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**Life after loss: Adjusting to the impact of different  
forms of bereavement**

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Finally, I would like to thank the six participants who took part in this study for giving me their time and trust. Your contributions were invaluable and I would like to dedicate this work to you.

## **Declaration**

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## Preface

While the work that forms this portfolio was not specifically designed around a theme, it became clear that various aspects of these different documents connect and overlap. Since the conception of my thesis several common links have emerged which bring aspects of theory, practice and research together. These links have prompted me to collate these pieces of work.

First, my research was driven by my clinical experience of working with spinally injured patients at the London Spinal Cord Injury Centre (LSCIC). Whilst working at this placement and during the research process, I was also working with bereaved clients at Cruse Bereavement Care. Undertaking both of these placements simultaneously, it quickly became clear to me that there were strong parallels between the therapeutic work I was engaging in with both client groups.

Bereavement can be defined as “the act or state of being bereaved or deprived of something or someone” (Merriam-Webster, 2017). As this definition suggests, bereavement may be experienced in many different situations, where some sort of deprivation has occurred.

Although typically this term is associated with a person’s death, bereavement is understood to extend beyond this. This was also strongly emphasised during my Cruse training, that the word bereavement can refer to many different life events, not only the loss of a loved one. Divorce, moving home, losing contact with an old friend and indeed loss of health are all forms of bereavement.

Spinal injury is in itself a significant bereavement and individuals experiencing this will go through a period of grief, mourning the loss of their mobility, identity and future hopes and

expectations. Indeed, in my clinical practice I have found that the main presenting difficulties and grief 'symptoms' were common to both my spinally injured patients and my bereavement clients.

While somewhat under researched, this link has also been reflected in the extant research. Dickson, Allan and Carroll (2008) conducted a qualitative study to explore the experience of loss post spinal injury. They found that this loss could be characterised by three themes; loss of control, loss of independence and loss of identity. These interrelated themes highlight the links between bereavement support and therapeutic intervention after spinal injury. In addition, researchers have also combined grief theory and knowledge regarding spinal injury rehabilitation to compile assessment tools, such as the SCI-QOL, which aim to measure loss and grief post-injury (Kalpakjian, Tulskey, Kisala & Bombardier, 2015; Tulskey, Kisala, Victorson, Tate, Heinemann, Amtmann & Cella, 2011). The development of such outcome measures, alongside more qualitative research studies suggests that the understanding of spinal injury as a form of bereavement is beginning to be acknowledged, both within the academic research and healthcare communities.

Spinal injury is usually sudden, unexpected and often violent and the extant research has shown that these factors in the context of a bereavement can lead to complicated grief (Worden, 2010). This is grief which is more complex in nature and often takes a longer amount of time and greater therapeutic support to resolve. In addition, the circumstances surrounding the injury may be complex, evoking trauma, shame and guilt in the client (Worden, 2010). These same themes are often present in bereavement work. The case study section of this portfolio centres on a Cruse client, with whom I was engaging in bereavement work, who presented with chronic grief and this seemed to reflect the chronic nature of spinal

injury. In addition, this client also presented with unresolved grief after a sudden and traumatic loss. These clear research, theory and practice links, prompted me to include this case study in the portfolio.

Secondly, the client who I have presented in the client study battled with Leukaemia as a child and now as an adult, has diabetes as a result. This client's health became an ongoing aspect of our sessions, having an impact on our therapeutic work. I have reflected that this is also the case in working with spinally injured patients. The ongoing health issues that emerge after spinal injury become part of my work with patients and it was often necessary for me to have knowledge of these health concerns. There seemed to be a practice link for me between the influence of health in the work with this bereaved client and my therapeutic work and research with the spinally injured client group. Indeed, IPA has its origins in health psychology (Smith, Flowers & Larkin, 2009), which is one of the reasons why this seemed an appropriate method for conducting research within the spinally injured community and this further highlights this research, practice link.

Thirdly, the theoretical approach I present in the client study was Person-Centered (Rogers, 1959). I adopted the person-centered framework, as this approach is generally considered to be the most appropriate in the context of grief work (Worden, 2010). The tenets of Person-Centered therapy set out by Rogers (1967) parallel the needs of bereaved clients, identified through research and clinical experience (Larson, 2013). Jordan and Neimeyer (2003) state that the most essential requirement of bereavement counselling is "the encounter with compassionate and empathically-attuned caregivers, who provide mourners with a healing experience of being understood and supported in their journey of loss" (p.780). The emphasis of the Person-Centered approach on a deeply empathic relationship seems to mirror this, as

well as the non-directive, client-centered nature of the approach and emphasis on client agency (Goodman, Morgan, Juriga & Brown, 2004; Haugh, 2012). Similarly, this is also the approach most used in therapeutic work with spinally injured patients.

The phenomenological underpinnings of the Person-Centered approach (Rogers, 1959) and IPA seem to suggest a further common theme linking my research and clinical practice. Both stem from a single epistemological root which highlights the importance of experiences and consciousness (Giorgi & Giorgi, 2008). The importance of client centered working within the Person-Centered approach and the importance of the lived experience within IPA are both products of this phenomenological origin.

It is for these reasons that I have chosen to gather these pieces of work together in this portfolio. The thesis, case study and research article underline the conception of spinal injury as a form of bereavement and to highlight the research, theory and practice links which explicate this view.

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## **PART I**

### **Dating with a Spinal Cord Injury:**

#### **An IPA Study**

## Abstract

Spinal Cord Injury (SCI) primarily affects young adults and approximately 52.3% of people are single at the time of injury (Spinal Cord Injury Facts, 2013). Several studies have revealed negative attitudes towards disabled individuals, particularly when asked to view them as a potential romantic partner (Chen, Brodwin, Cardoso & Chan, 2002; Rosenthal, Chen & Liveh, 2006; Hergenrath & Rhodes, 2007; Miller, Chen, Glover-Graf & Kranz, 2009; Marini, Chen, Feist, Flores-Torres & Del Castillo, 2011). Physical disability has also been found to interfere with establishing and maintaining romantic relationships (Howland & Rintala, 2001; Taleporos & McCabe, 2001a).

While previous literature has explored the impact of an SCI on marriages and existing relationships, very little research has attempted to explore the challenges and limitations of being single and dating with an SCI. The paucity of literature concerning the experience of dating with an SCI is concerning, considering that approximately 50,000 people in the UK are currently living with this type of injury (Spinal Cord Injury Facts, 2013).

This study aimed to explore the impact of dating with an SCI by asking six spinally injured women to describe their lived experience of dating post-injury. Data was collected using open-ended semi-structured interviews and were analysed using Interpretative Phenomenological Analysis (IPA). Participants' experiences clustered into four superordinate themes: a) Dating as a Journey; b) Challenges to View of Self; c) Perceived Societal Attitudes and d) Dating Concerns. The empirical findings suggest that dating after spinal injury is complex and process orientated. Participants reported an initial grieving phase during which time dating was not a priority. As participants moved further through the process of coping, they were able to be more open to the prospect of dating. Participants also reported being affected by the negative expectations of others, including gender stereotypes. They also explored the issues of disclosure and control in relation to dating. These findings are discussed in relation to existing literature and research. In addition, aspects of the participants experienced are considered in terms of their practical use in creating workshops for newly injured spinally injured patients on topics such as body image, sexuality and dating. Implications for counselling psychology and for further research are explored.

# Chapter 1

## Introduction

In this chapter, I will outline the rationale and aims of the current study. I will also explore and evaluate the existing literature, considering the limitations and shortcomings of previous research and the gap in the literature that the current study will fill. I will also explore the possible benefits of my findings for spinally injured patients and the implications that these findings might have for the field of counselling psychology.

### **Definitions of Terms**

When considering aspects of life with a spinal cord injury (SCI) and engaging in spinal injury research, it is important to have an understanding of certain terms and phrases that describe the nature of injury. These terms and phrases are used throughout the literature concerning SCI research and are replicated throughout this manuscript.

#### *Level of Injury*

The phrase ‘level of injury’ refers to the lowest level of the body that has normal sensation and motor function after an SCI has been sustained. Below this level sensation and mobility are affected in some way due to damage to the spinal nerves. The neurological level of injury may be different from the bony level of injury, which refers to the section of the spinal column that has sustained damage. The sections of the spine are; Cervical (neck) which is made up of seven vertebrae, Thoracic (chest) which is made up of twelve vertebrae, Lumbar (lower back) which is made up of five vertebrae, Sacral (hips) which is made up of five vertebrae and finally the Coccyx (tail bone) which is made up of four fused vertebrae (Diagram 1). The limitations in sensation and mobility sustained after an SCI will be

determined by the level at which the spinal nerves have been damaged. For example, the spinal nerves at the C4 vertebra control the diaphragm and therefore damage at this level or higher is likely to mean that a ventilator is required for breathing (Diagram 1). The nerves at C7/8 control the lower arms and fingers, while those at T1 control the movement and sensation in the hands, and the nerves at T7/8 control the muscles involved in coughing and laughing (Diagram 1). While only a general picture of the function of the spinal nerves, this gives some indication of the way in which level of injury indicates the limitations in mobility and sensation that an individual might experience post-injury.

### *Completeness of Injury*

The phrase ‘completeness of injury’ refers to the severity of damage to the spinal nerves at the level of injury. If the spinal cord is completely transected during injury, then the injury is described as ‘complete’. If the spinal cord has been damaged but has not been completely transected then the injury is described as ‘incomplete’. The sensation and mobility an individual will retain post-injury is determined by the type of damage to the spinal nerves and the level at which this damage is sustained. Therefore, there are many different types of spinal injury and each involves different physical impairments. Individuals with a complete injury are unlikely to have any movement or sensation below the level of injury. An individual with an injury at C4, where damage to the spinal nerves is complete, may have no movement or sensation below this point and require a ventilator to breath, whereas another individual with an incomplete injury at the same level may be able to walk. Where damage to the spinal cord is limited, despite a vertebral fracture, there may be no lasting loss of function or sensation after the spinal bones are stabilised.

### *Quadriplegia/Quadriplegic*

The term quadriplegic refers to an individual who is affected by paralysis caused by illness or injury that results in the loss of use of all four limbs and torso. This is known as a high level injury.

### *Tetraplegia/Tetraplegic*

The term tetraplegic refers to an individual who is affected by paralysis caused by illness or injury that results in the partial or total loss of sensation and motor function in both legs, arms, chest and abdomen. Tetraplegia occurs when there is damage to the spinal cord in the cervical area. While the category of 'tetraplegia' can be fairly general, typically tetraplegic patients are often able to move one arm fairly well and some are able to move the other to some degree. These patients often have limited or no ability to grip with their fingers. This may also be referred to as a high level injury.

### *Autonomic Dysreflexia*

This is a condition which can affect high level spinal injury patients. It occurs as a result of the damaged spinal nerves sensing pain from a part of the body below the level of injury. This manifests itself in an intense headache and increase in blood pressure. If not managed quickly and effectively, this condition can result in a stroke.

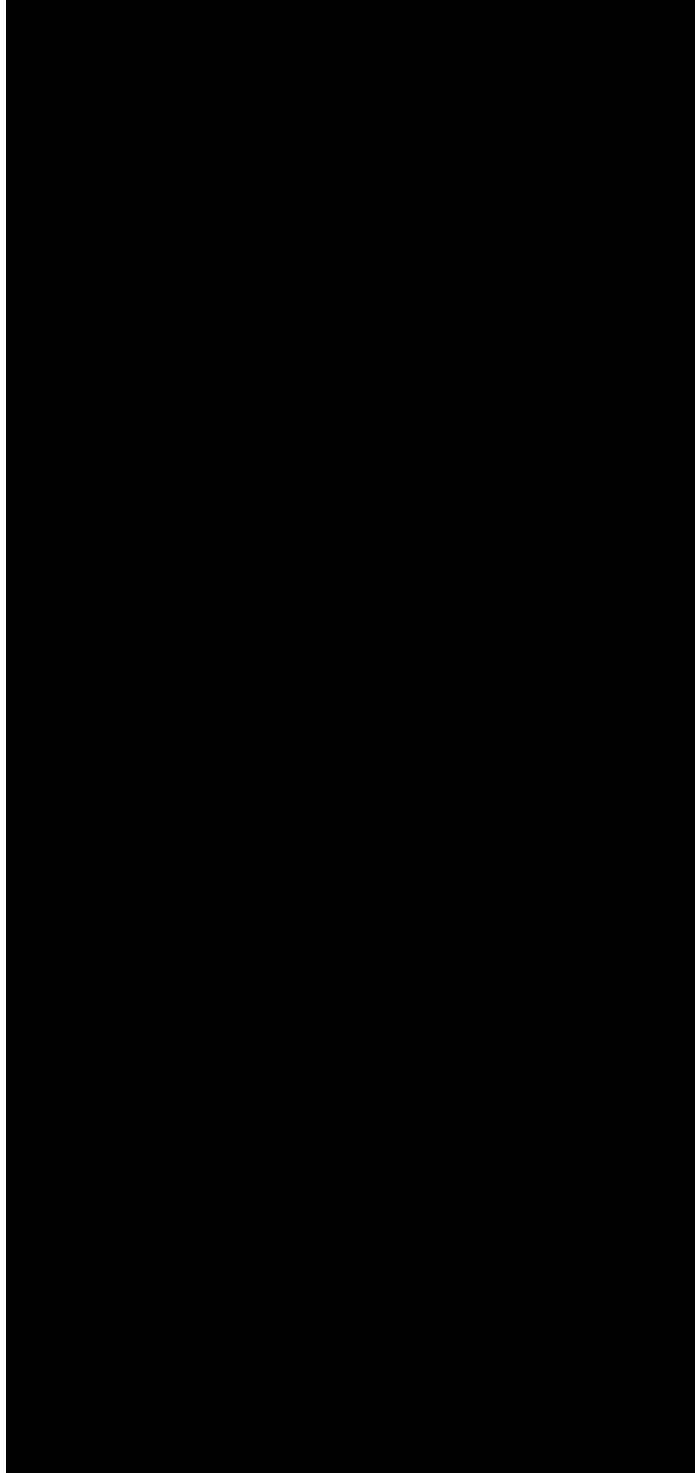
### *Paraplegia/Paraplegic*

The term paraplegic refers to an individual who is affected by paralysis caused by illness or injury that results in the loss of use of both legs. Depending on the level of injury, individuals may have limited sensation and movement in their thorax and abdominal muscles. This is known as a mid or lower level injury.

### *Walkers*

The term 'Walkers' refers to those with an SCI that affects movement and sensation but are able to walk some distance with or without walking aids (such as sticks or a frame). These individuals typically have sustained an incomplete injury, which allows sensory and motor signal to travel from the brain to the spinal nerves below the bony level of injury.

**Diagram 1: The Spinal Column and Function of the Spinal Nerves**



## **Rationale for this study**

Every eight hours a person in the UK is affected by SCI (Association for Spinal Injury Research, Rehabilitation and Reintegration, 2015). SCI primarily affects young adults and approximately 52.3% of people are single at the time of injury (Spinal Cord Injury Facts, 2013). As well as severe physical and psychological consequences, SCI also involves considerable social limitations (Marini, 2001; Taleporos & McCabe, 2001a; Rohmer & Louvet, 2009). Physical disability has been found to interfere with establishing and maintaining romantic relationships (Howland & Rintala, 2001; Taleporos & McCabe, 2001a) and several studies have revealed negative attitudes towards disabled individuals, particularly when asked to view them as a potential romantic partner (Chen, Brodwin, Cardoso & Chan, 2002; Rosenthal, Chen & Liveh, 2006; Hergenrather & Rhodes, 2007; Miller, Chen, Glover-Graf & Kranz, 2009; Marini, Chen, Feist, Flores-Torres & Del Castillo, 2011).

While previous literature has explored the impact of an SCI on marriages and existing relationships, very little research has attempted to explore the challenges and limitations of being single and dating with an SCI. The paucity of literature regarding the experience of dating with an SCI is concerning, considering that approximately 50,000 people in the UK are currently living with this type of injury (Spinal Injury Research, 2016).

Exploration of this topic will enable counselling psychologists working in this field to develop a greater understanding of the problems that arise for patients dating with an SCI and enable them to provide appropriate therapeutic support. These findings could have clinical implications, enabling rehabilitation professionals to work with SCI patients to combat the issues that arise surrounding dating. These findings could also lead to the development of educational programs for SCI patients undergoing rehabilitation, focusing on self-esteem,



body image and dating. In my clinical experience there is a lack of support aimed at single individuals facing dating with an SCI, when compared to the marital support and couples counselling that is offered to SCI patients, who are married or in a relationship. This research could raise awareness, among counselling psychologists, of the need for more focused counselling support for single SCI individuals.

## **Review of the Literature**

### **Majority Attitudes Towards SCI**

The literature in the area of majority attitudes towards SCI is limited and therefore I have also had to explore more general research concerning attitudes towards disability. As a result, throughout this review I will use language referring to the disabled community in general, as well as more specifically the spinally injured population.

Previous research has attempted to examine the attitudes of the general population towards those with disabilities and the main factor that has been found to influence attitudes are the stereotypes associated with disability which are held by society.

People with disabilities are generally regarded as weak, incapable and dependent (Louvet, 2007). Indeed, incompetence has been found to be the adjective that people most associate with disability (Rohmer & Louvet, 2009). Fiske, Cuddy, Glick and Xu (2002) found that, in addition to perceived incompetence, disabled people were regarded with ‘warmth’, suggesting that while people may overtly express that they like an individual with a disability, they do not necessarily respect them. This kind of attitude can be referred to as ‘paternalistic prejudice’ (Coleman, Brunell & Haugen, 2015); meaning a form of prejudice that is directed towards a group that is “disrespected but pitied” and carries overtones of sympathy and concern (Fiske et al., 2002).

Several studies have also found that non-disabled people display anxiety and fear when encountering a disabled individual, suggesting that these feelings stem from not knowing how to act around a person with a disability (Chen & Crewe, 2009; Schomerus, Schwahn,

Holzinger, Corrigan, Grabe, Carta & Angermeyer, 2012). Others have also suggested that this anxiety might result from fear for one's own health and acknowledgement of one's own vulnerability. As Zola (1982) stated: "When the 'able-bodied' confront the 'disabled', they often think with a shudder "I'm glad it's not me" ... The threat to be dispelled is the inevitability of one's own failure. The discomfort that many feel in the presence of the aged, the suffering, and the dying is the reality that it could just as well be them" (p.202).

Given these findings, it is no wonder that people with disabilities have been described as the most disenfranchised population within society (Marini, 2001). These prejudiced attitudes create barriers to positive social interactions and are responsible for much of the discrimination often encountered by disabled people in various aspects of social life (Rubin & Roessler, 2008). This has implications for disabled people within the context of dating and romantic relationships.

#### *Negative Attitudes: Disability and Dating*

Previous research has found that social interactions between non-disabled and disabled people tend to result in shorter and less personal conversations, less physical contact and less eye contact, than interactions between two people with disabilities or two non-disabled individuals (Antonak, 1981; Grand, Bernier & Strohmer, 1982; Antonak & Livneh, 2000). Moreover, several studies have found that attitudes towards disabled people are more positive in a workplace or educational setting and more negative within the context of dating and marriage (Chen et al., 2002; Rosenthal et al., 2006; Hergenrather & Rhodes, 2007; Miller et al., 2009; Marini et al., 2011). Indeed, Hergenrather and Rhodes' (2007) research study revealed that as the relationship becomes more intimate, from colleague, to friend, to romantic partner, to spouse, attitudes become increasingly negative. Miller et al. (2009) found that

participants were most willing to have a friendship with a disabled person, less willing to date and least willing to marry a disabled person. In other words, these studies show that people with disabilities are viewed at a 'social distance' (Anuar & Ghazali, 2015).

Social distance is defined by an individual's willingness to interact with a particular group in different social contexts, in this case people with disabilities (Wahl & Aroesty-Cohen, 2010). This is an important component of measuring attitudes in research (Anuar & Ghazali, 2015). Fichten, Robillard, Judd and Amsel (1989) found that non-disabled students viewed people with a disability to be different from themselves across several dimensions, including perceiving disabled individuals as more anxious in social situations and more reluctant to establish relationships with others. Conversely, Miller et al. (2009) found that non-disabled people who found that they had more in common with disabled individuals wanted less social distance from them. These findings indicate that social distance is likely to occur as a result of prejudiced attitudes towards disabled people and a lack of understanding from the non-disabled population. This is significant as social distance can lead to inequality within society, causing additional social barriers for disabled individuals, which can prevent them from actively participating in society (Anuar & Ghazali, 2015).

It has been suggested that marginalised groups, such as people with disabilities, may be viewed at a social distance due to the stigma associated with disability (Hergenrather & Rhodes, 2007). Physical disabilities such as SCI, which require the use of a wheelchair, are immediately visible during first encounters and can therefore be stigmatising (Rohmer & Louvet, 2009). Antonak (1981) found that, on first encounters, a noticeable disability is the most salient part of an individual to observers, overriding gender and race.

Some studies have found that negative attitudes towards disabled people in a dating context may be contributed to by a fear of 'stigma by association' (Hergenrather & Rhodes, 2007; Anuar & Ghazali, 2015). Fitchen, Goodrick, Amsel and McKenzies (1991) and Gordon, Minnes and Holden (1990) found that non-disabled participants expressed concern at being ostracised if they were to enter a romantic relationship with a disabled person. Indeed, Goldstein and Johnson (1997) found that the non-disabled partners of disabled people were perceived as less intelligent, less sociable and less athletic than partners of non-disabled individuals. This suggests that dating a disabled person also incites negative attitudes from others, with non-disabled partners of disabled individuals being devalued in the eyes of society.

Marini, Wang, Etzbach and Del Castillo (2012) explored reasons given by participants for not wanting to form an intimate relationship with a disabled person. The main three reasons reported by participants were perceived caregiver burden, perceived awkwardness and anxiety about being around a wheelchair user and the perception that a disabled partner would be unable to perform sexually. These findings indicate that unwillingness to form a romantic relationship with a person with disabilities may be prompted by ignorance and fear.

Similarly, several studies have also shown that having a prior relationship or contact with people with disabilities, has a significant impact upon negative attitudes. Anuar (2013) and Chen et al. (2002) found that participants who had frequent contact with disabled people held more positive attitudes and Chen et al. (2002) and Hamdy et al. (2011) found that these participants were more likely to date or marry a person with disabilities. Moreover, Rojan, Komelasky and Man (2008) found that undergraduate students who had a relative with a disability, rated their disabled and non-disabled peers as equally attractive and Marini et al.

(2012) found that those who had some form of contact with disabled people in their everyday lives or a relative with a disability expressed a greater willingness to interact socially with a wheelchair user. These findings suggest that ignorance of disability issues could be a cause of negative societal attitudes towards disabled people.

Research has also shown that the type of disability will determine the strength of negative attitudes. Findings from previous research studies have revealed a pattern, suggesting that the least stigmatised disability group are those with physical disabilities, followed by cognitive and intellectual disabilities, while the most stigmatised are those with psychiatric disabilities (Rosenthal et al., 2006; Miller et al., 2009). Moreover, the perceived severity of the disability has also been shown to affect a non-disabled individuals' willingness to form a romantic relationship with a disabled person (Howland & Rintala, 2001). Miller et al. (2009) found that participants were increasingly reluctant to date or marry a person with a more severe disability and Taleporos and McCabe (2003) found that participants, who were more severely disabled, were more likely to be single than those with less severe disabilities or no disability. Indeed, more than half of severely disabled participants were single. Miller et al. (2009) referred to this grading of negative attitudes towards people with different types and severity of disability as a 'hierarchy of stigma'. These findings have implications for those living with a spinal injury, suggesting that higher level and complete injuries, which are associated with greater impairments to sensation and mobility, might incur more negative attitudes from others than those with lower level injuries. This may also seem to suggest that walkers might be viewed less negatively than those who are paraplegic or tetraplegic.

It is important to note here that the majority of these attitude studies use a participant group made up of Caucasian university students, meaning that the findings from the sample groups

are not necessarily representative of the attitudes of the population as a whole. In addition, many of these comparative studies do not use matched samples, which impacts upon the validity of these results. Several of these attitude studies have also been criticised due to their failure to account for the 'stranger effect' (Wright, 1988). It has been argued that these studies have a common negative bias because they use surveys and questionnaires, which make disability the only salient aspect of the individual they are being asked to make judgments about. While this has the effect of isolating attitudes towards disability alone, other researchers have argued that in real-life situations we choose partners from observing them and knowing something about their personal life (Marini et al., 2011). Therefore, attitude studies that do not account for this bias are arguably methodologically flawed.

