation unit, and then in a location appropriate to your physical needs (e.g. your home environment).

Will the outcomes of the research be published?

Findings from the research will be published in a thesis to the University of Manchester. There is also possible potential for further publishing in academic journals.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. If they are unable to resolve your concern, or you wish to make a complaint regarding the study, please contact a University Research Practice and Governance Co-ordinator on 0161 275 7583 or 0161 275 8093 or by email to research.complaints@manchester.ac.uk

What if something goes wrong?

In the event that something goes wrong and you are harmed or suffer loss as a result of taking part in the research, you may have grounds for claiming compensation from The University of Manchester.

In order to protect you, The University of Manchester has insurance in place that provides:
• Compensation for non-negligent harm to research subjects occasioned in circumstances that are under control of the University,

• Cover for legal liabilities for injury, loss or damage to property, or financial loss arising from the University's actions or those of its staff or supervised students.

If you make a claim in respect of legal liability you may have to pay your legal costs.

Contacts for further information

Researcher Contact Information:
Esther Ingham: esther.ingham@postgrad.manchester.ac.uk

Research Supervisor Contact Information:
Professor Erica Burman: erica.burman@manchester.ac.uk
APPENDIX 3

CONSENT FORM

Therapeutic needs of individuals who have recently sustained a spinal cord injury: an interview study

Please initial box

1. I confirm that I have read the information sheet dated 12/07/16 (v. 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that the interviews I partake in will be audio-recorded and transcribed

4. I agree to the use of anonymous quotes
5. I understand that data collected during the study may be looked at by individuals from the University of Manchester, from regulatory authorities, or from the NHS Trust where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.

6. I agree that any data collected may be published in anonymous form in academic books/journals.

7. I agree to take part in the above study.

________________________  __________________________  ___________
_____  
Name of Participant     Date    Signature

________________________  __________________________  ___________
_____  
Name of Person        Date    Signature
taking consent
WITHDRAWAL DEBRIEFING SHEET

Therapeutic needs of individuals who have recently sustained a spinal cord injury: an interview study

Thank you for choosing to be part of this study. This research project aims to identify some of the specific psychological and therapeutic needs of individuals who have recently sustained a spinal cord injury, both during and after rehabilitation. You have decided to withdraw from the study and this is absolutely fine. I would like to reassure you that everything that you have shared as part of the study will remain confidential and anonymous, however, if you wish for anything you have contributed to be deleted from the data, please let me know.

If you would like any further information, you may contact me, Esther Ingham or my research supervisor Erica Burman or the Research Governance and Integrity Manager of the University of Manchester. Here are the contact details:

Ms. Esther Ingham: esther.ingham@postgrad.manchester.ac.uk

Prof. Erica Burman: erica.burman@manchester.ac.uk

Research Governance and Integrity Manager: research.complaints@manchester.ac.uk, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL Telephone: 0161 275 2674 or 275 8093

Thank you for your time.
APPENDIX 5

Semi-structured Interview Example

‘During the next hour I am interested in hearing about your experiences since you sustained a spinal cord injury. I would particularly like to hear about how you have found being in a rehab unit, how you feel about your injury and disability in general, and also any ideas you may have as to what you think could make your experience any easier emotionally and psychologically. I will ask a few open-ended questions designed to prompt you on these subjects, although you do not need to stick exclusively to them. I am mainly interested in whatever you feel it is important/would like to say in relation to your recent experience of spinal cord injury’.

Example questions:

How would you describe being in rehabilitation?

How would you describe being back at home?

What is a typical day like for you at the moment?

What does the word disability mean to you? Has it changed since your injury?

How have other people dealt with your injury?

What would make your experience/things easier?

What do you feel is important for you right now?

Minimal prompts will also be used such as:

Can you tell me more about that?

Can you give me an example (of that)?

How did (does) that feel?

What does that mean to you?
Tues 17th Jan.

Running - I feel a degree of frustration - whilst I'm grateful for the support & facilitation of the psych team here I also feel that if I had been allowed to chat to anyone on the wards then I might have had many more participants - I wonder if people are being unnecessarily protected from chatting. When it needn't be as traumatic as people feel. Is this part of a culture of accidental paternalism?

One gentleman wanted to speak with me, but not on record & could not consent to being part in the study. It was hard to disengage as he had a lot he wanted to say. I wonder about the fear (?) of being recorded - what did he think would happen... a need to talk - even to total strangers just as a one off but not confident about the consequences of being heard.

Another interview today. Another interview scheduled for 2 pm with — but she was sleeping and I didn't want to wake her. Another potential participant identified by the psych team has a full day of therapies today - meaning he is busy in a meaningful way, and then will be likely exhausted later.

Yesterday’s interviewees eager to chat again/same more. It seems once the door is open, that there is quite a need to talk - he was very interested in...
APPENDIX 7

Example of Transcript and Analysis

. sentence final intonation
, clause final intonation
! exclamatory intonation
? final rise
... pause of more than two seconds
italics editorial comments
R researcher
P participant

Different coloured highlighters indicate various themes