In response to this, more recent attitude studies have used photographs and vignettes (Man, Rojahn, Chrosniak, & Sanford, 2006; Rojahn et al., 2008; Marini et al., 2012). Man et al. (2006) compiled two versions of the same photographs paired with a short biography, one version describing the potential partner's disability and the other without. When these were randomly distributed to participants, no significant difference in attraction was found between disabled and non-disabled potential partners. However, Rojahn et al. (2008) criticised this study for not accounting for social desirability. When they replicated Man et al.'s (2006) research, they found that participants overtly expressed romantic attraction towards people with disabilities, however they implicitly displayed prejudice towards disabled people. Vilchinsky et al. (2010) revealed similar findings, reporting that participants displayed more positive reactions to wheelchair users than non-disabled people, yet despite this, participants held more negative emotions towards wheelchair users. The researchers suggest that the participants were attempting to conceal or overcome their automatic negative feelings towards wheelchair users and attribute these results to 'reaction formation'; where socially illegitimate

impulses are transformed into an acceptable and usually exaggerated positive attitude (Vilchinsky et al., 2010).

This is significant, as the format of these studies mirror the personal profiles on online dating websites and dating apps which are ubiquitous in modern dating. These findings suggest that in the context of dating apps, where people's choices will be private and not known to anyone else, prejudice against those who disclose their disability in their profile might be present. Indeed, Miller et al. (2009) conducted a similar study in which the answers were anonymous and found a preference for pursuing friendship with disabled people, rather than a romantic relationship. These findings suggest that this in built anonymity counteracted any social desirability bias and helped participants to be more truthful in their answers and reveal their underlying prejudices.

An individual's disability may also be perceived as more severe and debilitating than it actually is (Miller et al., 2009). Wright (1960) coined the term 'spread effect' to describe the phenomenon that, when a person has a deficit in one area, other people will assume deficits in other areas. Studies have shown that people with disabilities are perceived by non-disabled people to be deficient on several social dimensions, including being socially anxious, uncomfortable about dating and reluctant to develop relationships with others (Fichten, Robillard, Judd & Amsel, 1989). Therefore, an inaccurate impression that a disabled person is multiply impaired can be created.

These findings reveal how these common negative attitudes can lead to disabled people being perceived as poor potential romantic partners or, indeed, not being regarded as romantic prospects at all. The overwhelming evidence for this pervasive view of people with a



disability within the general population indicates the importance of this area of research. The impact that this might have on the psychological wellbeing of those with an SCI is concerning.

### *Discrimination and Loneliness*

The importance of a patient's support network in physical and psychological rehabilitation after SCI has been well documented, and is a key focus of clinicians working in rehabilitation. Having a strong social support network has been found to be associated with better physical and psychological health, functioning, coping and adjustment (Müller, Peter, Cieza & Geyh, 2012; Kennedy, Lude, Elfström & Smithson, 2012; Holt-Lunstad, Smith, Baker, Harris & Stephenson, 2015). In light of this, it is concerning that people with SCI are more likely to struggle in terms of dating and maintaining romantic relationships.

The psychological benefits of relationships have been explored in the literature, not just for disabled individuals, but also for the general population. Married people have been found to be more psychologically adjusted, less likely to have a mental health diagnosis and less inclined to suicide (Gove, Hughes & Style, 1983). Cramer (1991) found that marital status and increased social support were associated with fewer psychological health problems, while McCabe, Cummins and Romeo (1996) found that being in a romantic relationship predicted lower levels of depression.

Within the SCI population, these findings have been replicated. Taleporos and McCabe (2003) found that single people with an SCI had significantly higher levels of depression. Furthermore, married individuals with an SCI have been found to score higher on quality of life and life satisfaction measures (Holicky & Charlifue, 1999), while single participants

report significantly lower life satisfaction (Putzke, Elliot & Richards, 2001). Robinson-Whelen, Taylor, Feltz and Whelen (2016) conducted a study of 175 spinally injured people using measures of loneliness and found that loneliness was higher within the participant group than among the same age group in the wider population. In addition, they also found a slight relationship between loneliness and marital status, although this result was not strong enough to be significant. It is important to note that caution must be taken with this result, as these measures of loneliness have been criticised for their validity and this data was not longitudinal but cross-sectional, which may have impacted these results.

These findings reveal the importance of romantic relationships, not just to spinally injured individuals but to everyone and this highlights the importance of this field of research.

### **The Social Construction of Dating and Disability**

It is important to note that both disability and relationships are concepts that are complex and heavily socially constructed.

Being disabled in our society involves engagement with local councils and political agendas. From disability benefits to applying for wheelchairs and equipment, disabled individuals are subject to societal constructs surrounding disability (Barnes, 2009). The social model of disability highlights this fact; “In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society”, (Union of the Physically Impaired Against Segregation, 1976, p.3).

Previous studies have supported this suggestion, reporting findings that disabled people are unfairly discriminated against in gaining and sustaining employment (Graham, Jordan & Lamb, 1990) and that disabled people are more likely to have a lower socio-economic status, with a relationship being found between disability and poverty (Martin & White, 1988). Many of the supporters of the social model of disability have gone so far as to deny the biological realities of disability, paraphrasing the well-known quotation “there is no such thing as biology” (Kauffman & Hallahan, 2009; Anastasiou & Kauffman, 2013).

Other disabled researchers have argued that adopting this position risks ignoring the basic reality of what it means to live with a disability (Anastasiou & Kauffman, 2013). Anastasiou and Kauffman (2011) argue that some form of judgment or identification must exist, in order to ensure the assistance and benefits necessary to achieve social justice for disabled people. They argue that denying the biological imperative of disability risks negative long term socio-political shifts and cannot serve the interests of those with disabilities in the long run (Anastasiou & Kauffman, 2011). It seems then that an understanding of the complex and multifaceted nature of the concept of disability is essential to undertaking disability research, “clarifying the relationship among the biological and cultural, individual and social, psychological and behavioural, intrinsic and external factors affecting the lives of people without eliminating one of these levels of analysis” (Anastasiou & Kauffman, 2013, p.454).

With this in mind, the way in which disability is perceived in our society has been heavily commented on in the literature. I have already referred to previous attitude studies, which have shown that societal stereotypes and beliefs influence how people with physical disabilities are viewed (Rosenthal et al., 2006; Hergenrather & Rhodes, 2007; Miller et al., 2009; Marini et al., 2011) and that these stereotypes can be considered responsible for the

negative attitudes held by the majority of the population towards disabled people. It is also important to acknowledge how these stereotypes are proliferated within society.

Disabled people are virtually absent from most forms of media. It is rare to see people with disabilities advertising clothing or lifestyle products on television or in magazines and, when disabled people are portrayed in films or television shows, they are generally not depicted engaging in everyday activities, such as dining at restaurants, ordering pizzas or drinking in a bar. Instead people with disabilities are typically portrayed in one of two ways. Either as hospital patients or helpless victims, usually the subjects of tragic storylines with their characters in turmoil and rarely enjoying a 'happy ending' (Byrd & Elliot, 1988; Smart, 2009) or as the 'irredeemable villain' with their visible deformity or disability used as a tool to easily identify the character as evil and unheroic (Harnett, 2000). Moreover, the disabled characters in these storylines are usually played by non-disabled actors, rather than an actor with a disability (Harnett, 2000).

This representation of disabled people creates the message that people with disabilities are not part of mainstream culture and, given this, it is unsurprising that many among the general population would not view someone with a disability as a potential romantic partner (Marini et al., 2012). Whether the media directs or reflects societal attitudes has been the subject of debate among researchers and remains somewhat unclear (Milligan & Neufeldt, 2001). However, I feel that this is most likely to be a cyclical relationship. Members of the general public, especially those who have no personal contact with anyone with a disability, will have little understanding of the representational validity of these negative media portrayals of disabled people. This is likely to perpetuate the construction and maintenance of these

prejudices and the social barriers faced by disabled people, ensuring their further marginalisation within society.

It is also clear from previous literature that societal attitudes towards disability have evolved and changed over time (Neumann, 1979; Drench, 1992; Taleporos & McCabe, 2003), yet we are still far from achieving an inclusive and unbiased society. Man et al. (2006) and Rojahn et al. (2008) have attributed their findings that non-disabled participants will overtly express potential romantic attraction towards disabled people, however at the same time implicitly reveal prejudiced attitudes towards disability, to a 'social desirability bias'. In recent years, inclusivity has become a social norm and it seems that there is a tendency to outwardly express acceptance and inclusion but internally people are still subject to societal stereotypes.

In addition, the way that dating is constructed and understood within our society has changed significantly in the last few years. With the advent and popularity of social media, this medium quickly became applied to the context of dating and there are now a vast number of apps and online forums dedicated to dating. Tinder, which is considered the most popular dating app globally, reports at least 10 million active users each day (Ayers, 2014; Freier, 2015).

As this manner of dating has become a social norm, the implications of this change have been debated in the literature. Some suggest that dating apps have simply replaced the traditional role of 'matchmakers'; friends and family who introduce single people that they think might get on well with each other (Ansari, 2015; Slater, 2013) and allow people who have no previous social ties to form relationships (Rosenfeld & Thomas, 2012; Westcott & Owen, 2013). However, others take a bleaker view. Turkle (2011) argued that "these days, insecure

in our relationships and anxious about intimacy, we look to technology for ways to be in relationships and to protect us from them at the same time” (p.3). Indeed, the founders of Tinder described the purpose of their app as to “take the stress out of dating” and to be a type of “game that required less time and emotional investment to play” (Stampler, 2014).

To create a profile, these apps primarily use information from the user’s Facebook page and, as personal information is usually limited, the focus is predominantly on the user’s photos (Sumter, Vandenbosch & Ligtenburg, 2017). In addition, the apps use physical attribute selection tools to eliminate traits that one finds undesirable, with users being able to search by body type, hair colour and eye colour (Brookes, 2011). This method of dating has made it a social norm to choose potential partners on appearance alone, with a person’s photo and name being the only basis on which a user decides to ‘swipe right’ and decide to learn more about them.

While some might argue that this has simplified dating, there are implications to reaching a point where daters have too much choice. The overwhelming number of options seems to have led people to become overly selective and, as modern daters have become used to this level of choice, that this has caused their expectations to rise (Brookes, 2011). If a date falls short of perfection, there is less incentive to pursue a second date, as the app will inevitably produce more matches that might meet the desired criteria. Not only do these high expectations seem intimidating for daters in general, they leave those with a disability out in the cold.

It is important to have these aspects of dating in mind when conducting research in this field and, although the current study is focused on the lived experience of SCI individuals, it is

equally important to be aware of the politicised and constraining nature of disability and the impact of these societal stereotypes on relationships.

### **Gender, Dating and SCI**

Another concept which is constructed within our society is gender. Gender stereotypes are prevalent within our society and affect many aspects of day to day life. Moreover, these gender stereotypes seem to have a complex interaction with the general perceptions of disabled people. The body of literature examines the influence of gender in various different ways and can be categorised into two areas; research which examines the effect of the disabled person's gender and research which examines the effect of the non-disabled person's gender.

In terms of research which explores the influence of the disabled person's gender, physical disability in men has been found to stereotypically raise negative assumptions regarding loss of masculinity and being less capable of responsibility (Miner, 2000), while physically disabled women face negative assumptions regarding dependency and loss of attractiveness (Meekosha, 1998). This suggests that typical gender stereotypes are influencing the fact that disabled men and women might face different negative assumptions from the wider population. Traditional notions of masculinity in men and the societal importance of normative standards of beauty, attractiveness and desirability in women, may influence the way in which disabled people are perceived as potential partners.

In addition, previous research seems to suggest that women with a disability are perceived more negatively than men with a disability (Asche & Fine, 1988; Westbrook & Chinnery, 1990; Gartner, Lipsky & Turnbull, 1991). Indeed, women with physical disabilities have been

found to be significantly less likely to marry and form romantic relationships than men with disabilities (Longmore, 2003) and more likely to be divorced (Kreuter, 2000). Conversely, people have been found to show a preference for forming friendships with disabled women, over disabled men, in a non-romantic setting (Wong, Chan, Cardoso, Lam & Miller, 2004). It has been suggested that these findings signify that women are ‘doubly handicapped’ by being both disabled and a woman, as they have to contend with the stereotypes that accompany both identities (Hanna & Rogovsky, 1991; Lloyd, 1992; Scherer & Dicowden, 2008). A statement from the Manchester Disabled Women’s Conference captures this notion; “Even if we can’t lift an egg [it is assumed that] we can boil an egg” (Lloyd, 1992, p.207).

This idea has been explored within the feminist disability literature. Lloyd (1992) said of the position of disabled women to the women’s movement and the disability movement that “the former is orientated towards non-disabled women and the later towards disabled men” (p.207). She argued that this is the reason for the continued marginalisation and disempowerment of disabled women in particular. Indeed, the majority of current disability models have been constructed by men, including the social model of disability, which I have discussed previously (see The Social Construction of Dating and Disability section). This suggests that the voices of disabled women are less heard within the literature and the research community.

Lonsdale (1990) found that a greater proportion of disabled women were working in unskilled employment than both disabled men and non-disabled women, which seems to evidence the socioeconomic discrimination faced by disabled women. However, researchers also make clear that this employment disparity between disabled women and non-disabled women is less than that found between disabled men and non-disabled men. Lloyd (1992) reported that



British census statistics from 1988 revealed that 28% of disabled women and 60% of non-disabled women were in full time employment, compared to 33% of non-disabled men and 78% of non-disabled men. Feminist researchers argue that regarding a disabled woman's difficulties as resulting from her disability alone are only acknowledging one part of the problem (Lloyd, 1992). The discrimination and disadvantage that disabled people face within employment are faced to some degree by women anyway and this example of employment explicates the suggestion that disabled women face greater societal barriers. It is important to note here that this 'double handicap' might also be said to apply for LGBT disabled individuals, as they face both the stereotypes and societal discrimination of being both disabled and members of the LGBT community. However, this does not seem to have been explored in the extant literature.

Researchers have also examined how the gender of non-disabled people might affect their perceptions of disabled people. Several studies have found that non-disabled women express more positive attitudes towards people with physical disabilities than men (Chen et al., 2002; Findler, Vilchinsky & Werner, 2007; Panek & Jungers, 2008). Indeed, Hergenrather and Rhodes (2007) found that non-disabled women held more positive attitudes towards disabled people in the contexts of dating, marriage and work, than non-disabled men. This has been attributed in the literature to the common societal perception of women as caregivers (Lemos, Suls, Jenson, Lounsbury & Gordon, 2003) and indicates that women may either be responding to this existing societal perception or that it may be more socially acceptable for women to date disabled men than for men to date disabled women (Chen et al., 2002; Findler et al., 2007; Miller et al., 2009; Marini et al., 2011).

However, Cheausuwantavee (2002) found that women's willingness to form a romantic relationship with a disabled man was affected by his psychological adjustment to his injury and his level of independence, suggesting that this caregiving role might not be as simplistic or influential as the literature suggests. Moreover, some studies have produced contradictory findings. Hamdy et al. (2011) found that Egyptian male university students expressed more positive attitudes towards people with disabilities than women, particularly in the context of marriage. However, the researchers note that this finding may reflect cultural differences in attitudes towards disability, as the majority of the previous research has been carried out with American Caucasian university students. Yunker (1994) also found that it was actually non-disabled men who display more positive attitudes towards people with disabilities than non-disabled women, while Siller (1984) did not find any significant differences between the genders. Although there are a greater number of studies which report finding that women perceive disabled people more positively and these studies are generally more recent, the contradictory findings might indicate that further research is needed to better understand these gender differences.

It is important to note that in many of these studies, gender was examined as a necessary control variable and not as the specific variable under investigation. Despite this, these findings suggest that, due to the way in which gender is constructed and perceived within our society, the experience of being spinally injured is likely to be different for men and women.

### **Sex and Sexuality with an SCI**

As the majority of those affected by SCI are young adults when they sustain their injury, the question of regaining an active sex life might be more important for newly injured individuals than issues of fertility or forming longer term relationships (Reitz, Tobe, Knapp & Schurch,

2004). Indeed, a number of studies have found that sexual wellbeing is strongly correlated with overall psychological wellbeing, both in the wider population and among those with disabilities (Shuttleworth, 2000; Telaporos & McCabe 2002a; Telaporos & McCabe 2002b).

Despite this, sex and sexuality after an SCI has been somewhat overlooked in the literature, with little or no research being conducted into disabled sexuality prior to the 1970's (Milligan & Neufeldt, 2001; Di Giulio, 2003). The sexuality of disabled people seems to be regarded as something of a taboo subject, both within society and the research community (Sakellariou, 2006). In addition, more research seems to have focused on spinally injured men than on spinally injured women (Nygard, Bartscht & Cole, 1990). The research that has included women has predominantly focused on reproduction, seeming to define a woman's sexuality only by her ability to reproduce (Singh & Sharma, 2005). In addition, the majority of disabled sexuality studies are quantitative and have been criticised for failing to "capture the subjective experiences and constructions of their sexuality and sense of self" (Li & Yau, 2006; Parker & Yau 2012). Sexuality has also previously been regarded in a purely biological and physiological sense, despite the fact that the concept of sexuality is complex, holistic and encompasses intimacy, sexual pleasure, sexual orientation, identity, eroticism, gender roles and emotionality (Parker & Yau, 2012). Sexual function and sexual contact cannot be understood as the sum of one's sexuality and sexual identity (Northcott & Chard, 2000).

In a 2012 study, Marini et al. found that the main reasons given by non-disabled participants, for being unwilling to enter into a romantic relationship with a disabled person were a perception that they perceived that there would be too much demand in terms of caregiving, perceived awkwardness about being around a wheelchair using partner and anticipation that a disabled partner would lack the desire and capacity for a sexual relationship. This view of the

sexual ability of disabled people, which has been of concern to many authors, appears to have given rise to the myth that people with disabilities lack the capacity for satisfying sexual relationships and can be seen as asexual (Tilley, 1996; Milligan & Neufeldt, 2001; Taloporos & McCabe, 2001a; Chance, 2002; Li & Yau, 2006; Sakellariou, 2006). In the words of Anderson and Kitchen (2000) “Cultural representations of disabled people as ‘sick and sexless’ are supported and sustained by a set of myths. Myths in relation to disability and sexuality include disabled people being asexual, that is lacking in a biological sex drive and being unable to partake in sexual activity” (p.1164).

Vilchinsky, Werner and Findler (2010) found that ‘aroused interpersonal stress’, which usually occurs during a first meeting of two people of the opposite sex, was not present when the subject was a wheelchair user. This indicates that the disabled person was not perceived as a potential sexual partner. In addition, Milligan and Neufeldt (2001) found that sex acts involving people with disabilities were regarded more negatively than the same acts involving non-disabled people. This perception of disabled people as asexual has also been termed the ‘third gender’ due to the feelings of isolation that this evokes (Milligan & Neufeldt, 2001). Myths about disabled people being asexual have also contributed to the pervasive stigma associated with forming romantic relationships with disabled individuals (Miller & Marini, 2004). In addition, it has been suggested that the presumption of asexuality can become a ‘self-fulfilling prophecy’, leading disabled individuals to avoid intimate situations and sexual encounters (Milligan & Neufeldt, 2001).

It is important to note here that the word asexual when used by researchers in this context, refers to the perception of disabled people as not experiencing or receiving sexual attraction, desires or behaviours. However, asexuality is a recognised sexual identity, characterised by

someone who is not sexually attracted to others. While there may be disabled people who identify with the asexual community, these two identities are not synonymous. Although the meaning intended by the term asexual in these previous research studies seems to be clear from the context, I feel that it is important to clarify my use of this term within this manuscript. People who identify as asexual are still struggling for acknowledgement within society and it is my aim as both a clinician and a researcher to strive for the empowerment of minority groups.

While there can be some changes in physiological sexual response associated with SCI, such as difficulty achieving and maintaining erection, impaired vaginal lubrication and reduced sensation, these problems are dependent on many factors, such as level and completeness of injury (Sakellariou, 2006; Forsythe & Horsewell, 2006). There is no research to suggest that people with disabilities have lower sexual needs than the general population (McCabe, Cummins & Deeks, 2000, Taloporos & McCabe 2001a). Indeed, White, Rintala, Hart and Fuhrer (1993) found that 65% of female disabled participants reported having had sexual contact within a given year, which was only slightly lower than the figure of 73% reported by non-disabled women within the same year. While this study does not take relationship status into account, and it is likely that many of the participants were married, it is clear that the sexual needs of the disabled population are comparable with those of the non-disabled population. In addition, Ostrander (2009) reported that most physically disabled participants reported having satisfying sex lives. Disability clearly does not alter a person's need for intimacy and affection (Northcott & Chard, 2000). These findings therefore indicate that the perception of disabled individuals as 'asexual' or 'third gender' is unfounded and perpetuated by societal stereotypes.

Another factor which might perpetuate negative assumptions of disabled sexuality is an adherence to the traditional medical model of sexual response. Traditionally, sexual response has been understood in four stages of physiological functioning; excitement, plateau, orgasm and resolution (Masters & Johnson, 1966). This view remains very prevalent both within our society and in the arena of medical and psychological intervention. Indeed, the Masters and Johnson (1966) sexual response model is the basis for the categorisation, diagnosis and treatment of sexual dysfunctions and disorders in the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-5) (American Psychiatric Association, 2013). Any impairment in one of these stages, is classified as sexual dysfunction; “Sexual dysfunctions are a heterogeneous group of disorders that are typically characterized by a clinically significant disturbance in a person’s ability to respond sexually or to experience sexual pleasure” (American Psychiatric Association, 2013).

However, this traditional model seems to have several flaws. This view of sexual response is purely physical, disregarding the psychological components of sexual pleasure as well as the nuances and variability of sexual encounters. Also, in line with the medical field being predominantly dominated by men at this time, Master’s and Jonson’s (1966) stage model is male-centered and seems to have been designed to consider what might traditionally be seen as the male experience of sexual pleasure (Tiefer, 1991). This idea that the ending of a sexual encounter is defined by the male orgasm is more and more often being regarded as outdated and old-fashioned, disregarding the experiences of women in general and in particular same sex female encounters. In the words of Whipple and Brash-McGreer (1997) “it is also important for health care professionals to be aware that there is no right or normal way to have a sexual experience. Each person is unique and responds differently on many variables” (p.516).

Perhaps more importantly for the current study, this model is inadequate in understanding the sexual response of those with an SCI. A person's sexual response after a spinal injury might not follow these four stages and they might experience and achieve orgasm differently post-injury (Di Giulio, 2003). This does not by default mean that a spinally injured person's sexual experience is less satisfactory. Adherence to this model risks labelling a person's sexual response as dysfunctional, when it is regarded as highly functional by that individual. In addition, this serves to devalue and dismiss the sexuality of the spinally injured population even further and perpetuate the assumption that disability is synonymous with sexual dysfunction.

In contrast, more recent research has attempted to contradict these traditional assumptions regarding disabled sexuality. In the past, people with spinal injuries were told that they should not expect to experience any sexual response post-injury (Whipple, Gerdes & Komisaruk, 1996) and orgasms in both spinally injured men and women were described as "phantom" (Money, 1960). More recently these ideas have been refuted. Whipple et al. (1996) reported that some spinally injured women do experience arousal and orgasm, either through penetration or through stimulation of non-genital sensitive areas above the level of injury, such as the breasts or the neck. Whipple and Komisaruk (1997) also found that female spinally injured participants, with complete injuries, reported being able to experience orgasm through masturbation. It is now understood that the stimulation pathways that involve the primary genital nerves, via the vagus nerve, bypass the spinal cord which means that orgasm is possible after spinal damage (Whipple & Komisaruk, 1997).

Negative attitudes towards disabled people being perceived as asexual, have contributed to their reported limited success in establishing sexual relationships (Taleporos and McCabe,

2003). Moreover, these societal attitudes are easily internalised by those with disabilities, who have been found frequently to feel that they are sexually unattractive (Milligan and Neufeldt, 2001; Taleporos and McCabe, 2001b), impacting their self-esteem, in particular their sexual esteem and body esteem.

### *Sexual Esteem and Body Esteem*

Sexual esteem refers to one's "sense of self as a sexual being, ranging from sexually appealing to unappealing and from sexually competent to incompetent" (Mayers, Heller & Heller, 2003, p.270) and body esteem refers to one's own "overall positive or negative evaluation of one's body" (Mayer & Eisenberg, 1988, p.156). These concepts are closely linked with self-esteem and are significantly impacted by the negative attitudes of the wider population towards disabled people. Indeed, one of the many reasons that the prejudiced attitudes towards disabled people, evidenced in the literature, are so concerning, is that there is a strong relationship between a person's self-esteem and society's acceptance of their disability (Li & Moore, 1998; Nosek & Hughes, 2001; Nosek, Hughes, Swedlund, Taylor & Swank, 2003). Parker and Yau (2012) concluded that "the negative feedback and stigma attached to disability may compromise an individual's self-worth and result in a devalued sense of self" (p.16) (Nosek & Hughes, 2001; Nosek et al., 2003).

Researchers have only recently begun to examine sexual esteem and body esteem within the disabled population, reflecting that this existing societal perception of disabled people as asexual may be beginning to change, at least within the counselling psychology community.

Researchers have found that sexual and body esteem is lower among physically disabled participants than among non-disabled participants (McCabe & Taleporos, 2003; Benrud-



Larson, Heinberg, Boling, Reed, White, Wigley & Haythornthwaite, 2003). Indeed, Taleporos and McCabe's (2001a) findings suggest that physically disabled individuals might have lower sexual esteem as they perceive themselves as less sexually desirable than non-disabled individuals. Taleporos and McCabe (2002a) also found that sexual esteem and body esteem were strong predictors of overall self-esteem and depression in people with a disability, and that this relationship was stronger among the disabled participants than among their non-disabled participants. This suggests that sexual and body esteem might be considered more significant to a disabled person's overall psychological wellbeing than they are for a non-disabled person. Moreover, Taleporos and McCabe (2002a) also found that in men with disabilities sexual esteem was closely associated with overall self-esteem, while in females with disabilities sexual esteem was more related to body esteem. The authors suggest that this reflects the societal pressure placed on men to perform sexually and the pressure placed on women to conform to traditional normative standards of female beauty.

Previous studies have also shown that individuals with more severe disabilities tend to have lower sexual and body esteem than those with less severe impairments. These findings have been replicated by Benrud-Larson et al. (2003), who reported that women with more severe disabilities were more likely to be dissatisfied with their bodies. Moreover, Hassouneh-Phillips and McNeff (2004) reported that women with severe disabilities were more likely to perceive themselves as sexually unattractive and that this finding was more pronounced in women with acquired disabilities, such as spinal cord injury. Charlifue, Gerhart, Menter, Whiteneck and Manley (1992) replicated this finding, demonstrating that women with spinal injuries reported lower self-confidence post-injury than they experienced before their injury. Those with an acquired disability, such as an SCI, might face a different set of challenges to those with a congenital disability. Adjustment after a spinal injury also involves adapting to

changes in one's sexual identity and many newly injured individuals struggle to adjust to their new body, comparing themselves to their previously non-disabled selves.

Taleporos and McCabe (2001a) also found that a further reason for lower sexual esteem in disabled individuals is that they feel that their disability limits their sexual expression. Indeed, several studies have described various practical difficulties with sexual relationships and dating that have been reported by disabled participants in various studies. Rintala et al. (1997) found that women with disabilities report being less satisfied with their dating frequency than able-bodied women and that they perceive more societal and personal barriers to dating. The reduced mobility associated with physical disability can impede sexual expression and spontaneity (Howland & Rintala, 2001). Disabled individuals have described problems with sexual positioning, unreliable bladder and bowel control and where the injury is acquired rather than congenital, frustration due to comparison with their previously non-disabled self (Taleporos & McCabe, 2001a). These more practical issues have been shown to further impact sexual and body esteem in disabled individuals.

These findings highlight the importance of sexuality in this field of research and the need to pay close attention to the concept of disabled sexuality. Sexuality is a major component of dating and, as such, this is likely to play a significant role in the current study.

### **Previous Research: Limitations and Shortcomings**

The exploration of societal attitudes towards people with disabilities is important because many of the obstacles surrounding dating with a disability can be contributed to them (Antonak & Livneh, 2000). However, many previous attitude studies have been criticised for their methodology.

These studies have a common negative bias due to “stranger effect” (Wright, 1988), because they use surveys and questionnaires, which make disability the only salient aspect of the individual they are being asked to make judgments about. While this has the effect of isolating attitudes towards disability alone, researchers have argued that, in real-life situations we choose partners from observing them and knowing something about their personal life (Marini et al. 2011). More recent attitude studies have used photos and vignettes (Man, Rojahn, Chrosniak, & Sanford, 2006; Rojahn et al., 2008; Marini et al., 2012), however they also lack generalisability as almost all of these studies have used university students as participants. Many of these studies also fail to take into account the effects of confounding variables, such as ethnicity and race, which have been found to effect judgments of attractiveness (Man et al., 2006). In a review of disability related studies, Greenwell and Hough (2008) found that ethnic and racial minorities were underrepresented in these studies, suggesting a lack of recruitment diversity. It has also been argued that these studies are based on hypothetical situations and do not necessarily predict future behaviour (Marini et al., 2012). However, despite these criticisms there is clear evidence for the impact of societal attitudes upon perceptions of disability.

There are also examples in the literature of researchers’ own negative attitudes towards disabled relationships and a lack of understanding or consideration. Neumann (1979) found that 60% of non-disabled participants reported that physical attractiveness in a sexual partner was important to them and that they rated their disabled partners as attractive. Neumann accounts for this finding by suggesting that little prior sexual experience in the female participants “allowed them to find an SCI partner genuinely attractive”. While more recent articles are less negative, they can display similar prejudiced attitudes. Drench (1992) and Shakespeare and Tepper (1999) suggested that sexual adjustment would be easier for women

with a physical disability, as they place more emphasis on tenderness and emotional sharing rather than sexual gratification. This view is hugely generalised and is an example of the sexual needs of disabled individuals being dismissed. Furthermore, Taleporos and McCabe (2003) suggest that living together as a couple, when one partner has a disability can add burdens to a relationship and that this “reinforces the benefits of more casual relationships” (p.40).

In my clinical experience, SCI patients who are arranging their care plan, for when they are discharged from hospital, are advised not to have their partner perform the duties of primary carer, such as bathing or bladder and bowel routine, as this can put significant strain on their relationship. The researchers do not refer to care arrangements when forming their conclusions and seem too quick to suggest that non-cohabiting disabled couples are more likely to maintain a successful relationship. These examples also reflect changing attitudes towards disability and the way in which disability is discussed. It is important to note that many of the studies researching dating with a physical disability are more than ten years old and, considering that societal attitudes change rapidly over time, can therefore be regarded as outdated.

The body of literature is largely made up of quantitative studies, which use surveys and questionnaires to explore the difficulties concerning dating that are faced by physically disabled individuals. More recent studies have used focus groups (Taleporos & McCabe, 2001a; Vaughn, Silver, Murphy, Ashbaugh & Hoffman, 2015), however these have significant limitations. Using a group of participants can lead to disagreements or irrelevant discussion, some participants may also find this setting off putting and it can be difficult to ensure that everyone participates. As a consequence, these studies fail to gain insight into the

experience of dating with a physical disability. The best example of a qualitative study in this area, was conducted by Howland and Rintala (2001), however this study only focused on disabled women and is now 14 years old. As a result, the current literature is incapable of providing significant insight into the experience of dating with a physical disability.

### **The Aim of this Research Project**

While the concept of engaging in social relationships with a disability has been explored in previous studies, my review of the literature has shown that our understanding of dating with an SCI is limited. Most studies focus on disability in general and, as these studies have also mostly been qualitative, they have failed to recognise the phenomenological experience of spinally injured people. This indicates that a more thorough investigation at the subjective level is needed. In addition, as the nature of our society is constantly changing and the concept of dating has evolved drastically in recent years, a study focusing on the experience of modern dating with an SCI would seem to be called for.

Therefore, the aim of this study is to use phenomenological methods to develop an understanding of the lived experience of dating with an SCI. This study will answer the methodological gap in the literature that currently exists and will enable clinicians to gain better insight into the needs of single SCI patients.

The central question of this research is as follows: What is the lived experience of single people with an SCI who are currently dating or want to be in a romantic relationship?

The study, and especially the data gathering process, will be guided by the following three questions developed from my review of the literature and my clinical experience:

1. What are participants' expectations of dating and how do these expectations compare to their experiences?
2. What are participants' perceptions of societal attitudes and expectations towards their dating experiences?
3. Do men and women with an SCI experience dating differently?

## **Chapter 2**

### **Methodology**

In this section, the method of enquiry used in the current research is discussed, including details of the research design and ethical considerations that have been taken into account. This research employed a qualitative research design, gathering data from a small sample through semi-structured interviews. This data was then transcribed and analysed using Interpretive Phenomenological Analysis (IPA), (Smith, Flowers & Larkin, 2009). The decision to use a qualitative methodology, and specifically IPA, was based on exploration of the research question and the purpose of the study, as well as reflection upon my epistemological assumptions in relation to the research. This decision was also guided by consideration of how this research could influence the practice of counselling psychologists and in response to the vast majority of qualitative research studies, which have dominated the field of psychological research in the past. These aspects are discussed below in more detail.

#### **Rationale for a Qualitative Perspective**

The field of psychological research has traditionally been dominated by quantitative research studies, set within the theoretical underpinnings of positivism. Positivism is the theoretical perspective that there is one unified reality and that this reality is objectively knowable (Gray, 2014) and that through quantitative experimental research methodologies, it is possible to identify a single ‘truth’ (Morrow, 2007). Indeed, one positivist researcher wrote, “in order to behave like scientists, we must construct situations in which our subjects...can behave as little like human beings as possible, and we do this in order to allow ourselves to make statements about the nature of their humanity” (Bannister, 1966, p.24).

This desire to “behave like scientists” was and still is, driven by the necessity for the field of psychology to gain credibility within a world dominated by the medical model and the need to ‘prove’ the efficacy of therapeutic interventions. While this existing quantitative research has contributed a lot to the field of psychology, and indeed to the understanding of attitudes towards SCI within the population, there is a growing understanding of the limitations of these quantitative research approaches and that it might not be possible or necessary to produce objective, reliable findings within psychological research (Finlay, 2011). In particular, as counselling psychologists, the idea of creating a situation in which participants “behave as little like human beings as possible” seems to contradict the very nature of therapeutic work and the purpose of psychological intervention.

In contrast, qualitative research recognises that psychology is a human science (Finlay, 2011). While quantitative research seeks to identify causal relationships between phenomena through statistical analysis, qualitative research seeks to gain an understanding of meaning within complex social phenomena and life experience, through interpretation (Gray, 2014). Subjectivity, culture, discourse and reflexivity are acknowledged and considered, rather than being viewed as methodological weaknesses that need to be accounted for and defended against (Morrow, 2007).

A qualitative methodology seems most appropriate for the current research, which aims to gain an understanding of participants’ experiences of dating with an SCI and the sense that they make of these experiences. The emphasis of qualitative methodologies on meaning making, for both the participant and researcher, is necessary for the current research as each participant will experience dating with an SCI and make sense of these experiences in different ways. Moreover, qualitative research methodologies acknowledge the role of the



researcher in data gathering and analysis, which is especially important in the current research, given that I am a non-disabled researcher. Qualitative methodologies also encourage reflexive exploration of the relationship between the participant, the researcher and the data. This reflexive way of working greatly appeals to me as a researcher, as this mirrors my practice as a counselling psychologist and acknowledges the parallel roles of researcher and practitioner. I must note here that, in line with these core features of qualitative research, I have chosen to refer to myself as 'I' throughout this manuscript rather than 'the researcher'.

My final reason for a qualitative approach was my consideration of political issues concerning disability. Qualitative methodologies allow for a 'bottom up' approach to research, which permits the voices of the participants concerned to be heard. In addition, qualitative research is inductive, meaning that the imposition of categories and concepts on the participants is avoided (Willig, 2012). Therefore, qualitative research can be used as part of an empowerment agenda. This is essential when working with the disabled population, who are frequently marginalized both within society and psychological research.

There are numerous potential approaches within qualitative research, each with different philosophical underpinnings and methods of investigation. The qualitative approach I have chosen is IPA. Before discussing my reasons for this choice, I will describe my epistemological approach.

### **Philosophical Standpoint**

For researchers, identifying their own philosophical standpoint and its relation to the research question before designing and conducting a study is highly important. This will provide a structure for the research design, including what type of data is going to be gathered and how

that data is going to be understood, interpreted and applied (Gray, 2013). This practice allows for coherent and meaningful research to be conducted. However, there are a vast array of epistemologies, theoretical perspectives and methodologies, which are interlinked and terminology is frequently used inconsistently (Crotty, 1998). I have already aligned myself with a qualitative perspective and IPA allows for ‘epistemological openness’ (Larkin, Watts & Clifton, 2006), meaning a wide range of epistemological standpoints.

The focus of the current research is to examine the participants’ experiences and how participants are constructing meaning in their lives, rather than attempting to determine ‘truth’ (Willig, 2001). This means that the study assumes a relativist ontology, which states that there is no single external reality, but rather multiple realities that are socially constructed and experientially subjective (Hudson & Ozanne, 1988; Neuman, 2000; Gray, 2013). In terms of the current research question, aligning myself with a relativist ontology allows me to explore the lived experience of dating with an SCI and individual participant’s interpretation of that experience.

At the same time, the socially constructed nature of the concept of disability, and indeed of dating (see Introduction chapter), means that the social context of the current research must be taken into account. In line with social constructionism, I am of the view that social, cultural and historical processes are integral to how we experience the world and the way we construct meaning from these experiences (Eatough & Smith, 2008).

In contrast to a radical social constructionist approach, which assumes that there is nothing outside the participants’ words, meaning that the researcher is only interested in the “particular reality constructed for the purposes of a specific conversation” (Willig, 2013,

p.18), I assume a more moderate approach, which sees the participant's experiences within the wider context. This moderate social constructionist stance views the self as constructed through social context, yet the individual continually constructs new meanings through reflexive process, meaning that individuality is not lost in the social context (Smith et al., 2009). In other words, this approach "invokes a reality that pre-exists and indeed shapes the ways in which individuals ... construct meaning within particular contexts" (Willig, 2013, p.19). As such, this form of social constructionism is closely linked to a critical realist perspective (Willig, 2012).

This more moderate approach within social constructionism might also be termed symbolic interactionism (Blumer, 1969), which regards human beings as "creative agents who through their intersubjective interpretative activity construct their social worlds" (Eatough & Smith, 2008, p.184). Gray (2013) describes three central tenets of symbolic interactionism; actions are derived from the meanings people interpret from the world around them and may be different for others, meanings arise from a process of social interaction and meanings may be modified. This perspective emphasises the "subjective meaning-making of the person" and therefore is in line with an IPA methodology (Eatough & Smith, 2008, p.184). Although this approach differs from radical social constructionism, which holds that it is discourse which constructs reality, symbolic interactionism does view language as a central aspect of the way in which we experience the world (Eatough & Smith, 2008; Willig, 2012). Indeed, Eatough and Smith (2008) described reality as "being both contingent upon and constrained by the language of one's culture" (p184). I therefore paid close attention to both the language used by my participants and the language used within the existing literature to describe disability issues (see Evaluation of Research section).

Aligning myself with this approach when conducting this IPA study, allowed me to focus on the contextual setting of my participants, while at the same time exploring the meaning-making process they engaged in with regard to their lived experience (Eatough & Smith, 2006).

### **What is IPA?**

IPA has its origins in health psychology (Smith et al., 2009), which seems appropriate given that the current research is exploring the experiences of those with an SCI. Developed in the mid-nineties by Smith and a group of other researchers, IPA aims to explore the experiential rather than the experimental (Smith et al., 2009). The purpose of an IPA study is “the detailed examination of individual lived experience and how individuals make sense of that experience” (Eatough & Smith, 2008, p.179). These two parts of an IPA study are rooted in phenomenological theory and hermeneutics (Eatough & Smith, 2008). IPA draws upon both of these philosophical ideas and the name, IPA, reflects the dual nature of this methodology (Smith, 1996). IPA as a qualitative research approach, with prescribed guidelines, was only developed in the 1990’s however, the theoretical underpinnings of phenomenology and hermeneutics are much older (Giorgi & Giorgi, 2008).

Phenomenology (derived from the greek, meaning the *logos* – study of, *phainomenon* – that which appears) historically refers to the study of experiences and consciousness (Giorgi & Giorgi, 2008). Phenomenology is a broad philosophical idea which has been expanded by several theorists, all of whom place prominence on different aspects and hold diverse ideas about how to apply phenomenology to research (Smith et al., 2009). Husserl (1929), considered the father of descriptive phenomenology, was interested in exploring the world as it presents itself to the individual and suggested that the self and the world around us are

‘inextricable components of meaning’. He proposed that attention should be paid to the things themselves, meaning the content of experience, and that things should be examined on their own terms, rather than within the context of pre-existing assumptions and ideas. He emphasised the importance of understanding how the world around us is formed through experiences and conscious actions (Husserl, 1929). In order to achieve this, Husserl (1929) stated that it was necessary to strip away or ‘bracket’ pre-existing assumptions and attitudes; this concept of bracketing is a key component of IPA research. Husserl advocated adopting a ‘phenomenological attitude’, requiring reflective exploration of experiences in order to derive meaning from them (Husserl, 1929). This idea of reflexivity has become an important part of IPA.

Heidegger (1962) built upon Husserl’s (1929) work and proposed interpretive phenomenology. He believed that an individual should be seen as ‘being in the world’, meaning that it is the individual interpretation of the world around us and the personal meaning ascribed to experience that is important (Heidegger, 1962). This move towards interpretive phenomenology acknowledged that individuals are embedded in a world of language, culture and social relationships and therefore interpretation of experience is inevitable. Heidegger (1962) suggested that in order to study human existence, one must study the experiences that appear to an individual in their own way, which he called the ‘hermeneutics of factual life’. Hermeneutics refers to the meaning and interpretation of experience (Giorgi & Giorgi, 2008). Merleau-Ponty (1945) described this philosophical idea more concisely, writing that “man is in the world and only in the world does he know himself”.

IPA draws on this philosophy, proposing that lived experience can be understood through the 'lens of interpretation' (Smith et al., 2009). Moreover, not only is IPA analysis grounded in the data, the participants' interpretation of their own experience, but also involves interpretation by the researcher. This is known as the 'double hermeneutic' (Smith & Osbourne, 2003). While "the participants are trying to make sense of their world, the researcher is trying to make sense of the participants trying to make sense of their world" (Smith & Osborn, 2003, p.51). This concept of the double hermeneutic is especially relevant to the analysis of data in IPA (Smith et al., 2009).

Smith et al. (2009) propose the idea of a hermeneutic circle, referring to a dynamic relationship between the 'part' and the 'whole' at various levels. In order to understand any part, it must be examined individually and then in relation to the whole. Similarly, in order to examine the whole, it must also be examined both individually and in relation to the part. This can be applied at a number of levels, for example, a word can be understood in relation to the line of text and the meaning of the line of text is dependent on the cumulative meaning of the individual words in that line. Therefore, the process of IPA analysis is iterative, meaning that the researcher may move back and forth through various different ways of thinking about the data.

In addition, Smith et al. (2009) advocate adopting a centre ground between Ricoeur's (1970) 'hermeneutics of empathy' and 'hermeneutics of suspicion', later named by Larkin et al. (2006) as the 'hermeneutics of questioning'. The former refers to the researcher's unquestioning acceptance of the participant's understanding of their experience and the later refers to the researcher's attempt to illuminate the underlying meaning within the participant's experience, using psychological knowledge and theory (Smith et al., 2009). Childs (2007)

likened this dual process to a practitioner understanding a client's experience within a therapeutic relationship. This means that IPA analysis must be grounded in the details of the participant's experience but should also consider the nature and context of the experience being described. This non-linear style of analysis may allow for richer and more detailed interpretations than other forms of analysis.

A third philosophical concept which has influenced IPA is Idiography; this refers to an interest in the particular as opposed to the general. This means that IPA involves the examination of particular individuals in a particular context through detailed analysis. This stands in contrast to nomothetic approaches, which aim to make general claims about the wider population. In other words, the focus of IPA is the "detailed and nuanced analysis of particular instances of lived experience" (Smith et al., 2009, p.37). However, Smith et al. (2009) argue that the particular and the general are interrelated and therefore in depth idiographic analysis of particular experiences can inform us about wider experiences, shedding new light on nomothetic research. In other words, "the particular eternally underlies the general; the general eternally has to comply with the particular" (Goethe, in Hermans, 1988, p.785).

## **Why IPA?**

### *Strengths and Limitations*

There are a number of reasons why I judged IPA to be an appropriate methodology for this study. First, IPA allows the researcher to examine participants' perception of a particular phenomenon (Eatough & Smith, 2008). The influence of hermeneutic theory on IPA is the idea that reality is experiential and therefore subjective (Giorgi & Giorgi, 2008). As the subject under investigation was the experience of dating with an SCI, it was essential to use a

methodology that allowed for consideration of the subjective experience. One participant's experience of living with an SCI will be vastly different from another's, let alone their experience of dating and exploring romantic relationships with an SCI. Interpretation of individual experience is mediated by the participant's sense of self and the current research attempted to examine this mediation within the spinally injured population. Using IPA therefore enabled a greater understanding of the research question.

Another consideration is that IPA allows for flexible data collection (Smith, 1996; Eatough & Smith, 2008). The purpose of the current study was to examine the participants' experience of dating and as a result I did not impose any predetermined hypotheses upon the data. The interview schedule, compiled for the semi-structured interviews, acted as a guide, but I was able to focus on aspects of individual experience that emerged during the interviews. This allowed exploration of the participant's internal world that was not confined by subjective, predetermined questions. Participants had the freedom to explore a range of meaning making and I had the freedom to explore aspects of the account that appeared to be missing or only partially disclosed. Therefore, using IPA interview techniques allowed in depth exploration of the research topic (Smith, 2004).

IPA also acknowledges the position of the researcher (Eatough & Smith, 2008). As a non-disabled researcher my understanding of the experience of disability is very limited. This research must acknowledge that my interpretation of the collected data will inevitably be influenced by this, as any research would be impacted by my own experience, or potentially my lack of experience in this case. Using IPA allowed me to examine the lived experience of people with an SCI from the point of view of the participants and this was the best prism through which to attempt to understand these experiences.



Furthermore, IPA acknowledges the importance of interpretation (Smith 2004; Giorgi & Giorgi, 2008). Many aspects of data analysis in IPA are left to the discretion of the researcher, and while this has limitations regarding rigour, it acknowledges that conclusions from data analysis are subject to the researcher's interpretations (Smith et al., 2009; Pringle, Drummond, McLafferty & Hendry, 2011). IPA provides an opportunity to gain insight into an individual's internal world and to acknowledge that our insight is mediated to some degree by our own understanding (Biggerstaff & Thompson, 2008). This is the essence of the therapeutic relationship in counselling psychology and allows research findings attained through IPA analysis to inform clinical practice in a meaningful way.

Despite the strengths of this methodology and its growing popularity, IPA has been criticised by various theorists regarding its rigour and validity. In line with its idiographic influences, IPA guidelines (Smith et al., 2009) advocate using a small sample size. While other methodologies, such as grounded theory, use a larger sample to substantiate theory (Barbour, 2008), Smith et al. (2009) suggests that IPA analysis may be inhibited by a larger sample size. As the focus of IPA is detailed exploration of individual experience, using a smaller number of participants allows for a richer depth of analysis (Pringle et al., 2011).

It has also been suggested that IPA researchers, who are conducting interviews, may need to be skilled in interviewing techniques, in order to put participants at ease and gather rich data (Pringle et al., 2011). However, the qualities that are necessary for interacting with participants are the same core conditions necessary for therapeutic interaction. Aspects of the therapeutic relationship, such as empathy and unconditional positive regard, can be applied to interviewing participants in a research context and therefore it may not be necessary for researchers in this field to be trained in specific interview skills.

IPA, like most qualitative methodologies, is limited in terms of generalisability. Smith et al. (2009) emphasise the importance of using a homogenous sample in IPA research, however they also suggest that using IPA may “shed light on a broader context”. This is difficult to achieve if the sample used is too specific or unique. While Smith et al. (2009) suggest that the transferability of research findings should be determined at the discretion of the individual researcher, it should be acknowledged that using IPA as a methodology means focusing on depth of data, rather than breadth and reporting detailed findings, rather than assuming general claims (Smith, 2004).

Furthermore, this aspect of IPA that leaves certain aspects to the judgement of the researcher, contributes to this methodology’s vulnerability to researcher bias. Finlay (2008) suggests that researchers will find it difficult to disregard their prior knowledge in order to remain objective when interpreting data, however Smith et al. (2009) emphasise that acknowledging the position of the researcher is an important aspect of IPA. This raises further issues, as the same data may be interpreted very differently by different researchers and replicating individual findings may be impossible. This subjectivity in analysis suggests that findings may be limited in terms of validity or reliability (Golsworthy & Coyle, 2001), however an aim of IPA is to produce “a credible account, not the only credible account” (Smith, 2011). Smith et al. (2009) also suggested that subjectivity and researcher bias may be mitigated by using guidelines for IPA research and analysis (Smith et al., 2009), however Smith (2004) also highlights the dangers of using these guidelines as a ‘cookbook’ and emphasises the importance of tailoring the methodology to suit the research context (Smith, 2011). As IPA findings are constituted by the interpretation of one researcher, this methodology is also criticised in terms of rigour. However, Smith et al. (2009) emphasised that being open to external audit and working collaboratively to identify themes may increase rigour.

These criticisms of IPA, while valid, can be seen as a compromise for enabling the researcher to examine the in depth individual experiences of participants, and while acknowledging the position of the researcher in interpretation and analysis is important in IPA, this is also essential in all research. While it is important to take the limitations of IPA into account when engaging in IPA research, the strengths of this methodology made it suitable in the context of the current study.

### *Other Qualitative Approaches*

Other methodologies that could have been applied to this area of research are discursive approaches or grounded theory (GT). IPA shares various similarities with these methodologies (Willig & Stainton-Rogers, 2007). Phenomenological and discursive approaches both incorporate social constructionism (Eatough & Smith, 2008; Giorgi & Giorgi, 2008; Wiggins & Potter, 2008). Yet, while discursive approaches are rooted in poststructuralist theory (Eatough & Smith, 2008), IPA leans more towards symbolic interactionism (see Philosophical Standpoint section).

Like discursive theories, IPA acknowledges the importance of language (Giorgi & Giorgi, 2008; Wiggins & Potter, 2008). An individual's reality is based upon, and constrained by, their language (Eatough & Smith, 2008). However, IPA emphasises that language represents only part of an individual's experience. For instance, emotions may be described using language and have a discursive component, but this does not represent a complete account of the experience of that emotion and excludes the psychological and internal aspects of emotional experience, which may be indefinable (Eatough & Smith, 2008). Given that the experience of being spinally injured and dating are both complex and emotional experiences in and of themselves, combining these experiences requires a rich and detailed approach,

which focuses on the lived experience as a whole. Using discursive methodologies, such as Foucauldian Discourse Analysis (FDA), which focus on language alone, excludes components of an individual's lived experience and fails to attend to phenomenology.

Both FDA and IPA also emphasise the importance of reflexivity in research (Schwandt, 2000), as conclusions from data rely on the interpretation of the researcher. Both of these methodologies are compatible with an interpretivist position and, as a result, both acknowledge that different researchers would form different conclusions from analysis of the same data (Giorgi & Giorgi, 2008; Smith, 2011).

GT, like IPA and FDA, also acknowledges the importance of social and cultural process in individual understanding of the world around us (Willig, 2003). Therefore, GT is also suitable for research conducted from an interpretivist perspective (Charmaz & Henwood, 2008). However, the coding and analysis involved in GT is exhaustive and more time consuming than the coding and analysis required for IPA (Frost, Nolas, Brooks-Gordon, Esin, Holt, Mehdizadeh, & Shinebourne, 2010). Furthermore, GT requires theoretical sampling. This involves analysing data in relation to emerging theory (Charmaz & Henwood, 2008; Willig & Stainton-Rogers, 2007). This can be difficult for researchers to accomplish and if applied inaccurately, can lead to a lack of conceptual depth. Methodological errors can be more common using GT analysis than using IPA (Willig & Stainton-Rogers, 2007).

While both IPA and GT acknowledge the position of the researcher, the standpoint from which the researcher must view the experiences of their participants is very different (Willig, 2003). Grounded theory attempts to obtain a collective view from the outside of the participants' experience, while IPA examines the internal processes that form the individual

experience (Eatough & Smith, 2008; Charmaz & Henwood, 2008). This difference is essential to my choice of IPA over GT. IPA attempts to gain detailed insight into an individual's lived experience and regards this as the most important aspect of research (Eatough & Smith, 2008). This not only allows for rich data and more meaningful conclusions, but also mimics the therapeutic process. The counselling psychologist attempts to gain an internal view of a client's world, rather than taking a purely external standpoint. Therefore, conclusions gained through IPA may have greater applications to clinical practice and treatment in a therapeutic setting.

While discursive analysis and GT would have explored aspects of the current research questions, IPA alone allowed an examination of these aspects within the lived experience. This afforded a complete and in depth exploration of the research topic and allowed rich data to be collected.

## **Method**

### **Recruitment**

#### *Recruitment Procedure*

Participants were recruited through nationwide charities that support people with an SCI. These charities are BackUp, Association for Spinal Injury Research, Rehabilitation and Reintegration (ASPIRE), Spinal Injuries Association (SIA) and Wheelpower. Each of these charities provides support and recourses to spinally injured people in different ways.

The BackUp trust is an organisation that works with people of all ages, aiming to inspire independence and confidence in those affected by SCI. The organization has a mentor program, which aims to match spinally injured members with a mentor of a similar level of injury. They also have a mentor program for the family members and spouses of spinally injured people. BackUp also provides career advice, wheelchair skills training and telephone support. ASPIRE is an organization that provides practical help to people who have been affected by SCI. Their services include grants to fund specialist equipment, temporary housing, advice regarding benefits and meetings with Independent Living Advisors, who provide advice and guidance to patients. SIA is a user led organization that aims to provide advice and education on various topics to spinally injured people. They also provide a telephone counseling service. Wheelpower is a sporting organization promoting wheelchair sport and aiming to encourage anyone with an SCI to get involved with various teams and activities. They organize various competitions and events across the country.

Five different techniques were used during recruitment; copies of a flyer (Appendix I) describing the nature and purpose of the study were placed in leaflet holders where passers-by

could take them and the same flyer was also displayed as a poster on bulletin boards within the organisations. A digital copy of this flyer was also placed on the BackUp website to allow a wider pool of participants to access the information, particularly those with lower mobility. Additionally, I wrote an article describing the purpose of the study and explaining the research process for Forward magazine, a magazine produced and edited by SIA about various aspects of life with an SCI. This article was published in the October 2015 issue of Forward magazine. Finally, the snowball effect was used, which involves one participant introducing the researcher to another participant.

Of those who expressed an interest in taking part, who met the criteria for the study, six participants were selected on a 'first come first served' basis. The reason for this was to avoid turning away people who wanted to be involved in the study. The subject of spinal injury can be a sensitive one and it can be difficult for participants to relate their personal experiences of life with their injury to a stranger. To turn someone away who had decided that they wanted to take part in this research would seem to invalidate that person's experiences. No spinal injury can be measured as worse than another in terms of trauma and effect on an individual's life. Smith et al (2009) highlight the importance of considering ethical criteria when selecting participants and I have therefore chosen not to place one participant's experiences over another and to accept participants on a 'first come first served' basis. For these same reasons no pilot interview was conducted, as this too would seem to undermine or invalidate that participant's experience. Recruitment was stopped when the total of six participants had been reached. At this point more than enough rich data was considered to have been gathered to allow for rigorous analysis.

Recruitment for this project took over a year in total, from October 2015 to January 2017.

Recruitment was difficult, due to the sensitive nature of the research subject. If anyone who made contact did not meet the criteria for the study, they would have been thanked for their interest and time and I would have explained to them exactly how they did not meet the criteria for the current research project. However, all of the participants who expressed an interest in being involved in the study met the criteria for the current research.

#### *Inclusion and exclusion criteria*

As IPA is an idiographic approach, purposive sampling is required (Smith et al., 2009). This involves selecting a relatively homogenous group of participants. The study population consisted of participants with a diagnosed SCI that affects movement and sensation in some way. As the purpose of the current research is to explore the experience of dating with an SCI, participants must be physically affected by their injury in some way and this served as the main criterion for participation. This accounted for the homogeneity of the sample, in line with the phenomenological design of the study. Smith and Osborn (2008) advise that a relatively homogenous sample of participants is essential for effective IPA analysis.

As this criterion will account for the homogeneity of the sample, participants were not excluded on the basis of level and completeness of injury. As mentioned above, no spinal injury can be measured as worse than another in terms of trauma and effect in an individual's life. To exclude people with a particular type of spinal injury would perpetuate the exclusion that spinally injured individuals can feel within society and would not have felt appropriate to me as a clinician and researcher. Additionally, participants of varying levels and completeness of injury will have different experiences of dating and will have different considerations when preparing for a date and being sexually intimate with a partner. By not excluding participants



on this basis, a more comprehensive view of dating with an SCI and more in depth data will be achieved.

Moreover, recruitment included both male and female participants, as previous literature has found that experiences of dating and relationships may vary for men and women (Miner, 2000; Longmore, 2003). For this reason, the varying experience of spinally injured men and women was also included in the interview and is part of what the study is exploring. Despite this, no male participants expressed an interest in taking part in the study.

Participants were also not excluded on the basis of their sexuality. There is very little research surrounding the different experiences of heterosexual and LGBT disabled people, particularly in the area of romantic relationships. There seemed to me to be no reason to exclude on this basis, as the criterion of spinal injury was enough to account for the homogeneity of the study. Participants were required to be over eighteen but beyond this were also not excluded on the basis of age. Previous literature has tended to focus on adolescents and young people with physical disabilities, yet people of all ages are interested in dating and should therefore be included. Participants were accepted if they were currently involved in a serious relationship, but should have experienced being single and dating at some point since their injury.

Participants injured less than two years ago were not approached. The rationale for this is that during the first two years of recovery there can be significant improvements in sensation and mobility and it was essential that this study did not interfere with patients' rehabilitation. Moreover, this time is a huge period of transition for spinally injured patients, as well as

readjustment to life outside hospital and due to the sensitive nature of the research subject, I felt that only participants who had been injured for more than two years should take part.

## **Interview Procedure**

### *Semi-Structured Interviews*

While there are various methods that can be used when applying the IPA methodology, the most commonly used is semi-structured interviews. In the current study, data was gathered using semi-structured interviews, in line with the IPA guidelines set out by Smith et al. (2009). The aim of a semi-structured interview is to use open-ended questions to direct the interview, but to allow the researcher to be guided by the participants' responses. Using this open-ended format in the current study allowed the participants to give unrestricted accounts of their experiences and expand upon areas that were most significant to them.

### *Interview Schedule*

An interview schedule (Appendix II) was compiled, designed to answer the research questions and the aims of the proposed study. This consisted of prepared open-ended questions, supported by prompts of discussion points, to encourage further description and elaboration from the participant. These questions were guided by existing literature and my own clinical experience and were designed to explore participant's experiences and expectations of dating and intimacy with an SCI, their experiences of societal pressures and attitudes and how dating with an SCI might be different for men and women.

As the objective of the interviews was to encourage participants to explore aspects of their experience, the interview schedule was not strictly adhered to in each interview but rather acted as a guide to facilitate the process.

### *Interview Process and Data Collection*

The distributed flyers and recruitment adverts requested participants to contact me by phone or email. After initial contact, participants who met the criteria and expressed an interest in taking part were sent a detailed information sheet via email (Appendix III), which gave a brief description of the research project and carefully outlined the potential risks and benefits of participating in the study. Participants were informed that with all spinal injuries there is the possibility of psychological trauma, whatever the circumstances of the injury. Although the interview questions focused on dating, a possible risk of participating is that exploring these experiences may focus on aspects of their life that they find distressing. The information sheet informed participants that, “if at any time you feel upset and wish to stop the interview you can and contact numbers of places to go to for support will be provided for you”. Participants were also informed that there were no direct personal benefits to taking part, except that this research could lead to potential benefits for future patients and contribute to existing knowledge. Additionally, many people also report that talking to a researcher about their experiences can be beneficial.

Participants willing to proceed were offered a pre-interview phone call and an in person meeting, in order to introduce myself to participants and to discuss aspects of the study such as confidentiality and approximate length of interview. Due to travel limitations and busy schedules, none of the participants involved in the study accepted the offer of an in person meeting before the interview.

The interviews took place, either within the charitable organization through which the participant was recruited, or in another suitable meeting room within a public building (for example a university, hotel meeting room or office). This ensured that the premises and facilities were wheelchair accessible and made certain that there were other people on the

premises while the interview was being conducted, in order to ensure the safety of both parties. Due to potential travel limitations of participants, I travelled to the area that was most convenient for the participant.

At the beginning of the interview, confidentiality was discussed and informed consent attained from each participant (Appendix IV). Participants were assured that they could withdraw from the study at any time and that they could take breaks during the interview if needed. Each participant was also invited to choose a pseudonym to preserve their anonymity in reported findings. All participants declined to choose their own pseudonym, which I instead randomly selected in order to maintain confidentiality. These pseudonyms have been used throughout this manuscript. Some demographic data was also collected from the participants prior to the interview. Each semi-structured interview lasted for approximately 50 minutes, with interview times ranging from 29 minutes to 57 minutes.

During the data collection process, several aspects had to be accounted for to make certain that the interview process would be suitable for spinally injured participants. Participants who used carers were invited to bring their carers into the interview room, as participants with high level injuries might need assistance during the interview, for example with drinking water. Also, some participants with limited mobility in their hands were unable to sign the consent form, so the details of consent and confidentiality were discussed in detail and then the participant asked their carer to sign the consent form for them.

After the interviews, participants were thanked for taking part and given a debrief form (Appendix V), which would provide more information about the study. Participants were informed that they may retract their data up to two months after the interview; after this time

retraction would not be possible. If participants were interested in a copy of the results, they were told that they would receive these in 2 to 3 years, once the research was completed.

These interviews were audio-recorded using a Dictaphone and the recordings later transcribed verbatim, to be used for analysis. The recordings and transcriptions were kept on a password-protected laptop and the recordings deleted from the Dictaphone as soon as they had been uploaded to the laptop. Moreover, audio and transcription data were de-identified, with the assigned pseudonym as the only identifying information included on file names, in order to ensure confidentiality.

### **Data Analysis**

After the semi-structured interviews had taken place, IPA was then used to analyse the transcribed data. This model of data analysis enables deep and introspective interviews and produces rich data (Smith, 2008). Smith (2007) describes this type of analysis as “an iterative and inductive cycle”, meaning that the researcher must put aside their own preconceptions and repeatedly return to the source of the data when making findings. This involves close interaction between the reader and the text, using line-by-line analysis of each participant’s experiential understanding (Smith et al., 2009). The aim is to achieve a dialogue between the researcher, their own psychological knowledge and the data, in order to understand and interpret what it might mean for a participant to have particular experiences in a particular context (Smith et al., 2009).

Although IPA analysis is intended to be applied flexibly and multi-directionally, Smith et al. (2009) outline steps of analysis, which provide some structure and guidance for analysis. The transcribed interview data was analysed in accordance with these steps.

### *Stage 1- Reading and Re-reading*

During the first stage of analysis, I immersed myself in the data by reading and re-reading the first transcript carefully several times. Given IPA's Idiographic underpinnings, Smith et al. (2009) suggest analysing one case in detail before moving onto a second. They also suggest starting with the interview that felt most complex. Each reading has the potential to produce fresh insights and I was able to become as familiar as possible with the data. At the same time, I listened to the recording of the interview repeatedly. It was also important at this stage, to reflect on my memory of the interview and to make notes of initial thoughts and observations of the transcript, in order to bracket these off and remain close to the data.

### *Stage 2 – Initial Noting*

During the second stage, while engaging in this close line-by-line examination of the text, I noted any content that seemed significant or interesting and these annotations were made in the right-hand margin of the transcript. These comments were either descriptive, linguistic or interpretive and were colour-coded in order to identify them (Appendix VII). At this stage, interpretations should come from an iterative process of description and interpretation, being rooted in the original data. This process was carried out for the entire first transcript.

### *Stage 3 – Emergent Themes*

In the third stage, these initial comments were used to identify emergent themes. I adapted the initial notes made in the right-hand margin into concise phrases, which captured the essential meaning of the text. These more concise phrases were then annotated in the left-hand margin (Appendix VIII). The aim of this was to reduce the volume of comments, while maintaining the complexity and to produce themes which reflected both the participant's own words and

my own interpretation. In this way, an initial list of potential themes was compiled, in what may be described as an open coding process (Smith & Osbourne, 2003).

#### *Stage 4 – Connections*

During the fourth stage of analysis, similar themes that had been identified throughout the transcript were clustered together in order to identify thematic patterns. A chronological list of the emergent themes was compiled and I attempted to make connections between them grouping certain themes together. Smith and Osborn (2003) describe this as a “magnet with some of the themes pulling others in and helping to make sense of them”. At this stage, it was important to re-read the previously coded transcript alongside the identified themes, in order to ensure that the themes appropriately fitted the original text. Although this form of analysis is subjective, it was important to constantly check interpretations against the participants own words. With this in mind, I keep a note of the participant’s specific phrases, that supported identified themes, recording the page and line numbers. Once emergent themes were grouped together, I compiled a summary table which was then used to identify the ‘subordinate’ themes and the ‘superordinate’ themes that emerged. Certain subordinate themes, which captured a particular aspect of the participant’s experience, were grouped together and were given a name or ‘umbrella’ theme, known as the superordinate theme. These were recorded along with the page and line reference, to enable examples of each theme to be found within the transcript at a later time.

#### *Stage 5 – The Next Case*

After these four stages had been completed for the first transcript, I then repeated this process for the remaining five interview transcripts. The list of superordinate themes from the first analysed transcript was used to inform the analysis of the other transcripts. By keeping in

mind themes that had already emerged, it was possible to discern repeating patterns but also to identify new emerging themes.

#### *Stage 6 – Patterns Across Cases*

Once this process had been carried out for each transcript, it was then necessary to discern patterns between all six interviews. I examined each summary table of themes and identified connections between them to compile a colour-coded final or master table of superordinate themes, which represented the phenomena experienced by the participants (Appendix IX).

### **Evaluation of Research**

Given the qualitative nature of this study, the concepts of validity (accuracy of results) and reliability (consistency of results) are measured differently than they are in positivistic research (Lyons, 2000). Willig (2012) argued that criteria used to evaluate qualitative research should be consistent with the researcher's epistemological position and Cho and Trent (2006) define validity in qualitative research as "determining the degree to which researchers' claims about knowledge correspond to the reality (or research participants' constructions of reality) being studied" (p.320).

In the current study, I have attempted to adhere to the four criteria for achieving validity in qualitative research set out by Yardley (2008); sensitivity to context, commitment and rigour, coherence and transparency and impact and importance.

In considering *Sensitivity to Context*, I conducted a thorough review of the theoretical literature (see Introduction chapter), ensuring that the study was sufficiently supported by existing theory and exploring the social and cultural context within which the participants'



experiences took place. As already discussed, due to the socially constructed nature of disability and dating, it has been essential to remain mindful of the influence of societal beliefs and expectations on the spinally injured population and to understand the participants' data within this context. In addition, I also remained sensitive to the context within which the data was collected and analysed, namely the relationship between myself as a non-disabled researcher and my participants and the influence of my own beliefs and assumptions upon the research process (see Reflexivity section).

Yardley (2008) describes *Commitment and Rigour* as “demonstrating strong engagement with a topic and competence in the research approach” (p.246), as well as achieving completeness in data collection and analysis. My two years working at the London Spinal Cord Injury Centre (LSCIC) has given me training and insight into working therapeutically with the spinally injured population and I have read widely within the related research and popular literature. I also attended seminars regarding IPA theory and a research group, which practised IPA analysis and I ensured that the data collection process was carried out accurately. During the analytic process, I attempted to ensure that analysis was grounded in the original data by referring constantly to the participants' own words, yet also attempting to avoid the ‘too-basic analysis’ by developing my own interpretations (Smith et al., 2009).

With regard to *Coherence and Transparency*, I have detailed thoroughly all aspects of the data collection process and all stages of the analysis within this chapter. I have also provided access to original data through samples in Appendices and extracts within the Analysis chapter. In addition, reflexivity has been a key component of the research process and various measures have been used to ensure that I am aware of my personal motivations, assumptions and beliefs that may impinge on the research. To this end, I have kept a reflexive diary and

engaged in the practice of ‘bracketing’ throughout the data collection process. Bracketing involves a researcher thoroughly examining their own personal biases toward the phenomena being studied and attempting to set these aside. Keeping a reflective diary throughout the research process, enabled me to engage in self-exploration and allowed me to gain insight into the ways in which my personal experience might impact the research and conversely how conducting this research may have an impact upon me. In addition, at the start of analysis, I reflected on my memory of the interview and made notes of my initial thoughts and observations of the transcript. These measures were taken in an attempt to ensure that I was able to bracket my own preconceptions and attitudes.

However, the limitations of bracketing are clear; namely that it would be impossible for any researcher to completely set aside their own thoughts when engaging in analysis. Indeed, the idea of bracketing also seems to contradict another philosophical root of IPA, the double hermeneutic; analysis should not only be grounded in the participants’ interpretation of their own experience, but also requires interpretation by the researcher (Smith & Osbourne, 2003). This required interpretation seems at odds with the phenomenological tradition of bracketing. IPA is a dual methodology, drawing upon both of these philosophical ideas and this can cause aspects of analysis to seem slightly contradictory. While conducting this analysis it was essential to recognise and mediate my own personal beliefs and values, while at the same time accepting that I could not expect to eliminate these. It is this balance that can be hard to find when engaging in IPA, but which I strove for while conducting this analysis.

To further enhance transparency, I used the technique of researcher triangulation; the idea that if two sources produce similar findings then the credibility of findings is enhanced (Patton, 2002). I asked two colleagues to read through my list of themes and to evaluate whether the

name of the superordinate theme reflected the extract from the original data. Overall, the researchers agreed with my interpretations and where alterations were suggested, these were incorporated into final table of themes (Appendix IX).

I have addressed the *Impact and Importance* criterion, by considering the relevance of the current research to counselling psychology in the Discussion chapter of this study. I believe that my research questions have elicited new information regarding the experiences of the spinally injured population and the societal expectations and implications of dating with a spinal injury. I hope that this research will be a platform to increase awareness of these issues within the field counselling psychology and spinal injury rehabilitation and to practically apply these findings to benefit spinally injured patients, developing new approaches within therapeutic work and linking research to clinical practice.

### **Ethical Approach**

I obtained permission for this study from the SCI charities that were used for recruitment and ethical approval for this study was obtained from Psychological Research Ethical Committee at City University, London (Reference number: PSYETH (P/L) 15/16 50). This research was carried out in accordance with accepted practice guidelines (Bond, 2004; BPS, 2010; BACP, 2010).

Throughout the study, the participants' needs took precedence over the research process and I gave ethical issues consideration at each stage. Key among these was the issue of informed consent. In line with Blease, Lilienfeld and Kelley's (2016) recommendations, informed consent was seen as a process, rather than a single disclosure of information and both written and verbal disclosures of information were provided. If at any time participants wished to

withdraw from the study, their participation was not pursued. To reduce any difficulty participants might feel over withdrawal, payment was not offered for taking part in the research.

A further consideration was assuring patient anonymity. I informed participants of their rights regarding privacy and the protection of their confidentiality and, as in clinical therapeutic work, the only exception to this privilege of strict confidentiality was if I was made aware that danger to a participant's self or others was present. Paper copies of the participant transcripts were kept in a locked filing cabinet and only I had access to the key. In addition, names and identifying details were changed during transcription and pseudonyms were assigned to each participant in order to preserve confidentiality. Participants' identifying data, such as signed consent forms and identifiers for participant pseudonyms, was kept separate from the research data. Audio and digital files were kept on a password-protected laptop, which was only accessible by me. The recordings and transcripts will be kept for five years, in accordance with guidelines set out by the BPS (2010). After this time, the recordings will be deleted and all of the transcripts and paper documents will be destroyed.

Ensuring that the psychological and physical wellbeing of both myself and the participants were safeguarded was paramount. Professional boundaries were maintained, by locating safe, private and wheelchair accessible rooms in which to conduct interviews. To ensure that the participants felt safe during the interview, it was important to take the time to build rapport and trust with each participant, by being warm, empathic, engaging in active listening and pacing the interview according to the participants' needs. Additionally, as all SCI could be described as psychologically traumatic, regardless of the circumstances of the injury, it was possible that participants may potentially have been experiencing some degree of post-

traumatic stress. I remained mindful of the possibility of psychological trauma throughout the research process. After the interviews, I provided participants with a list of appropriate sources of support such as their GP, the Samaritans and the SCI charities; BackUp, SIA and Aspire. If participants presented symptoms consistent with Post Traumatic Stress Disorder (DSM-5, 2013) and they were not currently in treatment, they were given the name of the relevant clinician attached to the hospital where they initially received medical treatment for their injury.

In addition to these ethical considerations, it was also important while conducting this IPA research to reflect on the ethical implications of interpretation. In a clinical setting, it is usual for a psychologist to interpret the experiences of their client to some degree, depending on the theoretical approach being employed. Interpretation in this context seems different to interpretation in research, primarily because in a clinical setting the client is present and able to voice their opinion on the interpretation and correct the psychologist if they feel that this interpretation is inaccurate. In a research setting, the participant is not present and interpretations are being made retrospectively, using the recording of the interview and the transcript. It could be argued that this form of interpreting imposes the view of the researcher onto the participant's experience, without allowing the participant to respond to these interpretations.

It was also important to consider the ethical implications of interpreting data as a non-disabled researcher, conducting research with disabled participants. When conducting a research study there is an inherent power dynamic between the researcher and the participant. When the participant is disabled and the researcher is not, this power dynamic becomes further exacerbated by the power relationship that exists between disabled and non-disabled

people in society (Stone & Priestley, 1996). The disabled community endures stigma and oppression in many aspects of social interaction and it is essential that disability research does not perpetuate the marginalisation of disabled people (Stone & Priestley, 1996).

While previous research does not advocate an exclusive approach, where disability research is carried out solely by disabled researchers (Kitchin, 2000), Stone and Priestley (1996) highlight several principles for producing emancipatory research within the disabled community, which should particularly be followed by non-disabled researchers. They suggest that researchers need to make themselves more accountable to disabled people and take steps to introduce a sense of ‘vulnerability’, that may begin to counteract the potentially harmful power dynamic between a non-disabled researcher and disabled participant. They suggest that this may be achieved by being transparent regarding research rationale and methodology (see Evaluation of Research section).

Previous disability research has been criticised for epistemological and methodological shortcomings and it has been suggested that “disabled people have come to view research as a violation of their experience” (Oliver, 1992). Researchers within the positivist and interpretivist paradigms have been particularly criticised for perpetuating oppression, by assuming the role of expert and viewing disabled participants as “passive research subjects” (Abberley, 1987). Stone & Priestley (1996) suggest that researchers should adopt a social model of disablement, moving away from positivist and interpretivist paradigms and surrendering objectivity for subjectivity within the epistemological approach to research. In addition, Kitchin (2000) suggests that disabled participants should be regarded as consultants within research and Stone and Priestly (1996) advise that “anti-oppressive practices must begin within the research process itself”. I have already described that my epistemological

position regards language as a central aspect of how we construct meaning in the world. With these emancipatory research principles in mind, I was reflecting on the nature of disability language used within society and existing literature, in particular the phrase ‘able-bodied’. This term has become somewhat controversial, given the implied negative connotations towards disabled people and the fact that many disabled people, particularly those who are athletic and involved in sport, consider themselves to be ‘able-bodied’. Despite this, the existing literature uses this term constantly. With this in mind, I decided to consult my participants as to the use of language, and particularly the term ‘able-bodied’ within research. They generally felt that they did not oppose strongly to the term, although many felt that it was out-dated and could be offensive to some within the disabled community. On the strength of this, I decided to avoid the term ‘able-bodied’ within this manuscript, except where I quote directly from previous literature or the participants’ own words.

While a degree of interpretation is necessary in IPA, Smith et al. (2009) make it clear that while the researcher is the theoretical expert, the participant is the expert of their own experience. IPA guidelines also make it clear that interpretations should always be based on the words of the participant and be able to be traced back to the original data (Smith et al., 2009). These principles were at the forefront of my mind while I was analysing the participants’ data.

### **Researcher Reflexivity**

In order to achieve integrity and trustworthiness, a researcher should engage in constant examination of their personal and professional influences on the research process at all stages of inquiry (Finley, 2002). Husserl (1929) advocated the importance of adopting a ‘phenomenological attitude’, requiring reflective exploration of experiences, in order to derive

meaning from them. For me, the process of reflexivity began at the conception of this research, when I began to keep a reflexive diary.

The act of keeping a reflexive diary, echoes the philosophical underpinnings of hermeneutic phenomenology, that understanding is a product of interpretation and experience and also the phenomenological concept of intersubjectivity, which acknowledges that people are inextricably linked to others and the world around us (van Deurzen & Kenward, 2005). By keeping a reflexive diary, I was able to examine my influence upon the research process and to bracket off preconceptions and assumptions, while still acknowledging that I could not separate myself from the research process (Finley, 2008).

This research was driven by my clinical experience of working with SCI patients at the LSCIC, at the Royal National Orthopaedic Hospital (RNOH) in Stanmore. I thoroughly enjoyed my time at this placement and I learnt a lot from my patients, my supervisor and the multi-disciplinary team. I became immersed in the world of rehabilitation and learnt a lot about the implications of spinal injury; both in terms of medical and physical changes and in terms of lifestyle changes. Despite the medical environment of the ward and the essential nature of the physical care, great importance was also placed on the patients' mental health. I am aware that this is not always the case within a hospital environment treating physical injury and I feel that my time at LSCIC has given me insight into how an MDT can function in a holistic way, regarding both physical and psychological wellbeing as important aspects of recovery. I have worked with both inpatients and outpatients, some who have been injured for weeks and some who have been injured for years. I have worked therapeutically with patients who are single and patients in relationships and it seems to me that the single SCI population has been overlooked, both in research and in therapy. It is my clinical work with



these patients that prompted me to read more around the area of dating and disability and this was my motivation for the current research.

It has been essential for me to reflect upon my position as a non-disabled researcher in relation to my disabled participants. Despite my clinical experience, I am not spinally injured. While I can empathise with my patients', and participants', experiences and achieve a therapeutic understanding, I have no personal experience of becoming spinally injured. When I decided to undertake this research I was concerned about how this lack of experience might impact on my research. The IPA framework assumes that while the researcher might be the theoretical expert, the participant is the expert of their own experience (Smith et al., 2009). Therefore, it is not necessary for the researcher to have had a particular experience in order to explore that experience. Indeed, this may enable research that is less biased by the researchers own experiences. I am single and I have been single and dating during the research process. I sometimes found that as my participants described their experiences of using online dating and dating apps, that this would make me think of my own dating experiences. I had to ensure that I put these to one side during the interviews and was able to reflect on this afterwards.

Another area that it has been important to reflect upon is my dual roles as researcher and practitioner. This line can become blurred as the differences between these roles are not always clear (Hart & Crawford-Wright, 1999); both IPA research and therapeutic intervention attempt to understand and explore the client or participant's world and to empathise with their experiences. It was important to maintain boundaries during the interview process and only discuss topics that the participants wanted to share, in order to avoid establishing a more therapeutic relationship in which the participant might share too much and feel distressed after the interview was concluded. I wondered how establishing this more boundaried

research relationship with the participants might feel, both for me and my participants, as my therapeutic work is usually directed by the client’s needs. However, all of the participants responded well to the brief nature of the interview process and saw the interviews as an opportunity to help me as a researcher and potentially other spinally injured individuals who might benefit from the study.

## Participants

Participants in this study ranged in age from 25 years old to 47 years old, with a mean age of 37 years old. Participants also varied in level of injury and ranged from 2.5 to 20 years since injury. This information is consolidated in the table below (Table 1).

**Table 1: Participant Information**

<b>Name</b>	<b>Age</b>	<b>Sexual Orientation</b>	<b>Level of Injury</b>	<b>Years Injured</b>
Participant 1 (P1) “Christina”	37	Heterosexual	Paraplegic	8
Participant 2 (P2) “Alexandra”	45	Heterosexual	Tetraplegic	12
Participant 3 (P3) “Miranda”	47	Heterosexual	Paraplegic	20
Participant 4 (P4) “Meredith”	30	Bisexual	Walker	2.5
Participant 5 (P5) “Sophia”	36	Heterosexual	Walker	10
Participant 6 (P6) “Margaret”	25	Heterosexual	Paraplegic	7

## Chapter 3

### Analysis

In this chapter, the findings which emerged from the analysis of the interview transcripts are presented. I have endeavoured to accurately convey the content of the participant's accounts, presenting material which gives voice to the individual experiences, while at the same time is representative of the experiences of the participant group. As discussed in the Method chapter, IPA offers different levels of interpretation (Smith et al., 2009). As such, some of the themes presented here offer a relatively descriptive account of the participants' experiences, while others offer a more interpretive stance. Deeper level interpretations are explored in the Discussion chapter.

The analysis elicited four superordinate themes, consisting of several subordinate themes, which were shared by the majority of the participants (Table 2).

**Table 2: Table of Themes**

<b>Superordinate Themes</b>	<b>Subordinate themes</b>
Dating as a Journey	Surviving vs Thriving: The Process of Coping Loss & Grieving Sex & Intimacy
Challenges to View of Self	Sexual Esteem & Body Esteem A Burden Lowered Expectations
Perceived Societal Attitudes	Expectations from Others The Role of Gender

	Ignorance: Moving Towards Understanding
Dating Concerns	The Same Concerns vs New Ones Disclosure Control & Vulnerability

The following excerpts were selected based on how effectively they captured these themes. In some instances, chosen extracts might be applicable to other themes as well. Minor hesitations have been removed and ... reflects a longer pause. The device [text] denotes explanatory material added by me and [ ] signifies that some material has been omitted.

### **Superordinate Theme 1: Dating as a Journey**

This theme captures the way that all of the participants described dating after their injury as a process. They reported their experiences and expectations changing significantly over time. The title, The Dating Journey, aims to reflect the transformative and evolving nature of these experiences. Within this theme fall three subordinate themes; *Surviving vs Thriving: The Process of Coping, Loss & Grieving* and *Sex & Intimacy*.

#### *Surviving vs Thriving: The Process of Coping*

This theme relates to the changes in the participants' attitudes towards dating, from initially after injury to the present.

Margaret, like many of the participants, emphasises how dating was not a priority for her initially after her injury.

*“You’ve got so many other big worries [ ] you’ve got your rehab to think about, where you’re going home to, college, education, erm, so yeah, dating was not very high on that agenda”.*

*(Margaret: 5, 1)*

While Margaret does suggest that dating was a concern, this was eclipsed by the practical aspects of recovery, such as physical rehabilitation, living arrangements and, in Margaret’s case her university place and these initially took precedence over dating. Christina expounds on this;

*“It’s only when you come out of hospital you realise, not everybody is in a wheelchair, [ ] the ground isn’t flat. There is, people do say stupid things to you, people ask you about what’s happened to you. You’ve got so much to contend with that really, yes, I wanted to settle down, but it wasn’t a priority because I had to figure out day-to-day how, this new body of mine, how does it work? It was like being reborn again, learning everything so it was a concern but it was only when I, sort of, got in a routine and started going out, meeting people, going out with friends, you know, that’s when it hits you, you know, my life is coming together now so what does the future hold?” (Christina: 7, 3)*

Christina’s description of her life straight after she left hospital highlights her experience of coping with her injury and functioning in the world outside the hospital. She emphasises the idea of rebirth; trying to relearn how to do old tasks and reconcile her new body with her old life. Her words seem to emphasise her struggle and her use of a rhetorical question seems to emphasise her uncertainty and the overwhelming experience of adjusting to her new body. It was only when the process of coping was underway that she could turn her attention from ‘striving’ to ‘thriving’ and look to dating and her future hopes.

In a helicopter assessment of her experiences Alexandra goes further, describing how she initially felt that her injury marked the end of dating because she was so consumed by it.

*“From when I first got injured to now ... it’s completely different because when I first got injured [ ] that was kind of like the end of my relationship life and that I just have to get on with other parts of my life, then, since then things have moved on a lot because I have been injured now for ... over twelve years.” (Alexandra: 12, 20)*

For Alexandra, the difference between her situation after her injury and twelve years on seems huge and her hesitation seems to convey her surprise at how long it has been since her injury, reflecting on how far she has come. Her words “the end of my relationship life” reflect the loss and grief that she felt initially in contrast to how she feels now. This links closely to the next theme *Loss & Grieving*.

While this initial struggle moving towards coping is common across the participant group, there are differences in how individuals describe how far through the process of coping they have come. Their current situations vary based on the amount of time that has passed since their injury.

Meredith is the participant with the shortest time since her injury; two and a half years. As stated in the Method chapter, improvement in movement and sensation post-injury tends to plateau at the two-year mark. Meredith describes how her experience of dating is much easier now that she has reached this point:

*“It is still quite hard, but it is easier now [ ] because before when I was on a date it was like*

*people constantly saying to me, “so, are you going to be right one hundred percent when you get better?” and I would be like, “oh, I don’t know”, but now I can just be like “no”. It is actually so much easier for me explaining it to people just to be like, “no that is it ... that is it”.*” (Meredith: 28, 13)

While Meredith describes things as “easier” than before, she still seems to be struggling with certain aspects of dating. Her repetition at the end of this excerpt seems to indicate her continuing adjustment to the fact that her physical condition is unlikely to improve further. It makes sense that having been injured for less time she might not be as far through the process of coping as other participants who have been living with their SCI for much longer.

Christina, who has been injured for eight years, says;

*“It still can take years, I mean I am finding situations I do not handle very well at times. It is part of your learning.”* (Christina: 18, 18)

Christina describes this ongoing process of coping and suggests that she still finds that she struggles with particular situations, despite having been injured for several years. In line with the idea of an ongoing process, many of the participants also describe eventually seeing dating as a positive activity that they enjoy.

*“I feel like dating is good for my recovery because I can do that and it does not make me feel disabled when I am doing it.”* (Meredith: 5, 24)

*“It is fun though, dating, it really is, isn’t it? If you have the confidence to go out and put yourself out there and get those dates then it is quite good fun.”* (Margaret: 26, 11)

This seems to contrast significantly with the participants' descriptions of their early attitudes towards dating and suggests that they have undergone a change overtime.

*“Whereas I think twenty years ago I would have had lots of negative things [ ], “oh well, they probably think that I couldn't do this and I couldn't do that and that our future will be hard together [ ]”. Now, twenty years down the line I feel like actually [ ] even if I chose, say, for instance somebody who was into sport, their expectations will be, well, they might have chosen somebody that wasn't into sport anyway.” (Miranda: 27, 13)*

Miranda's words here emphasise this change as she reflects on how aspects of dating that would have made her feel insecure are no longer a concern for her. Her concern with dating initially after injury seems to have been her expectation that potential partners were thinking negative things about her and her future prospects, perhaps reflecting her own fears regarding her future. Now she seems to be less concerned with the expectations of others and more accepting of her injury.

Meredith, Miranda and Christina describe how they have learnt to cope with aspects of dating and spinal injury;

*“I think how I react to it completely dictates how other people react to it, if I'm having a really low day and I am actually feeling quite pessimistic about it all, I think that totally puts people off. But if I make light of it [ ] then other people are okay with it. I think this is the same with everything else with disability, if you are okay with it then everyone else is.” (Meredith: 34, 10)*



*“It is about how you put yourself out there, you know, happy, smiley, just, I call it my bar face when I used to work behind the bar [ ] if I am not going to be happy and out there I am not going to get the best from people. So, I think I use that a lot.” (Miranda: 32, 12)*

*“I think it just then gives you that boost and my hope is it starts with the person who is disabled themselves and then other people respond to it. They are drawn to an energy, everyone wants to be surrounded by positive, happy people, but it does take time.” (Christina: 19, 2)*

All three participants suggest that retaining a positive attitude, helps them to get positive reactions from the people that they meet. They have found this to be a tool to cope with their injury and in turn this seems to help others cope as well and to respond in a more positive way.

These extracts convey the fluid nature of this process, from initially learning to cope with everyday struggles to moving towards being able to engage with dating. The participants seem to be initially consumed with their recovery and the more practical aspects of their lives and only later do they have the ‘headspace’ to consider their romantic life. When the participants describe their experiences of ‘striving’ or struggling to cope, they convey a sense that this was overwhelming and emotionally exhausting for them. The enormous effort that they had to put into the practical aspects of their lives in order to function really came across to me. Their experience of this growing hopefulness seems to imply a growing self-contentedness and moving towards ‘thriving’ appears to have happened gradually overtime. This relates strongly to the next theme, experiences of coping as a process have close links to the process of grieving.

### *Loss & Grieving*

This links closely to the previous theme, *Striving vs Thriving*, but focuses on the sense of loss that the participants described feeling initially after their injury. Although this theme seems much less hopeful than the previous one, grief too can be seen as a process. As is the case in all bereavement, the initial loss can feel all-consuming but over time it is possible to move through the grieving process towards a more hopeful place. I will discuss this further in the Discussion chapter.

Particularly common among the participants was the sense of loss of their old life and old self. Meredith and Sophia described the loss of old hobbies or activities that they used to love.

*“I was a huge cyclist and I used to love mountaineering and all these things that made up my identity, [ ] that is what kind of defines me as a person but I can’t do it anymore”. (Meredith: 4, 1)*

*“I used to go to galleries and things but I find that very, very difficult now because sort of, I am all right walking, but standing is just a killer for my back [ ] It is the same thing, like the theatre as well that I find seats so uncomfortable so I do not even really know necessarily where I would go with somebody. I mean, there is always the whole thing, I suppose, of going and having a drink, except that I do not drink now because of all my medications”. (Sophia: 7, 14).*

Sophia recounts how her losses have affected her dating life; the activities she loved she can no longer enjoy and this impacts her dates. She seems to be remembering all the things that she cannot do in the moment and the list she describes emphasises the number of activities

that are closed to her now. Meredith describes the loss of her hobbies as a loss of identity, being unable to do the things that make her who she is. Later she also says, *“literally everything I used to do I cannot do anymore”* (Meredith: 13, 17) further highlighting her lost sense of identity. Similarly, Margaret describes the loss of her sex life.

*“I find it a bit, I don't know, it's kind of a bit depressing really, because it was a big part of my life before I was injured and I have no sensation from the chest down now. It's like, I know, I don't really enjoy sex as much as I used to but it's not awful, does that make sense? It's not bad, but it's just not as good as it was and that's annoying ... really, really annoying.”* (Margaret: 29, 13)

Margaret described herself before her injury as *“promiscuous”* (Margaret: 3, 20) and seems to be a very sexual person. This lost enjoyment of sex is something she is grieving for. She describes her loss as annoying but her feelings seem deeper than that and her pause felt as though she was reflecting on her grief here.

Meredith speaks more explicitly of grief;

*“I was on my way to a date and I had like a little mini grief moment, like a panic attack, because I saw someone running and they were like out of breath, it was a lovely winter's morning and I just sort of like, can't do that, and sort of like had a little panic attack, you know, the grief as well. And then got to the date and then she was like, “so, what do you do to keep fit?”.”* (Meredith: 28, 25)

Meredith describes a very physical grief reaction here and this is accentuated by her repetition

of “panic attack”. This seems to have been a very painful moment for her and her loss here is clearly conveyed. She speaks of grief again but in a less explicit way;

*“It was just a bit annoying because he kept talking about climbing and rock climbing, I used to be a climbing instructor and I was like, “oh shut up” (laughs) [ ] it’s not helping, I can’t do it.” (Meredith: 9, 17)*

Despite her laughter here, her words convey her feelings of loss and this suggests that the laughter here is part of her personal language, that she laughs as a way to cope with her strong emotions. This also seems common to other participants who use the words “frustration” or “annoying” when the feelings they are exploring seem to be much deeper than those words would suggest.

*“I can find it quite frustrating that there are things that I would like to do, places that I would like to be able to go, that are just not really practical for me.” (Sophia: 22, 20)*

*“It was so frustrating, I am like, I just want a normal person, I just want to be normal” (Margaret: 19, 16)*

Alexandra goes on to describe how she also lost her old friends;

*“Then your friends kind of disappear a bit because you are no longer able to do a lot of things that you used to do.” (Alexandra: 20, 12)*

Some participants explore the loss of their expected future. Both Alexandra and Christina

describe their lives stopping or being set back;

*“All my friends at that time were getting married or having children, it was very, very difficult but you are happy for them but your life stops.” (Christina: 6, 18)*

*“I was not a part of that anymore. They kind of moved on but I was kind of still back where everybody was before.” (Alexandra: 20, 17)*

Similarly, Alexandra and Meredith describe their lost expectations of having children.

*“The whole thing about children is a bit, it sort of twinges it a bit, because I know that I am able to have children but it will be such an extremely harrowing and painful experience, because like I find it hard with my gait and pain and everything already and I just think with all my fatigue and everything that I couldn't really, I couldn't deal with bringing up a child.” (Meredith: 32, 3)*

*“And then at the age I got injured was 33, erm, a lot of my friends started to get married, settled down, have children and I wasn't a part of that anymore.” (Alexandra: 20, 16).*

The pain that both women feel seems to be conveyed here. Alexandra also describes loss in terms of diminished control.

*“You hate the chair so much, because you've got to be in it and you do not want to be in it, but you have to get in it because that is the only way you can sort of function day to day.” (Alexandra: 10, 2)*

Alexandra describes her lack of control in the context of her wheelchair. Her language here is emphatic and her grief seems evident.

Some participants also describe trying to replace their loss, moving through to a place of acceptance.

Meredith describes her attempts to find other activities to replace those she has lost;

*“I feel like I have not got to the point where I have built up an array of physical activities to replace that yet. I do not think I will because, yes, because, I just sort of the fatigue and the demands that it caused and everything.” (Meredith: 11, 6)*

Meredith here describes her efforts to move past her loss and her struggle with this. Having earlier described the loss of aspects of her old life, she later describe her sense of her new life.

*“You cannot actually avoid it because it is such a central part of your life that it affects everything. My whole life is built around it. It explains, like, the massive interruption in my life, where I am living, who I know, what I am doing, yes, everything.” (Meredith:13, 4)*

Meredith seems to be describing a sense of acceptance here; the idea of building up your life around grief is common to all bereavement and this seems to be what Meredith is experiencing. Miranda also describes this in different language;

*“I would say from point of injury at twenty-seven, probably a good five years to find myself again, to be Miranda again.” (Miranda: 4, 23)*

In contrast to the references participants have made to the loss of their old self, Miranda here describes returning to where she was before her injury; her old self. This suggests that she has moved on from her initial loss.

Meredith also goes on to describe the gains or positives that her injury has brought to her life;

*“I find it a positive because it has given me such a depth of human experience [ ] Usually people open up to you very quickly as well about something in their life and you very quickly share a bond. Then they also immediately see you as a person who has understanding rather than somebody who might not. Actually, I think it has been, forming relationships is definitely much better.” (Meredith: 7, 2)*

*“Also I think because if you go through something like that [ ] people immediately view you as a resilient person, and that also is a positive reflection on you.” (Meredith: 35, 7)*

In summary, each participant described different losses that they had suffered associated with their injury and the impact that this had on their lives. However, there seems to be a sense of moving from grief to acceptance and recognising the positives in their new situations. This reflects moving through the grieving process to a place of acceptance and growth and highlights the process orientated nature of loss.

### *Sex & Intimacy*

The theme of sex and intimacy was also described by participants in the context of a continuing process. Most participants felt that their first experiences of sex post-injury were bad.

*“I had an indwelling catheter in. I strapped it to my leg as best I could. He laid on top of me and I let out lots of wind, I was feeling really unsexy at this point. My stomach had changed shape, being a racing cyclist before my injury, erm, I was okay with my body and now my stomach changed, my legs had gone [ ] I just looked at him and went, “I don't feel anything”. I burst into tears and that set our sex life up at that point for a not very good start.”*

*(Miranda: 19, 12)*

*“I have to say I think my first, like, physical experience was not the bestest because I had full on autonomic dysreflexia [ ] because I think it maybe was the first time, my body went into some sort of shock and that was a way it kind of showed me the dysreflexia. So that was my first encounter and it kind of put me off a bit because, you know, with autonomic dysreflexia the pain, the headache is excruciating, that you could not deal with it. [ ] So I thought, oh, I do not even know when I would enjoy this experience and whether even to bother to carry on.”* (Alexandra: 17, 8)

Miranda and Alexandra both describe bad experiences during their first sexual encounters which convey a sense of pain and sadness that links closely to the previous subordinate theme (*Loss & Grieving*). Both of these experiences appear to have been devastating and frightening. Perhaps, because sex is such a physical act, the significant changes in the women's bodies were made more poignant and their loss more painful. They go on to talk about how these initial experiences put them off further encounters at first.

*“So then he was scared to initiate. I was scared to initiate because I did not want to go there again because I thought, well if I don't feel anything what is the point?”* (Miranda 19, 21)



*“So I left it for a while because I thought the headaches are too difficult to deal with and it is quite dangerous and I did not want to have a stroke. So we left it.” (Alexandra: 17, 25)*

The fear that Miranda felt is clear here and her bad experience seems to have initially caused her to give up on sex. Alexandra’s words remind me of the previous theme, *Striving vs Thriving*, as her struggle to cope with the frightening and painful symptoms of autonomic dysreflexia is clear. Both participants convey a sense that these negative encounters have resulted in lowered sexual esteem. Conversely, Meredith describes her first sexual encounter differently;

*“My first sort of experience of physical contact after, was surprisingly, like, it was good, it was surprisingly different. I found that I have different preferences now, because obviously it has changed according to the sensations that I can receive.” (Meredith: 19, 11)*

Her use of “surprisingly” seems to suggest a fear that her experience of sex would no longer be enjoyable after her injury but that this sexual encounter challenged these perceptions. Miranda and Alexandra both go on to talk about sex post-injury as a learning process, something which evolved over time.

*“I started to learn a lot and then bring that into the bedroom and he was just like, “oh, am I just a guinea pig again?” (laughs) I suppose that changed things for us in a lot of ways.” (Miranda: 20, 20)*

*“Then as you try something new [ ] you think okay, my body is accepting it so that’s fine. So you move onto the next bit and you try something else but then when you try something else,*

*your body does not like it so dysreflexia sets in. Then you kind of learn, okay, you try it and if that happens [ ] you think of something else. That's how you kind of learn to listen to your body and what your body will let you do and what it will not let you do. So that's how you learn, a whole new way of having an intimate relationship with your partner and with your new body.” (Alexandra: 18, 6)*

Alexandra describes developing her relationship with her body and the necessity to relearn her body's sensations. In contrast to her initial experience of sex, she seems more accepting of those moments when she experiences autonomic dysreflexia. Instead of this putting her off another encounter, she now sees this as her body's way of telling her to try something else instead. This seems to suggest that Alexandra is more at ease with herself, her body and her sexuality.

Meredith and Miranda also describe adjusting to these changes in bodily sensation;

*“I have impaired like senses down the right side, so I never feel completely naked because I always feel like I am wearing clothes [ ] so that was kind of weird, not weird but it was strange having sex for the first time since the injury because I just noticed that I cannot feel, I can't use both hands so I had to like adapt.” (Meredith: 10, 18)*

*“It is that learning, I think I am quite aware now of what works for me. Before my injury I used to feel very guilty about masturbation, so I did not do that [ ] but now I want to know what works for me so I have looked at the vagal system, I look at sort of touching my nipples [ ] in the shower I can touch my own nipples and get sensations in my genital area. So that was through learning” (Miranda: 24, 6)*

Miranda describes using personal exploration and learning to understand her body and which areas were more or less sensitive post-injury. She conveys a sense of her confidence and ease with her own sexuality, which contrasts strongly with the sadness and insecurity that she felt in her first encounter.

As well as relearning bodily sensitivity and new sensations, the experience of which is described by participants in a positive way and as something to be enjoyed, they also described new aspects of their post-injury body that they must contend with during sex.

*“With the sort of bladder problems and things which is all really embarrassing enough already, but then without kind of being in an intimate sort of situation, yes, I do worry about that.” (Sophia: 17, 19)*

*“Whereas before I was a very tactile person and I would sort of be very tactile, I would want to touch someone's hair and everything, because [ ] it's hard physically to do, I find that I just do not do that anymore. I have to like, remind myself to do that, it's kind of strange as it's different. Also my right-hand, my right body gets freezing cold really quick so, I don't want to throw this icy lump at someone.” (Meredith: 20, 4)*

Both Sophia and Meredith convey their concern for what their sexual partner might be thinking of them. Sophia's embarrassment at her bladder problems suggest that this is an obstacle to her feeling sexy and confident and that she is fearful that her sexual partner might react negatively to this. Meredith seems torn between her enjoyment of being tactile and wanting to maintain this aspect of her sex life before her injury and her concern that the changes in her body might make this an unpleasant experience for her partner.

In line with these concerns, Miranda also raised the issue of oral sex;

*“My bladder is never going to work properly, so he is never going to get his head down there ever.” (Miranda: 40, 5)*

She is referring to her indwelling catheter and her reluctance for her partner to give her oral pleasure. Her reminder of her bladder and bowel issues is not something she seems to want to associate with sex, suggesting that she could not feel comfortable or sexy in this situation. Her emphatic language highlights her feelings here.

In addition, Miranda raises the issue of sexual health among the spinally injured population;

*“A lot of women with spinal cord injury often go, “you know, what, if I do not feel it down there and I can't see what's going on, well, forget it, and forget it is there”. Some people have, I know people that it has been their third partner and they have got HIV. So, it is, I think sometimes people can just sort of disregard it because they do not see it and do not necessarily feel what is happening. So, I think it is a blind spot for a lot of people.” (Miranda: 18, 17)*

Sexual health within the spinally injured population seems to be an important issue and I will discuss this further in the Discussion chapter. Finally, Meredith, Miranda and Alexandra all described the gains they have experienced in their sex life post-injury.

*“I am much more in tune with my body now and so much more like in charge of it. I am so much more aware of it that I think that has helped me in a lot of ways because I am so much*

*more direct.” (Meredith: 19, 13)*

*“I definitely say that I am having better sex as an older female than I was 20 years ago as a 27-year-old, but then again that could be lots of things, that is age, that is relaxation, that is feeling at ease with me and my partner.” (Miranda: 25, 22)*

*“Sometimes it’s a bit more fun because you use different pieces of equipment to help you [ ] whereas in an able-bodied relationship you know you do, it is more or less similar sort of things, so you can make it more, I suppose, exciting even though you can’t move [ ] then you can also understand your body more and certain parts become more, I suppose, sensitive than parts that you have lost and you get to enjoy in that respect.” (Alexandra: 12, 9)*

The participants convey their enjoyment of sex here and a sense of control over their sex life that seems to contrast with their earlier experiences. They also seem to be more at ease with their sexual selves and have increased sexual esteem.

While all of the participants seem to have very different sexual lifestyles, the theme of sex and intimacy post-injury as a process emerged clearly. Much like grief and coping, it seems as though this is something that develops over time. It is important to note that the two women who were most open to discussing sex and who described most positive physical and psychological improvements to their sex lives post-injury were Miranda and Alexandra, the two participants who have been injured for the longest. This too supports the notion of sex post spinal injury as a process of learning and discovery over time.

## **Superordinate Theme 2: Challenges to View of Self**

This theme is rather self-explanatory, focusing on how participants described different aspects of themselves and their relationship with the self. This theme encompasses *Sexual Esteem & Body Esteem, A Burden and Lowered Expectations*.

### *Sexual Esteem & Body Esteem*

Many of the participants described struggling with feeling unattractive after their injury.

*“One of the things you think is no one is going to love me and no one is going to find me attractive [ ] and that is why it’s so awful.” (Margaret: 4, 21)*

*“It was very much, well that is me done. There is literally no one that is going to find me attractive or want to date me.” (Margaret: 13, 22)*

*“Because I just thought is anyone going to find me attractive.” (Christina: 2, 13)*

These extracts convey the participants’ sadness and isolation and indicate their lowered sexual esteem here. For Alexandra, this feeling of unattractiveness was experienced in relation to her wheelchair;

*“Nobody will be interested now because you are disabled, you are ugly and you sit in an ugly chair.” (Alexandra: 10, 10)*

She expresses hatred towards her chair here and her words suggest self-loathing. Alexandra and Margaret describe their sense of body image in relation to their chair;

*“I think I probably end up getting a bit more self-conscious about what I am wearing and how it looks sitting down. You’re a whole different body shape to how you are stood up.”*

*(Margaret: 25, 1)*

*“When you are really high level, your body shape changes because of the paralysis and we all hate the, what we call our tetra tummy because we see that as being fat, so, and fat is kind of related to ugliness.” (Alexandra: 9, 16)*

Sophia and Miranda also reported feeling more conscious of the way that their bodies looked after their injury.

*“I almost felt like I was a scar with a person attached.” (Sophia: 31, 22)*

*“I don’t spasm but I am conscious of the way my legs look because they are really thin.”*

*(Miranda: 17, 8)*

The changes in body shape and appearance can be significant after spinal injury and the participants report how this affected their confidence and body esteem.

Christina described her sense of attractiveness in relation to the media and traditional representations of beauty;

*“This societal pressure and the magazines and what you are supposed to look like, I felt I did not quite fit in that, that I was supposed to be walking because that is what society sort of told me.” (Christina: 16, 11)*

*“And, you know, news readers, presenters, it is just, we are used to people being young, slim and beautiful I guess and I did feel for a while that people looked at me and I did not feel as attractive as I used to.” (Christina: 14, 3)*

In contrast, several participants also described developing confidence and feeling attractive again.

*“It sort of happened and I think, because I said to one of my partners “why, why would you choose me, who is sat down in a chair, over somebody else?”. He said “because you are beautiful, because you ooze confidence and because I could see that fun and you do not stop smiling”, so it’s about confidence, I am sure it’s about that, about holding yourself as well as you can and having that confidence about you.” (Miranda: 4, 9)*

*“I think being comfortable with themselves, because being confident and comfortable in your own skin, that is sexy, that is attractive, because I think most people to say they would rather go out with a girl who, yes, they are in a wheelchair but they are confident, you know, they enjoy life.” (Christina: 18, 5)*

Both Miranda and Christina also described ways in which they learned to establish this confidence;

*“I think often people have the perception, especially newly injured people [ ] that they are always going to have to wear trainers and track suits, and it’s not quite that extreme. So I always make sure I have either got a dress on, amazing underwear, that is the key, amazing*



*underwear (laughs) a dress and sitting straight and I have my high heels on, I have got three different footplates for my high heels.” (Miranda: 10, 8)*

*“[Going on dates] was [ ] very nerve-wracking but I knew it was something I had to do to increase my confidence and think, yes, I can be attractive and this person wants to spend time with me and why not, you know.” (Christina: 8, 12)*

Although the title *Sexual Esteem & Body Esteem* might seem a little clinical or removed from the participants’ words, these concepts capture the unattractiveness that the participants felt after their injury and how their confidence took time to develop again. This process did not only occur when the participants were in a relationship but instead seems to have been dependent on the participants themselves. They took steps to establish their own confidence again, taking risks by going on dates and putting effort into their own appearance.

### *A Burden*

Another theme that emerged among the participants was that they saw themselves as a burden to other people. They particularly spoke about feeling like a burden to a romantic partner in the context of dating.

*“The worst thing in the world is going somewhere and it’s completely inaccessible, you feel like a burden, you feel, you’re, it’s a problem.” (Christina: 3, 3)*

Christina uses very emphatic language here, which emphasises how awful this feeling is for her. She begins to say “you’re” a problem but catches herself and says “it’s” instead. This suggests that she is unconsciously distancing herself from these painful feelings and the idea

of herself as a burden.

Miranda describes needing reassurance from her partner when she was feeling like a burden to him.

*“I did not think about it at the time because I was trying initially to end, for the relationship to end with him because I thought, “Why would he want to be burdened with this?”, but then actually realisation kicked in and I realised that he did love me.” (Miranda: 5, 17)*

In addition, Alexandra describes feeling like a burden to any potential partner;

*“I thought that even he [ex-husband] couldn’t cope with a disabled wife, so why would anyone else cope with a disabled partner.” (Alexandra: 3, 7)*

Alexandra here recalls her husband leaving her for another woman soon after her injury and her belief that this was because he could not cope with her disability. Her belief that she is something to be coped with demonstrates her feeling that she is a burden to others. Similarly, Meredith describes herself as *“a big decision for them to take on” (Meredith: 15, 5)*, highlighting this idea that she also believes a partner would have to cope with her and be burdened by her disability. There is a sadness conveyed by these words and a sense of isolation, which seems to give insight into the participants’ sense of self-worth. Perhaps the process of adjusting to their spinal injury and the emotional, and psychological adjustment that this entails, has lead participants to anticipate similar experiences in their potential partners. Sophia relates an experience in line with this idea, describing her partner getting frustrated with her because of her limitations;

*“He [ ] got frustrated that he would like to be able to go somewhere or do something and then it was a case of either he goes and does it on his own or we do a modified version of it together.” (Sophia: 23, 5)*

Although she does not directly refer to herself as a burden, this encounter suggests she felt that her boyfriend was frustrated with her limited mobility, the very thing that other participants have described being afraid of; being seen as a burden by their partner.

### *Lowered Expectations*

Four of the six participants described lowering the expectations they had of a potential partner. They tended to describe this in terms of lowering their standards.

*“Some women probably go for a man that is not what they would really prefer but they would go with them because they do not have a choice anymore. They have to kind of lower their standards because now they are disabled and in wheelchair.” (Alexandra: 11, 2)*

Alexandra alludes here to loss of choice, implying that spinally injured women lower their standards because they have less men to choose from. This suggests that she feels that more ideal men would not be interested in her.

Margaret expands on this, comparing the men she has dated since her injury to the men she dated before;

*“So no dates with people that I actually want to date, if that makes sense, I think my dating history since my injury seems to be a string of guys that I would not have really dated before*

*the injury.” (Margaret: 6, 18)*

Margaret seems to be suggesting here that spinally injured women might not attract the same men that they would have done prior to injury. Meredith and Miranda explore this idea further, sharing experiences dating partners who might not be their usual type.

*“It was never going to work in the long run, but I would never normally have dated someone like that but it sort of made me, it was easier for me to date someone who was quite inactive because then the issues did not come up [ ] it was my first relationship after the spinal injury and I suppose it was a bit of a cop out as in like, I did not feel disabled when I was with him.” (Meredith: 4, 21)*

*“So, I was like, “Okay, well, because I am in a chair I should be able to accept this, this and this and this from this person”, and then a lot of my friends were saying “well, I can't see you with him, he's just not your type”.” (Miranda: 5, 23)*

There is a sense from these accounts that Meredith and Miranda were ‘settling’; accepting that they were not capable of finding men with whom they were more compatible.

On face value, these comments might seem unkind or uncaring towards the potential partners that the participants are describing, but at a deeper level this theme seems to be closely linked to the idea of low self-esteem. Just as with the previous theme, *A Burden*, these words seem to be conveying insight into the participants’ sense of self-worth. The participants’ words also indicate that they are comparing aspects of their dating life and romantic potential after their injury to before their injury and this suggests that the acquired nature of spinal injury might

be important here. I will discuss this further in the Discussion chapter.

### **Superordinate Theme 3: Perceived Societal Attitudes**

This theme explores the impact of societal norms on the experience of dating with an SCI.

Aspects of this theme are *Expectations from Others*, *The Role of Gender* and *Ignorance: Moving Towards Understanding*.

#### *Expectations from Others*

Many of the participants described their experiences of societal expectations and the impact that these have on them. First, these expectations can be described as being defined by disability.

Margaret and Christina describe feeling that society does not have any expectations of disabled people to have romantic relationships.

*“Yeah, I think there is an expectation for me not to date, but that would be like a false one obviously. Yes, I do not think society really expects a huge amount from me in that respect.”*  
(Margaret: 32, 2)

*“Most people would ask me about work, not meeting someone. To be honest probably society [ ] they have such low expectations of someone in a chair. They probably do not think that you will marry or date.”* (Christina: 12, 22)

Margaret and Christina expound on this, describing their experiences of other people not regarding spinally injured people as sexually active or attractive.

*“A lot of people [ ] probably think; can you have sex even if you are in a wheelchair? Which seems ridiculous, but people just assume disabled people don’t have any intimacy or sexual relations with anyone, which is very sad because it’s almost like you are invisible in society.”*

*(Christina: 12, 2)*

*“Yes, maybe that’s a thing where people do not expect a wheelchair user to necessarily be able to give that same amount of affection that an able-bodied person might, because there is a wheelchair that seems to get in the way of intimacy or getting close to each other.”*

*(Margaret: 31, 8)*

*“If you are in a chair you are not supposed to have [attractiveness] or nobody is supposed to fancy you because that’s not what society expects of you.” (Christina: 15, 3)*

Secondly, perceived expectations from others were described in the context of imperfection.

*“Some of my carers told me that I should forget about dating and relationships because I wouldn’t be able to give my partner anything.” (Alexandra: 2, 22)*

Alexandra’s words here seem to convey a sense of something lacking, the idea that she is missing something because she is in a wheelchair, namely ‘able-bodiedness’. This seems to link to the previous theme, *A Burden*, and suggests a belief that a spinally injured partner would be more of a burden than an asset. This idea of imperfection is further explicated by Sophia, Christina and Margaret.

*“As I say, it’s the whole thing of being used, being damaged goods.” (Sophia: 23, 8)*

*“I mean someone has said to me you’re too good looking to be in a wheelchair [ ] It is like are people in wheelchairs supposed to be unattractive? [ ] I am not saying everybody believes that but I do think there is a little bit of truth that some people do feel that, you know, it’s not the model of perfection.” (Christina: 14, 7)*

*“Guys here know that there are so many other options, so, why the fuck would they go for someone who is not what they see as perfect? Which, is hard to accept [ ] It’s because in the modern world there are so many options. They know that if that one is not absolutely perfect there is going to be like ten more girls around the corner that are on an app that they can just meet up with like that.” (Margaret: 12, 7)*

Alexandra explored the theme of imperfection by comparing herself to non-disabled women;

*“It’s kind of you know it is kind of out of reach, sort of thing, because you will never be able to be able-bodied again. Then you tell yourself that that is why you will never be able to date anybody or have a serious relationship with anybody because they will always choose the able-bodied females.” (Alexandra: 26, 24)*

The two categories of defined by disability and imperfection give some indication of the ways in which spinally injured people are talked about within society and the negative stereotypes held against spinally injured people. This seems related to aspects of discursive theory, which explore the regulation of certain groups through societal discourse. The discourses of defined by disability and imperfection seem to position the participants as undesirable people to date. I will discuss this further in the Discussion chapter.

### *The Role of Gender*

All of the participants discussed perceived gender differences concerning aspects of dating with an SCI and most felt that dating was easier for spinally injured men.

*“I think it could be different with males and females about disability. I think it’s easier for disabled men to find partners than females I think.” (Alexandra: 8, 5)*

It is important to note that this theme relates to the experiences of spinally injured women, as all members of the participant group were female. This will be explored in greater depth in the Discussion chapter.

Alexandra goes on to describe how she feels men and women differ in their behaviour, after spinal injury.

*“Men in wheelchairs I find are a lot bolder in approaching able-bodied females. They are quite sort of cheeky and they kind of win them over with, I suppose, the cheekiness and charm and their disability. So there is a difference in how men and women behave in dating after a spinal injury. Definitely men are bolder, I think, well, the ones I have come across anyway. But women are more, they shy away from it and it is a lot to do with self-esteem [ ] females are a bit more cautious.” (Alexandra: 27, 10)*

Alexandra suggests that men have more confidence, or regain more confidence, post-injury than women and that this dictates how they act with potential partners. This might suggest that women are more cautious or reserved because they struggle more with self-esteem post-injury than men. I am also left wondering whether men being more forward than women in



approaching someone they find attractive is not only common to the spinally injured population, but a difference between the genders that might be observed in the wider population. I will explore this further in the Discussion section.

Alexandra also alludes to traditional notions of gender roles and the stereotype of women as the caring sex, something that is a theme for other participants as well.

*“I think there is something in women that makes them more nurturing and more like “oh, he is in a wheelchair, I can look after him” and what not.” (Margaret: 14, 20)*

*“Yeah, it’s easier for blokes to find women because women are more caring and accepting. They sort of look for different qualities, especially in my age bracket as well.” (Meredith: 25, 3)*

Meredith seems to suggest here that women in their early thirties might be looking for long term partners to settle down with and that this might make them less likely to reject someone on the basis of their injury. She alludes to women looking for different qualities, implying that women are less motivated by appearance than men.

Meredith recalls this view of men being less receptive to dating spinally injured women as something she was told very soon after her injury:

*“He was like “yeah, well, you know blokes, yes, well, we can pick up women really easily because women are really nice but, yes, blokes, yeah, they’ve got not sympathy, yeah, women do not get blokes if they have got an injury”, and I was like “mate, I am a girl” and he went,*

*“whoops” (laughs) so my immediate expectation was that it was going to be harder for me as a woman, for a bloke to be understanding basically.” (Meredith: 25, 10)*

The implication here is that men are not accepting of a potential partner in a wheelchair.

Alexandra suggests that this might be because men are *“a bit more afraid of disability than females.” (Alexandra: 7, 21)*

Despite all of the participants being female, several participants also discussed how spinal injury might contradict traditional male gender roles.

*“Men who are in a chair may feel emasculated, that they feel they need to be, this is all very old fashioned, the protector and the bread winner and the one who does the handy, the DIY stuff and you know, picks the woman up.” (Christina: 16, 5)*

*“I suppose we still live in a society that does have sort of frustratingly traditional ideas about a woman's role and a man's role, so there probably are people [ ] that have very distinct views upon, you know, the man's role, the woman's role and very much the man, head of the household, the provider, the protector and I can see how people like that would have much more of a problem if it was the man that was in the wheelchair.” (Sophia: 24, 13)*

Both Christina and Sophia, having expressed their experience of dating being more difficult for women, attempted to look at the other aspects of gender roles and imagine how it might be difficult for spinally injured men to conform to these traditional ideas of masculinity. This might be something that spinally injured men struggle with, particularly in the area of dating. However, while it seems likely that spinally injured men will not meet this very traditional

idea of a man's role in society and the family unit, as Christina says, this is a very old fashioned view. In recent years, the traditional ideas of masculinity have been challenged and less dominant male traits seem to be more desirable. Indeed, Miranda expounds on this idea, suggesting a different reason for non-disabled women being drawn to spinally injured men.

*“Sometimes I talk to people who are dating paralysed men and what I find really interesting is that they have had some sort of abuse or something happen in the past and they feel they are safe with their paralysed man. They are safe because they are not going to get thrown around or jumped on when they don't want to”. (Miranda: 37, 6)*

Miranda's experience seems to be that many women dating spinally injured men have experienced abusive relationships in the past and that they might consider their current relationship safer. Despite this, Miranda was the only participant who felt that dating was not necessarily easier for men than for women.

*“I do not feel that I have come across that [ ] It's about how we feel about ourselves isn't it? If we are very traditional we might feel that we have lost our femininity or our manhood [ ] I think as a woman I probably get away with more because I can get away with all sorts of, “Oh, can you just”, flutter my eyelids and get someone to change a puncture.” (Miranda: 33, 12)*

Therefore, while most participants felt that spinally injured men are more successful at dating several different possible reasons for this were explored. Perhaps more important, is the idea of traditional gender roles and the participants' awareness both of their injury changing how

they conform to these roles and how non-disabled men and women might respond to dating someone who is spinally injured.

### *Ignorance: Moving Towards Understanding*

This theme represents the lack of awareness about spinal injury among the general population that the participants have experienced. Despite this, they also describe how society might be moving forward, to a place of greater understanding and tolerance.

*“It’s fear of the unknown, people don’t know what it involves, especially if they don’t know the person very well [ ] and they are too afraid to actually ask [ ] even, I guess some far-fetched things as “Oh, maybe she won’t live as long”, it sounds like a really weird thing to say but in the long term, if you are looking at a long-term partner, you know, is she going to be ill all the time? Am I going to have to take care of her? That is another thing, am I going to have to take care of her?” (Margaret: 9, 11)*

Margaret here relates some of the fears that the men she dates might have and their uncertainty about how to approach those questions with her. Her list of rhetorical questions and repetition at the end of this extract highlight this idea of ignorance among the men she meets.

Christina expands on this:

*“But if people don’t know, not many people know about spinal injury and what it entails, it’s not just not walking, it’s bladder, bowels, skin, [ ] infections, you know. If someone does not know all of that, I didn’t even know before I was injured, I have had to learn about it.”*

*(Christina: 4, 1)*

Christina highlights the amount that she has had to learn since her injury and seems to view this lack of understanding surrounding spinal injury as something very widespread. She admits that she herself was ignorant about spinal injury.

Sophia describes an experience she had of a friend's ignorance:

*"I went to an opera with a friend of mine and, you know, she sort of made the comment that, oh, you know, every single interval I was getting up to, you know, to go to the loo and she was teasing me a little bit about that and I was just a bit sort of cross. I just said, "Well, yeah, my bladder does not work properly now because of the spinal cord injury". She was quite sort of, "Oh, okay", obviously had not even thought anything about it, she knew sort of about the mobility side of things and the pain side of things. She sort of apologised after and said that it genuinely never occurred to her that other things are also affected by the spinal cord injury and I think that is it."* (Sophia: 4, 12)

Meredith and Sophia also relate this ignorance back to their invisible disability as walkers;

*"I think most people, I tell them and they are like, "well, you look fine" (laughs) I am like, yes, and then like the more and more we talk, the more they realise how massively it affects my life. But I think most people do not actually realise, you know, because I can, I look very normal, like I am moving around. I do not have a completely flaccid hand".* (Meredith: 6, 12)

*“[Another SCI patient] just sort of went, “that’s nonsense. If you had a spinal injury, you cannot still walk”, so we were kind of getting into a little bit of a debate in the corridor sort of about my right to go through [the spinal injury ward] to get to physio. So that is it, I mean, if other spinal cord injury patients are not even aware that we exist, you know...”.* (Sophia: 9, 7)

Both Meredith and Sophia use emphatic language to highlight their sense of marginalisation and being misunderstood and dismissed. In contrast with this, Meredith describes how it feels to be on a date with someone who does understand what spinal injury entails;

*“As soon as someone mentions that they have some understanding of it, I am just like, oh thank God that they know. That actually is really a positive experience for me when they express an understanding of someone else they know who has it or something.”* (Meredith: 16, 12)

Another facet of this theme of ignorance is the idea of representation. When describing the ignorance Sophia has experienced from people in general she explores a potential reason for this:

*“I think, you know, for some people it might be the first time they have met someone with a spinal injury because, you know, people I think in schools maybe, it is not something that children come across.”* (Sophia: 13, 1)

This is expounded on further by Christina;

*“I get a lot of looks from children because they don’t know that staring is, you know, in society it is seen as rude and they ask questions, like they say to their mum or dad, “Why is she in a chair?”, and actually I don’t discourage that because they are only learning. But some parents kind of look so embarrassed about it and pull their child away and that child then gets a message they are not supposed to say that, they’re not supposed to interact. It is learnt from a very young age.” (Christina: 19, 18)*

She says earlier in her interview that she also feels that there is a lack of representation of spinally injured people in the media;

*“I did not see anybody in a chair, you know, in the media or in fashion, even in soaps it was all very depressing story lines and their disability was the focus of the story line. So I did not see anyone who represented me.” (Christina: 16, 11)*

This suggests that spinally injured people are being marginalised within society.

Margaret describes how the disability that is represented on TV might be not be presented in a helpful context;

*“I do not know whether shows like the Undateables help or hinder. I do watch it and quite enjoy it, but then I am like, I am not sure whether I should, like, I am never sure whether it is helping or not, because it is showing that disabled people date and are perfectly capable of dating. I think the problem is that they tend to go more for people with intellectual disabilities and you are never quite sure whether that is the same thing because, I do not know, I mean you wonder whether people are laughing with or at.” (Margaret: 27, 8)*

Margaret suggests here that this type of representation is increasing ignorance, by grouping physical and mental disabilities together. There is also a sense that this is commercialising disability and using disability as entertainment.

Some participants also described examples of good or improving representation of disabled people in society;

*“I think you know, the Paralympics has changed the attitude of a lot of people and you know lots of programmes on TV about disability has kind of changed the outlook on, you know, disability, that just cos you are disabled it does not mean that you are kind of useless”.*

*(Alexandra: 25, 1)*

*“I found myself watching something on CBeebies over Christmas with a younger cousin, which was actually quite enjoyable. I was quite surprised, it was like a Nutcracker thing, but there were people with disabilities all over the shop. Like one girl did not have an arm, there was, The Queen of the Rats or something, was a wheelchair user but she was really pretty and she was like a princess [ ] Kids are really open to disability. They do not give a shit. They will, they are so open minded, they are like sponges. They will learn what you teach them so if you teach them that being in a wheelchair is a completely normal part of life they will go with that. That exposure as well, if someone in a wheelchair is automatically put into a special school then they are not going to get that exposure. So inclusivity is the way forward.”*

*(Margaret: 31, 24)*



#### **Superordinate Theme 4: Dating Concerns**

This theme title seems quite general but is intended to group together specific dating concerns that have been related by the majority of the participants. This includes; *The Same Concerns vs New Ones*, *Disclosure* and *Control & Vulnerability*.

##### *The Same Concerns vs New Ones*

Four of the six participants related how some of the concerns they have before a date are specific to their injury but also how many of their concerns are the same as those they experienced dating before their injury and indeed which are faced by non-disabled women as well.

Alexandra describes these two aspects of getting ready for a date;

*“Getting ready was kind of like I suppose like you would if you were able-bodied, you know, you are dressing up and making yourself looking half decent or whatever, but the other part I also thought about, “Oh, what do I do when I get there?”, because obviously it is a date, I do not want my carers to be sat either side of me, you know, during my conversations and everything.” (Alexandra: 14, 7)*

Sophia goes further, suggesting that her doubts before a date were not to do with her injury;

*“I suppose I am still probably more worried about the things that I would have been worried about beforehand, about sort of them liking me for who I am and sort of all of that.” (Sophia: 27, 14)*

Margaret describes how modern dating methods raise issues for everyone, not just spinally injured people;

*“Yes, I think it’s the dating app game that I think makes life difficult these days, because modern day is so focused on that and especially in London, as like a sort of millennial in London, it is so bloody difficult. It’s difficult for everyone. Like, all my able-bodied friends that are single also find it difficult.” (Margaret: 7, 10)*

*“I have got my one [non-disabled] single friend who [is] lovely, 26-year-old kind of blonde, blue eyes, not ugly, she does not have a problem getting a date, but like even she has that same issue of like, “oh, I had a lovely time but now he has just not contacted me” and “oh, we went out a couple of times but now he is just ignoring me”. It is because in the modern world there are so many options.” (Margaret: 11, 24)*

Margaret’s frustration with these dating concerns is clear. She feels that these issues are common to all millennials dating using apps, and implies that these would still be issues for her if she were non-disabled. Christina also recounts how standards of beauty raise self-esteem issues for all women;

*“I think all women feel, to some extent, a little bit inadequate which is terrible, you know, actually women have themselves to blame at times, because if you look at [ ] magazines and it’s, we’re obsessed, I am obsessed, you know, about diet, what we look like, oh, look she has got cellulite, you know, [magazines] circle it [in photos]. Someone in a wheelchair does not actually fit into that model of perfection but then I think a lot women feel this anyway, it’s a pressure that we put on ourselves.” (Christina: 13, 2)*

Although there are many issues within the context of dating that are faced by spinally injured people, the participants make the point that many of the dating concerns they experience are felt by the wider population. This highlights the ways in which dating might not be different for spinally injured compared to non-disabled individuals.

### *Disclosure*

This theme refers to the participants' experiences of telling potential partners about their spinal injury. This theme was prevalent among all of the interviews and there were different aspects to it.

First, disclosure was discussed in the context of online dating or dating apps. Most of the participants had experienced the dilemma of whether to share their disability on their profiles.

*“It’s almost like a job interview and having to disclose a disability, it’s kind of like when do I disclose that? Do I put it in my pictures? Do I mention it in my profile? Or do I just not mention it and wait until I meet the guy? You just don’t know.” (Margaret: 7, 19)*

Margaret's use of rhetorical questions really highlights her uncertainty here. Despite this, most of the participants who used online dating and dating apps reported that they had decided to disclose their disability.

*“I thought it would be better to be honest about my situation than pretend to be, like, able-bodied and then they kind of get a shock when they meet you, so I thought it would be better to be honest.” (Alexandra: 7, 17)*

Alexandra's use of the word "pretend" suggests that she felt that not disclosing would have been deceitful in some way. She also refers to her fears about the reaction from her date if she did not tell them about her injury beforehand. Christina also describes her fear about the reaction from her dating partners as her reason for disclosing:

*"So I just thought that I need to be able to be honest with that person and it made me more comfortable doing that, because [ ] if you think about what the alternative is, not saying anything and turning up, actually it could cause a problem [ ] I did not want the awkwardness. I would rather be rejected by someone not even emailing me because of the reason that I am in a wheelchair, than turning up and then finding out, oh, this is an issue. So it was self-preservation."* (Christina: 5, 6)

This last word, "self-preservation", feels very strong and really emphasises Christina's belief that disclosing her SCI will benefit her in the long run. She touches on the idea that some potential dates might not contact her because she has disclosed her disability. While many other participants felt that being open early on about their SCI would be better in the long run, they also feared that this would prevent people from getting in contact or 'swiping right'.

*"In my profile I actually wrote, that I have carers and am severely disabled, but I don't go into like real detail you know, what I could and what I couldn't do and I think that put a lot of people off because they can't cope with the disability".* (Alexandra: 4, 14)

*"It is difficult to know how much to say without it being a bit sort of, overwhelming and sounding, I suppose, like you are damaged goods in a way."* (Sophia: 22, 1)

Sophia's last phrase again feels very strong and emotive and seems to reflect the hurt and

rejection she fears from the reactions of others. This idea of rejection after disclosure is something which Margaret also describes as she recounts a particular experience on a dating app:

*“It did happen to me once where I experimented with taking the picture of my wheelchair out and got chatting to a guy, lovely, and then he asked me about surfing and asked me if I had ever been surfing. I said “No”, and he asked, “Why not?”, so I said, “Oh, have you not seen all of my pictures?” and I quickly inserted the one of the wheelchair, and lo and behold he stopped talking to me right away.” (Margaret: 26, 20)*

Meredith was the only participant who uses dating apps who had come to the decision not to disclose her injury before a date.

*“The problem is because I advertise myself, I put old pictures up of me doing things that I can't do now. I think that is the thing and then when I say then on a date that I can't do them I think that is where their expectations might be different, because I feel like somehow I have been fraudulent but then if I did not do that I would not be expressing who I was as a person. But that person picked me because they were like, “Oh, well, I like doing that too”, but then I have to disclose that I can't do it. So, yes, it is a bit of an odd one but if I did not, I would just have pictures of me sitting down or standing places and I am like, well, that is not me.” (Meredith: 22, 18)*

Meredith decided to put up pictures of herself doing activities that she can no longer do but which she feels reflect her personality. She seems to be struggling here between dating as her old self and dating as her post-injury self. She expresses her fear that to put up these pictures

might be dishonest or lead to false expectations in her partners, however she feels that these pictures are representative of her identity and this seems to be a difficult dilemma for her. This sense of not wanting to be defined by disability is common to other participants within the context of disclosure.

Margaret describes her decision to let potential dates know in advance that she is a wheelchair user but seemed determined for this not to be the defining thing about her.

*“I personally have a picture of me in my wheelchair but, you know, it is also one with like a nice background, a mountain or something so I am very careful to be like, “Yeah, I am in a wheelchair but look at all the amazing stuff that I do as well”.” (Margaret: 7, 24)*

While she does disclose her SCI she also gives an indication of her active and adventurous life. This seems to indicate that she has found a middle ground between the other participants.

Another facet of this theme is the idea of visible and invisible disability. Christina, as a wheelchair user, describes how she might not disclose her disability if it were something she could initially conceal.

*“It should not make a difference but we know that it does. I mean, would I mention if I had a scar down my face? Would I mention if I had alopecia? I do not know. I think, sometimes a picture can say a thousand words, just have it there and it is done. Would I want to know if that person had one leg, for example? You know, I guess my disability is so visible that people think it will be strange if you don’t mention it but if someone had alopecia and they had a wig*

*on they would not necessarily get into it because you cannot see it immediately.” (Christina: 5, 9)*

This concept of visible and invisible disability is relevant for participants in different ways, depending on their level of injury. Christina as a wheelchair user feels she has to disclose this fact before a date, while in contrast, Sophia who is a walker, finds her invisible disability hard to explain on a date.

*“In some ways it would almost be easier if I think [ ] if I was in a wheelchair because then it is obvious that there is kind of, it is something sort of wrong, whereas being a walker, it is, I do not know, it is just unclear as to exactly what is sort of wrong.” (Sophia: 8, 12)*

Finally, participants also talked about disclosure at a deeper level than informing a date that they have an SCI. They described sharing information about their daily life and how this is affected by their injury.

*“How I am going to tell them about bladder and bowels? How am I going to tell them about how I move? How am I going to tell them about how I transfer and all of those extra things?” (Miranda: 9, 12)*

Miranda’s uncertainty is clear here. She seems unsure about how to approach these questions with a potential partner and how she wants to answer them. Meredith described the initial disclosure of her SCI on a date, leading on to deeper level questions.

*“They say, “so, what are you doing?” I say, “I do occupational therapy”, “what made you*

*study that?”, “oh, well, I broke my neck”. So eventually I have to give like a history of it.”*

*(Meredith: 12, 15)*

Meredith also described the emotional impact that this can have on her.

*“You are constantly having all these intense personal interviews. You are like, “I am asking that question myself” or “I don't have an answer for that”. It sort of feels a bit weird that you do not have an answer for it, you sort of feel like you are not ready yet. Yes, and it sort of brings a lot of emotion. In a way it's kind of like mini counselling sessions, it is quite good. Lots of mini counselling with alcohol, it's little dribs and drabs with strangers.” (Meredith: 29, 14)*

Meredith seems to experience sharing this personal information on dates as quite overwhelming. As she is the participant who has been injured for the shortest time, it makes sense that she would feel uncertain about many questions she might be asked and not feel that she has the answers yet. Her use of the word strangers here seems to highlight her vulnerability and how exposing it might be to have to disclose this kind of personal information on a date.

Disclosure seems to be a common issue, unique to the field of dating and disability and the participants all relate to this theme in different ways.

### *Control & Vulnerability*

The final theme refers to experiences of control and vulnerability that have been described by participants, within the context of dating.



*“Sometimes the attention you get from people will be the people that actually care, but there’s just a few that you’ve got to be careful with on the control side of issues.” (Miranda: 26, 21)*

Miranda describes how some of the men that express an interest in her might be interested in the perceived power dynamic of dating a disabled woman. Margaret expounds on this, relating two experiences of men her wheelchair user friends were dating;

*“One of my best friend’s boyfriend [ ] he controls what she eats and he does her hair and it’s just a bit of an odd dynamic. I know there are other people as well, they just quite like being in control of their wheelchair user girlfriend.” (Margaret: 15, 9)*

*“He was violent, again really controlling and it adds a sense of like fear for me dating because I am like, I do not want to end up with someone who is going to be dating me specifically because he thinks he can control me. It is quite scary.” (Margaret: 16, 14)*

These experiences of witnessing her friends’ controlling relationships seem to have greatly affected Margaret, causing her to be more cautious when it comes to meeting new potential partners. She goes on to discuss this further;

*“My disability is a massive vulnerability. I can’t physically run away from people if I need to or whatever, so I feel like people could exploit that. Mentally I am quite strong willed and will argue my point [ ] there are some things I physically can’t do and that is run away from a punch or something.” (Margaret: 17, 1)*

Margaret conveys this contrast between her mental strength and abilities and her physical abilities. Her vulnerability in certain situations is something which she is very aware of.

Miranda also alludes to this, describing the safety measures she put in place before a date;

*“I did not know this person for a start so I wanted to meet in an open space. I also had an appointment to go to so I had also made myself safe in that I had to leave at a certain time.”*

*(Miranda: 11, 9)*

Alexandra also explored another facet of this theme, describing her experiences of the fetish group ‘Devotees’. This is a group of mostly men, who are particularly attracted to disabled women in wheelchairs. Alexandra came across members of this group while she was talking to people who she thought were also spinally injured on an online forum.

*“Later on I found out that they are not actually girls in wheelchairs, they are guys who are pretending to be girls who are disabled to make contact. There is a group of guys or people who are called devotees and they are attracted to people who have some sort of disability.”*

*(Alexandra: 3, 22)*

She recalls asking members of Devotees for the reasons behind their fetish;

*“Some of them think they are born like that and some of them think it is because of something that happened in their childhood, maybe they saw somebody who was disabled and vulnerable and how they got cared for or the attention they got, that kind of sparked something off but none of them can explain why they are like they are.”* *(Alexandra: 4, 6)*

Although Alexandra does not specifically refer to control, the deceptive nature of the way in which members of this group made contact with her suggests an element of duplicity and her sense of these men being attracted to the vulnerability of a disabled woman suggests that it is this control that they are seeking.

While participants make it clear that they are not suggesting that everyone who expresses interest in them is drawn to this element of control, they describe being mindful of their vulnerability and taking steps to ensure their safety.

In summary, these four superordinate themes capture the various aspects of participants' experiences of dating with a spinal injury. The process orientated nature of the experience is conveyed clearly by the first superordinate theme, **Dating as a Journey**. In addition, other aspects of the participants experiences were also described in terms of process, such as developing confidence. The impact of SCI on the self is highlighted by the theme, **Challenges to View of Self**, and the affect that this had on their romantic life is explored. The theme, **Perceived Societal Attitudes**, gives insight into the participants' experience of others. Their experience of societal prejudices and highlights the recent changes in societal attitudes, conveying a sense of hope and direction for the future. The final theme, **Dating Concerns**, explores the participants' experiences of concerns that they faced when dating before their injury in comparison with new concerns that they face post-injury. This highlights both the ways in which many dating issues are common to all single people, regardless of disability, and also the aspects of dating which are particularly problematic for spinally injured single people such as disclosure and control. There are areas of overlap between these main themes and these will be explored further in the Discussion chapter.

## **Chapter 4**

### **Discussion**

In this chapter, the findings of the analysis are summarised and discussed in relation to the existing body of literature, providing the opportunity to contextualise the current study and explore links between these findings and existing theory and research. While this is important in understanding the significance of the current research, it might be argued that exploring the findings in this way encourages researcher to select aspects of their findings which reinforce previous studies. This has the effect of sustaining certain theoretical constructs and reducing the opportunity for new meaning to be derived from the data. To obviate this, this section will also explore how the findings might differ from the body of literature, incorporating my own reflexivity and interpretation of these findings. In addition, I will also critically evaluate this study, identifying any limitations and the possible future direction of research in this area.

#### **Overview of Findings**

During the interviews, the participants engaged in a process of self-reflection and exploration in order to ascertain and understand their experiences of dating with an SCI. My analysis revealed that they were experiencing dating as a process which reflected their physical and psychological recovery after their injury. While recovering in hospital, after sustaining their spinal injury, dating and romantic relationships seemed to be experience as just one concern or fear that the participants felt for the future, as just one of several unknowns at this time.

The participants reflected on the time after they left hospital and described having to learn how to function in the world again. At this time, dating was not seen as a priority for the participants and seemed too out of reach or too difficult to contemplate, given that they were

trying to navigate everyday life. It was only later that the participants could contemplate their romantic life. They described the initial loss, of their mobility, future hopes and expectations and their old life. Some described their initial sexual experiences in terms of loss, believing that they would no longer experience a satisfying sex life. In line with this was the initial loss of self-esteem, particularly sexual and body esteem, as the participants struggled to adjust to the changes in their body and appearance. Participants struggled with seeing themselves as a burden to others and with lowered expectations for themselves and their romantic partners. This seemed to reflect their own damaged self-worth post-injury.

Participants felt that the way in which they were experiencing aspects of dating evolved over time. They moved from 'striving' to cope with everyday tasks to 'thriving' as they adjusted to their new circumstances. They experienced their feelings of loss moving towards greater acceptance and hopefulness as they moved through the process of grieving. They also experienced an increase in their self-esteem and confidence.

In addition to this concept of the process, the participants also recounted their perceptions of societal attitudes towards themselves in a dating context. They explored their experiences of being seen as imperfect, or defined by their disability, by potential romantic partners and of the ignorance, both of those close to them and of the general public. However, they also described this ignorance within society as a fluid concept which most of the participants felt might be moving towards greater understanding. Most seemed hopeful that their experiences of other people's ignorance might be changing.

The participants also explored the role of gender. All of the women perceived dating as more difficult for them than it was for their male counterparts. In addition, they experienced the

effects of traditional gender roles and stereotypes influencing their dating and romantic lives. Finally, the participants also recounted particular concerns related to dating, and the comparison between the aspects of dating they had worried about before their injury and new concerns which they had now. These included the dilemma of disclosure, which the participants experienced as a difficult decision with many implications. Some participants also recounted their fears regarding their vulnerability to controlling relationships and reflected on their experiences of safety within the context of dating.

These findings from the participant interviews were distilled into several themes, as presented in the Analysis chapter. These key themes were categorised within four superordinate themes; Dating as a Journey, Challenges to View of Self, Perceived Societal Attitudes, Dating Concerns. The key findings which emerged from these themes are explored in more detail below and this chapter will also explore the overarching links between them.

### **Process Orientated Nature of the Experience**

A central theme which emerged from all of the participants' accounts was the concept of process. Several of the key themes that emerged from the analysis were experienced by the participants as a process over time. This was captured by the superordinate theme **Dating as a Journey**, which included *Striving vs Thriving: The Process of Coping, Loss & Grieving*, and *Sex & Intimacy*. The subordinate theme of *Sexual Esteem & Body Esteem* also seemed to be experienced as a fluid and developing process, from initially feeling unattractive to experiencing developing confidence.

The understanding that dating with an SCI is experienced as a process has not been previously examined in the extant literature. Although it is understood within the field of physical and

psychological rehabilitation that the process of recovery post spinal injury will take time, this understanding has not been expanded to the context of dating within previous research. This is not necessarily a surprising finding; it may be that some professionals would suggest that the idea of process is understood in early rehabilitation post spinal injury and therefore would be implicitly understood for experiences later. The reason for the paucity of previous research in this area is perhaps that dating does not relate to immediate physical or medical wellbeing and is therefore not regarded as a priority by healthcare professionals. It is also likely that, as the current findings indicate, dating usually becomes an issue for spinally injured individuals once they have left hospital and are no longer in frequent contact with most rehabilitation professionals.

### *The Process of Adjustment*

The participants seem to describe several aspects of their experience as process orientated. Perhaps what the participants are describing here is a process of adjustment; the process of adjusting post-injury, in various different aspects of their lives. As this adjustment is all encompassing, it follows that the current findings indicate that process is relevant to various aspects of their experience.

It is important to emphasise here that the finding that the experience of dating with an SCI is process orientated, does not indicate that this process has a clear endpoint. Although the participants describe significant changes in their experiences and expectations over time, they do not suggest that this process is ended or fully achieved at a certain point.

Adjustment has been defined in the literature as “a response to a change in the environment that allows an organism to become more suitably adapted to that change” (Sharpe & Curran,

2006). While this definition of adjustment implies that adjustment occurs over time, it suggests an ‘outcome’ of this process. Indeed, although adjustment to physical injury or disability has recently begun to be explored in the literature, researchers frequently refer to a desirable final state or end point (Brennan, 2001). This is likely to be because, within a medical context, an understanding of a desirable end state means that it is possible to measure outcome and progress.

More recently, Parker and Yau (2012) explored sexual adjustment in particular post spinal injury. They defined sexual adjustment as a “social, psychological, and physical adaptation to sexual limitations or changes in sexual functioning, overall quality of life and attitudes toward sexuality”. I consider this definition to be very helpful in this context and believe it can be applied more generally to an understanding of adjustment to spinal injury in all aspects of life, perhaps paraphrased; “social, psychological, and physical adaptation to the limitations or changes in functioning, overall quality of life and attitudes”.

Parker and Yau (2012) also suggested that adjustment is an ongoing or cyclical process, rather than a linear one with a clear end point. This supports the current findings which suggest that the process of adjustment after spinal injury is best understood as an ever changing process of adaptation and growth. Before exploring the experience of process in more detail, it is important to clarify the nature of adjustment in relation to the current research.

#### *Adjustment, not Adjustment Disorder*

It is important to note here that adjustment in the context of the current research is understood as a typical psychological process that occurs in response to a significant life change or bereavement (Folkman, 2013). When this process is prolonged or damaging, it is known as an



Adjustment Disorder. However, there is a fine line between recognising the psychological impact of significant life events and pathologising normal or expected adjustment reactions.

This contradiction has been a topic of contention recently, within the context of grief and bereavement because the current version of the DSM (DSM-V, American Psychiatric Association, 2013) removed the ‘bereavement exclusion’ from the diagnosis of Major Depressive Disorder (MDD) and the new version of the ICD to be released next year (World Health Organisation, 2015) is set to do the same. I have already expressed my understanding of spinal injury as a form of bereavement and will explore this further later in this chapter. However, even those opposed to this understanding can appreciate the similar difficulty with the definition of adjustment disorder and its application to the context of spinal injury.

The ICD-11, which is currently being compiled, describes adjustment disorder as “a maladaptive reaction to identifiable psychosocial stressor(s) or life change(s) characterized by preoccupation with the stressor and failure to adapt. The failure to adapt may be manifested by a range of symptoms that interfere with everyday functioning ... in order to be diagnosed, adjustment disorder must be associated with significant distress or significant impairment in personal, family, social, educational, occupational or other important areas of functioning” (World Health Organisation, 2015). This definition of adjustment disorder seems to identify many of the characteristics of adjusting to spinal injury being experienced by the participants in the current study. The participants describe “significant distress” post-injury and “impairment in ... important areas of functioning”. The main difficulty with this definition is that it is unclear as to what constitutes a “failure to adapt”. This seems to suggest that there should be a recognized timeline of recovery and psychological rehabilitation post-injury.

The DSM-V offer little more guidance. The main criteria for adjustment disorder are stated as “the development of emotional or behavioral symptoms in response to an identifiable stressor(s) occurring within 3 months of the onset of the stressor(s)” and “these symptoms or behaviors are clinically significant, as evidenced by one or both of the following: Marked distress that is out of proportion to the severity or intensity of the stressor, taking into account the external context and the cultural factors that might influence symptom severity and presentation” (American Psychiatric Association, 2013). The primary difficulty with this definition is the lack of clarity regarding what constitutes distress that is “out of proportion”.

While there are some spinally injured patients who experience pervasive depression and distress as a result of their injury, attempting to apply guidelines to distress and adjustment seems to be a particularly complex and sensitive issue. The period of distress experienced by the current participants constitutes a normal and expected reaction to the devastating impact of spinal injury.

The process of adjustment that is described by the participants in the current study, moving to a more positive and accepting experiential understanding, suggests that there is no “failure to adapt” and may indicate that a discussion of the concept of adjustment disorder is not relevant in this context. However, I believe that a discussion regarding the usefulness and value of these criteria and, more importantly, the clarification of my use of this terminology is essential here.

### *The Process of Coping*

The subordinate theme, *Striving vs Thriving: The Process of Coping*, perhaps exemplifies the notion of experiential process most clearly.

Previous research has suggested that the ways in which people cope with life stressors can influence their psychological and physical health. The extant literature in the field of coping has led to two different perspectives (Pennebaker, Colder & Sharp, 1990). The first suggests that individuals use their own specific personality characteristics to cope with trauma. This means that each individual would be expected to cope differently with a particular stressor or life event, depending on their own personality traits. This implies that there is no 'normal' way to cope following a stressor or traumatic event, such as sustaining a spinal injury. Meanwhile, the second approach suggests that people progress through a predictable series of coping stages and that there are predictable changes in coping over time (Pennebaker, Colder & Sharp, 1990). This perspective implies that there is a 'normal' way to cope with a traumatic event and suggests that something is 'wrong' if an individual does not move along these stages.

The finding that all of the participants in the current study experienced coping as a process does suggest some universal aspect to the experience of coping. However, the ways in which participants found themselves able to cope and the time it took for them to move through this process were different for each participant. Perhaps then the current findings indicate that these two perspectives on coping from the existing literature are interrelated and a combination of these perspectives exemplifies the coping process most clearly.

### *Process and Phenomenology*

The experience of process itself has not been specifically explored in the existing literature. However, an understanding of the process orientated nature of experience reflects the central tenants of phenomenology.

Indeed, the person-centered approach to therapeutic intervention, which has its origins in phenomenology, regards the nature of therapeutic change as a process (Rogers, 1967; McMillan, 2004). Furthermore, the IPA methodology also has its roots in phenomenology (see Methodology chapter) and the core concepts of person-centered counselling, empathy, unconditional positive regard and congruence, are central to an effective interview process.

The findings that have emerged from the current study regarding the process orientated nature of experience, while not specifically evidenced in the extant literature with regard to spinal injury, were not necessarily surprising to me. These findings seem to reflect previous research regarding the nature of therapeutic change (Rogers, 1967; McMillan, 2004). This has caused me to reflect on these findings with regard to my position as a researcher.

As this concept of process is in line with my own understanding, I was given to wonder whether my own assumptions and prejudices had influenced the analysis in some way. However, I took steps during the analysis of the data to bracket my own beliefs and understandings, in line with the guidelines set out by Smith et al. (2009) (see Methodology section) and I believe that I was able to achieve this during the various stages of analysis. I also reflected on whether the phenomenological nature of IPA had increased the likelihood of these findings; the process orientated methodology and the resultant process orientated findings. However, the process orientated nature of experience is not a finding that has been evidenced by all IPA research projects and I therefore believe instead that the current findings can be said to add to the existing literature on the nature of change.

## **Spinal Injury as Bereavement**

As demonstrated above, the subordinate theme of *Loss & Grieving* was experienced by the participants in the form of an ongoing process. I have already described the impact of spinal injury as a form of bereavement (see Analysis chapter) and in recent years, researchers have begun to explore the impact of SCI with regard to bereavement literature (Dickson, Allan & Carroll, 2008; Kalpakjian, Tulskey, Kisala and Bombardier, 2015).

In addition, the current findings reflect the existing work of several researchers, who have emphasised the process-orientated nature of bereavement (Parkes, 1966; Stoebe & Schut, 2010; Worden, 2010). Indeed, grief is understood within the literature to be an aspect of the human condition that is a natural process that everybody will experience at some point in their lives. Previous research also indicates that grief will lessen over time and lead to psychological growth (Larson, 2013). In line with the nature of change as a process, the existing literature suggests that the grieving process will occur naturally without therapeutic intervention.

This would seem to reflect the current findings, as while several of the participants had access to therapeutic services during their time in hospital, none engaged in long term therapeutic intervention during the time since their injury. Despite this they all experienced changes in coping and adjustment and seemed to experience loss in this way, as a process of grieving moving towards acceptance and growth. This was also reflected by the fact that the participants, who had been injured for the longest time, seemed to be the most adapted and accepting of their loss (see Analysis chapter). In addition, those with the more severe SCIs seemed to have taken longest to adjust to their loss. This reflects bereavement research regarding the nature of complicated grief (Worden, 2010).

The participants' experienced the grieving process as building their new life around their loss, on a foundation of this grief experience. Meredith even described the positives in her new life as a result of her loss, and all the participants described this grieving process as occurring gradually over time. This experience of loss seems to reflect the Tonkin model of grief (Tonkin, 1996). This model suggests that, initially after a bereavement, the loss is devastating and all consuming. The grief fills the individual's entire life and they are generally able to focus on little else and struggle to cope with everyday tasks.

Over time, they learn to function in the world that exists for them after their loss. However, rather than the grief diminishing, as some other grief models indicate, as one moves towards an end point, Tonkin suggests that a person's life grows around their grief. The initial loss does not lessen and is still as devastating and significant as it always was, however the bereaved person is able to expand their world around this grief and find enjoyment, hopefulness and acceptance. This model acknowledges that there is no clear end point to grief but rather that the grief becomes easier to manage as the individual rebuilds their life around it. This model of grief seems to reflect the participants' experiences and can be applied to an understanding of the impact of spinal injury.

### **Sex & Intimacy**

The experiential understanding of sex and intimacy as an ongoing process, which emerged from the current findings, has already been addressed (see Process Orientated Nature of the Experience). The participants' experiences of sex post-injury are reflected within the extant literature.

Several of the participants in the current study related an expectation that sex with an SCI would not be satisfying and indeed described bad sexual encounters initially after injury. This would seem to reflect previous findings that both men and women report a decrease in sexual desire and frequency of sexual activity after sustaining an SCI (Reitz et al., 2004; Forsythe & Horsewell, 2006). However, these studies identify this decreased sexual desire and activity at a particular point in time and do not explore ongoing sexual experiences post-injury.

These previous findings could therefore be regarded as misleading, as they suggest that this state of decreased sexual interest or lessened sexual pleasure is a permanent feature of life after SCI. The current findings differ, in that they reveal a view of sexual experience over time. Indeed, the participants experienced their sexual experiences as improving over time. In addition, half of the participants explicitly described gains and improvement in their sexual experiences post-injury in comparison to their pre-injury sexual experiences.

This reflects the previous findings of several studies that have identified the potential positive effects of an acquired disability on an individual's sexual experiences. Researchers have suggested that disability can have the effect of making a person's sex life more mutually pleasurable and creative (Richards, Tepper, Whipple, and Komisaruk, 1997; Chance 2002). In addition, Ostrander (2009) reported that spinally injured participants described their sexual experiences as more satisfying post-injury, which reflects the current findings.

The reasons for this improvement are unclear. The previous literature in this field does not indicate whether this positive effect on sexual experience after injury encourages further positive sexual adjustment, or whether the positive impact of the disability is "recognized

within the reconstruction of sexuality” (Parker & Yau, 2012). In the context of the current findings, the former would appear to be indicated, although these links remain unclear.

### *Sexual Esteem & Body Esteem*

As previously discussed, the subordinate theme of *Sexual Esteem & Body Esteem* was also experienced by the participants as a process. They described initially feeling unattractive after their injury and their growing sense of confidence over time. It is important to note that they did not describe their confidence or increased sexual esteem as having reached an ‘end point’ or as returning to the same level as they experienced pre-injury. There seems to be no specific previous literature to support or refute this, as no previous research has sought to compare sexual esteem pre and post spinal injury.

However, the experience of sexual esteem increasing over time has also been reported in the literature. McCabe and Taleporos (2003) found that spinally injured individuals who had experienced their physical impairment for a longer period of time, reported significantly more positive feelings regarding their own sexuality. In addition, Hassouneh-Phillips and McNeff (2004) found that women who had sustained an acquired disability were likely to experience a decrease in their sexual esteem. This seems to reflect the current participants’ experiences of lowered sexual esteem post-injury.

Furthermore, previous researchers have found that individuals with a more severe disability were more likely to perceive themselves as sexually inadequate and unattractive than those with a less severe disability (Hassouneh-Phillips and McNeff, 2004). This perhaps suggests that individuals with a higher level and completeness of injury would experience lower sexual esteem than those with lower level injuries. However, conclusions regarding this finding



cannot be reached on the basis of the current research as no objective measure of the participants' sexual esteem is possible from the interview data.

### *Sexual Health*

The issue of sexual health was only raised by one of the participants in the current study but seems to be an important concern in need of further exploration.

Previous studies have revealed that both SCI patients and healthcare professionals have identified sexual health as an important aspect of spinal injury rehabilitation (Giulio, 2003). It has also been suggested that there are gaps in the existing knowledge regarding the “clinical skills necessary for assessing the sexual health of patients” and indeed in providing education on sexual health to patients during the rehabilitation process (McAlonan, 1996; Kroll, Beatty, Bingham, 2003). The previous research suggests that people with disabilities are more vulnerable to contracting sexually transmitted diseases. Groce (2003) suggested that people with disabilities are more likely to have known risk factors for contracting HIV. He suggested that people with disabilities may be disadvantaged in negotiating safer sex and potentially vulnerable to controlling or unstable relationships. He also suggested that the sexual health concerns of disabled people are rarely the subject of intervention by medical or sexual health professionals (Groce, 2003). Indeed, Cheng and Udry (2002) found that only 78% of physically disabled women had received sexual education compared to 91% of non-disabled women.

However, these studies include both congenital and acquired disability and do not make a distinction between the two. While in the current study, Miranda highlights the need for sexual education post-injury she also offers a different view of this potential neglect of sexual

health among spinally injured individuals. She suggests that this is due to the changes in sensation post-injury and not being able to feel penetration in the same way. She suggests an “out of sight out of mind” attitude as being responsible for a lack of care regarding sexual health.

Whatever the reasons, it seems clear that further exploration of sexual health among the spinally injured population is required and as well as an exploration of steps that might be taken to improve understanding and sexual safety among spinally injured individuals (see Opportunities for Future Research).

### **Acquired Disability**

Another important aspect, which emerged from the current findings, was the impact of SCI as an acquired disability. Giulio (2003) suggests that acquired disability, such as SCI, entails different challenges to congenital disability. While some individuals may experience SCI in childhood, the majority of people sustain their injury during young adulthood and this was the case for the current participants.

Common to many of the themes in the current study was the idea of comparison between the participants’ non-disabled experiences before their injury and their current experiences post-injury. This seemed to be reflected particularly within the context of the following themes; *Sex & Intimacy, Sexual Esteem & Body Esteem, Lowered Expectations* and *The Same Concerns vs New Ones*. Having acquired a spinal injury, it is understandable that the participants would compare aspects of their dating life now to before their injury and might become preoccupied with aspects that they feel have changed or feel out of reach after their injury.

Moreover, this reflects previous findings which have suggested that acquired disability can challenge an individual's established sense of self (Galvin, 2005). In addition, participants have reported that adjusting to their new limited mobility and integrating their disability into their identity can be very difficult, particularly for newly disabled people (Kedde & van Berlo, 2006).

Previous researchers have reported that despite the difficulties that are associated with acquired disability, individuals are able to gradually adjust to their altered mobility and become increasingly more accepting of their disability over time (Chance, 2002; Ostrander, 2009). In addition, McCabe and Taleporos (2003) and Richards et al. (1997) found that there was a long latency period from the time of the initial injury to the eventual reintegration of sexual identity and that individuals would experience this reintegration at different rates and within their own timeframe. This seems to reflect the experiences of the participants in the current study.

Some of the participants in the current study described finding themselves again or returning to their old self while others talked about becoming a new version of themselves. This rhetoric is also reflected in the extant literature. Researchers have found that those with an acquired disability may attempt to reconnect with their experience of self and their identity before their injury, while others seek to construct a new identity and a redefined and meaningful self (Chance, 2002; Gordon, Feldman & Crose, 1998)

The unique impact of acquired disability has particularly been explored in the context of sex and intimacy. Tepper (2000) found that participants who compared their sexual experiences after incurring a spinal injury to their experiences preinjury reported experiencing

uncontrollable, intrusive thoughts during sexual activity. Participants also reported being preoccupied with engaging in sexual activity “in the normal way”. Li and Yau (2006) reported similar findings. They reported that spinally injured individuals, who held an established sexual identity prior to their injury, had a tendency to compare their current sexual experiences to their memories of what they had regarded as ‘normal’ sexual experience before their injury.

This seems to reflect many of the current participants’ early experiences of sexual contact post-injury and the feeling of devastation at experiencing sexual intercourse differently post-injury. Many of the participants went on to relate very enjoyable sexual experiences and this is also in line with previous research. In line with this, Tepper (2000) also reported that participants who were able to “relearn their bodies” and relearn how to experience sexual pleasure post-injury were more hopeful about their sexual lives and found sexual activity much more enjoyable. They also reported introducing fantasy into their sexual lives and were more likely to accept their post-injury bodies. Li and Yau (2006) suggested that individuals with an acquired disability must reconstruct their sexuality and sexual identity against their pre-injury experiences and expectations. This seems to be particularly important for people with an acquired disability.

The concept of acquired disability that has emerged from the current findings, seems to be important in understanding the impact of spinal injury on dating and romantic life. The current findings, along with this previous research, suggest that the impact of acquired disability may be experienced in different ways by different individuals.

## **Expectations of Others**

The expectations that the participants perceive from others seem to reflect the previous attitude studies which have already been conducted in this field (see Introduction chapter).

The discourses which the participants experienced from others regarding being defined by their disability and the notion of imperfection are also reflected to some extent in the existing literature. These findings are significant as societal discourses are frequently used to regulate certain groups within society such as disabled people, often to the detriment of those groups. The discourses can contribute to prejudiced attitudes towards people with disabilities and contribute to the social construction of disability.

Many of the participants described the idea of imperfection by contrasting a potential romantic partner's expectation of themselves, in comparison the expectations they would have of non-disabled women. This reflects previous findings regarding participants' tendency to compare their current abilities and expectations to those they experienced prior to their injury. As societal attitudes in the context of the current study are being examined through the prism of the spinally injured participants' experiences, it is not surprising that there is an overlap between their own perceptions of themselves and their perceptions of how others view them. This is reflected by Taleporos and McCabe (2001) who reported one of their participants' words; "having an acquired disability, you really notice how people treat you differently after the accident. It's very obvious. You can see how easily some people become conditioned to feel negatively about their disability". This seems to mirror the experiences of the current participants.

In addition, Hahn (1981) found that women with disabilities often feel that they are seen as someone who is “damaged” or “less than” by society. As Hwang (1997) stated “in a society that still often judges a woman’s attractiveness and desirability largely on standards of physical perfection, women with disabilities are by definition excluded”.

### **The Role of Gender**

Findings emerged from the current study with regard to the concept of gender. However, as all of the participants were female, it is important to understand that these findings relate only to the experiences and expectations of women with an SCI.

Most of the current participants perceived dating as more difficult for spinally injured women than spinally injured men. This perhaps reflect some of the extant literature which suggests that women with disabilities are perceived more negatively than men with disabilities (Asch & Fine, 1988; Westbrook & Chinnery, 1990; Gartner, Lipsky & Turnbull, 1991).

The reason for these findings remains unclear. This could reflect the fact women in the current study have direct experiences of their own struggles and therefore perceive these as more significant than those of others, in this context men. On the other hand, it is possible that this finding that dating is more difficult for spinally injured women reflects traditional gender norms that exist generally within our society. The emphasis is generally placed on women to meet an aesthetic ideal and to be beautiful and thin. It is likely then that spinal injury impacts female gender roles more than it impacts male roles. This would expiate the findings that have emerged from the current study and the previous literature that women with an SCI might struggle more with dating than men.

This would mean that the various findings regarding gender roles within this study reflect the gender roles that exist within society generally but spinal injury contradicts and therefore exacerbates some of these roles.

The participants also felt that men were less receptive to dating someone with a disability than women would be. In addition, the finding that spinally injured men are bolder and more forward when it comes to dating was attributed by the participants to men having more confidence or regaining more confidence post-injury than women. However, it seems likely that these findings also reflect gender roles more generally.

### *Intersectionality Theory*

The findings regarding gender roles and wider societal norms have led me to consider the intersectionality. Intersectionality theory refers to “the relationships among multiple dimensions and modalities of social relationships and subject formations” (McCall, 2005). In other words, this refers to the tensions and connections between interrelated and intersecting social identities, where gender, sex, culture and of course disability intersect. Particularly intersectionality theory explores systems of oppression and discrimination in relation to different social identities (Yuval-Davis, 2006).

The participants in the current study hold several different social identities. The current study could be construed as exploring the ways in which the participants’ disabled identity and single identity intersect and their experiences of this phenomena. In addition, the current findings show that their female identity also intersects with these other social roles. I have already discussed extant literature which suggests that disabled women are ‘doubly handicapped’ the societal prejudices associated with both identities (see Introduction section)

and how this might include sexual identity as well. This, along with the current findings, highlights the importance of acknowledging the participants' various interrelated identities and how this might impact their experiences of dating in the current study.

### **Ignorance: Moving Towards Understanding**

The current participants described their experiences of ignorance and fear from others within society. These findings closely reflect previous findings within the literature that, prior contact with disabled people reduces non-disabled participants' negative attitudes towards disability (see Introduction chapter). The current findings also seem to support previous findings that ignorance is closely linked to a lack of representation of disabled people within the mainstream media (see Introduction chapter).

These previous studies reflect the current findings regarding the importance of representation and education in improving understanding within society. These findings are important as they suggest that increasing education and awareness about disabilities may combat existing negative attitudes towards disabled people, particularly in the context of dating and romantic relationships. Indeed, it seems that one of the main obstacles for disabled people seeking an intimate relationship is the negative attitudes and stereotyped views held by the majority of people without disabilities. In the current research the participants described helpful forms of representation as people with disabilities being shown as successful and athletic, such as in the Paralympic Games or being represented on children's television programmes. This finding indicates that perhaps more positive and widespread representation of people with disabilities in the media and education around the nature of disability, particularly within schools would be the best way to begin to alter these stereotyped views.



This idea is also reflected in the extant literature, particularly with regard to representation among children. However, while this is vital, it also remains just as important to develop understanding among adults too. As Zola (1989) stated “children spontaneously express an interest in wheelchairs and leg braces but as they grow older they are taught that ... it’s not nice to ask [about] such things” (p.200). Previous researchers have suggested that the most effective way to reduce negative attitudes towards people with disabilities was a combination of contact and information provision (Corrigan and Penn, 1999; Pettigrew and Tropp 2006). In addition, Vilchinsky et al. (2010) argue that this distributing of information regarding people with disabilities as sexual beings would alter the perception of disabled people as asexual (see Introduction chapter). They argued that it was important that the sexual aspects of disabled people’s identity were no longer neglected.

### **Visible vs Invisible Disability**

Another factor which emerged from the findings was the impact of visible and invisible disability and the different experiences that this entails among spinally injured individuals. Damage to the spinal cord is perhaps unique, in that the varying severity and position of the injury can result in vastly different limitations to mobility.

In the current study, two of the participants were walkers while the other four were wheelchair users. The findings revealed that the themes that emerged were mostly shared by the participants, however, within the theme of *Ignorance: Moving Towards Understanding* revealing that walkers might face different forms of ignorance to wheelchair users. While these differences do not seem significant enough to interfere with the homogeneity of the study, it seems important to reflect on the nature these different experiences.

Meredith and Sophia experience other people dismissing the seriousness of their disability due to the fact that they can walk and do not necessarily 'look disabled'. Sophia also described her experience of the ignorance that sometimes exists towards walkers from wheelchair users (see Analysis chapter). Walkers seem to have been overlooked in the literature, as no previous research seems to exist regarding the experiences of walkers specifically. While walkers face difficulties which arise from their invisible disability, it is clear that wheelchair users face different challenges resulting from their visible disability.

Howland and Rintala (2001) found that disabled women reported that the visible signs of their disability, for example wheelchairs, made them less attractive to a potential romantic partner. In addition, individuals with a visible disability have been found to be more likely to experience negative body image than someone with a less visible disability (Nosek and Hughes, 2001; Taleporos and McCabe, 2002). This seems to be mirrored by the current findings. Margaret and Alexandra experienced their negative body image being in relation to their wheelchairs.

While the wheelchair is an obvious sign of spinal injury which can generate prejudice from other people, walkers face different prejudices because of their unobvious injury. Walkers frequently feel excluded, dismissed and unheard within the SCI population. This is certainly reflected by their lack of representation in the existing literature. Although the contradiction between visible and invisible disability did not arise as a central theme in the current study, it is important to acknowledge its impact on the participants' experiences.

## **Disclosure**

The theme of disclosure also emerged from the current research as a significant finding. The concept of disclosure has been reported recently in the extant literature. In recent years, dating has moved into the online arena and ‘blind dates’ with people met on dating websites have become more common. This has led to disabled people feeling as though they have to make a choice about whether to display photos on their profile, which disclose their disability.

The participants in the current study all felt that some sort of disclosure was necessary, particularly in the context of online dating or dating apps. Indeed, some of the participants feared that not to disclose their SCI to potential date would be dishonest. This fear is perhaps justified as Saltes (2013) found that disabled participants reported negative experiences when their potential partner later learned of their disability. This is something that I have come across in my own clinical practice. These findings would appear to highlight the importance of the issue of disclosure for those with a spinal injury, particularly in the context of modern dating.

However, the current participants seemed unsure of how and when this disclosure should take place. Furthermore, some of the participants experienced rejection from potential partners when they did disclose their disability (see Analysis chapter). This indicates that those who engage in online dating and dating apps face a double edged sword; they may face rejection if they initially hide their SCI and they may face rejection if they are open and honest about their disability.

Very little research has been conducted into the experiences of disclosure among the spinally injured population. The paucity of the literature makes it difficult to link the current findings

to extant research, however several aspects did emerge from the findings which seem important.

Participants were preoccupied with how they should present themselves. Many struggled with wanting to disclose their disability, for example by showing their wheelchair in their photo, but did not want this to be the first photo and wanted to also show themselves engaged in adventurous or exciting activities as well. The participants wanted to present themselves as rounded individuals, not defined by their disability. This idea of being defined by disability is one of the discourses which emerged from the participants' experiences of the expectations of others (see Expectations from Others section). It is uncertain whether this expectation from others lead to the participants' fear of being defined by their disability, or if it is this fear in the participants that leads to recognising this attitude in others.

In addition, the participants seem to experience disclosure somewhat differently depending on their level of disability. Meredith and Sophia describe not being able to disclose in photos as they have no visible signs of their disability. They have to choose between disclosing in a message before a date or disclosing during a date. Meredith describes her experiences of both instances and, while she describes many of the same experiences of varied rejection and understanding from others, having the option to disclose her disability during a date after she has built up a rapport with a potential partner is a choice that is not open to the wheelchair using participants.

Another aspect of disclosure, which was described by participants was the experience of the initial disclosure leading to further disclosures about daily life and functioning with a disability. The participants experienced this as both somewhat intrusive and also as making

the date very serious by discussing such a significant issue. This was part of the reason that the participants felt the emotional toll of the disclosure, both in person and via dating apps.

These findings seem to give insight into the process of disclosure. In the context of modern dating, the concept of disclosure has become all the more relevant for spinally injured individuals. The lack of research in this area suggests that further studies should be carried out to explore this particular aspect of dating (see Opportunities for Future Research section).

### **Control & Vulnerability**

It is important to note that the participants who discuss the dangers of control and vulnerability in their romantic relationships make it clear that they are not suggesting that everyone who is interested in dating a spinally injured person has an interest in controlling their partner. Instead, they are just relating their experiences of a few instances of control that they have experienced in these relationships.

Some previous literature has also engaged with this aspect of dating. Hassouneh-Phillips and McNeff (2004) found that the combination of negative self-perception in disabled women and a strong desire to be in a romantic relationship may increase their vulnerability to entering into and remaining in abusive or controlling relationships. This finding suggests that not all disabled women will experience this, only those with specific risk factors. This may reflect the current findings that not all of the participants had experienced issues of control and further suggests that this is not a common aspect dating with a spinal injury.

However, this study, like most of the limited research in this area, focuses on the control and vulnerability of women rather than men. While this is relevant in the context of the current

research, it may suggest that existing gender roles and norms are influencing the researchers in their research design. It would traditionally be considered more likely for a man to be violent and for a woman to be more vulnerable to violence. Perhaps when the female partner is also spinally injured, researchers assume this dynamic will be heightened. This approach to research fails to recognise the instances of female violence towards their male partners and indeed the potential vulnerability of wheelchair using men, who will face similar vulnerabilities as wheelchair using women.

Furthermore, some of the research in this area seems to perpetuate negative attitudes towards spinally injured people in a dating context. Piotrowski and Snell (2007) suggested that disabled women might get into or remain in controlling relationships as they are thankful that they are in a relationship, regardless of their own safety. This suggests that the researchers are engaging in research from a foundation of existing negative societal attitudes and prejudices towards disabled individuals and not from a foundation on empowerment.

### **Limitations of this Study**

Steps were taken during this research to ensure that the data collection and analysis processes were carried out in accordance with good practice guidelines set out by the BPS (2010) and the BACP (2010). In addition, attention that was paid to issues of rigour and validity by adhering to Yardley's (2008) criteria (see Methodology chapter). I have explained how this study met the criteria sensitivity to context, commitment and rigour and coherence and transparency in the Methodology chapter and the final criterion, impact and importance, will be addressed by the Implications for Counselling Psychology section (see below).

Despite these efforts, there are some limitations of the current study, which need to be taken into account when evaluating this research. These issues may have a potential impact on the transferability and robustness of this research, although as the research process was not driven by specific hypotheses, these issues must not be seen purely as obstructions empirical truth or knowledge.

### *Methodological Issues*

Although the essential limitations of IPA have been previously set out in the Methodology chapter, there are certain aspects of this method of analysis, which may have impacted the current findings.

First, the small sample size, which is typical of IPA as it allows for in depth exploration of the lived experience, means that it is not possible to reach more general conclusions about the breadth and nature of the experience of dating with an SCI. While generalisability is not the goal of IPA research, as it is in most quantitative approaches, Smith et al. (2009) do suggest that findings may “shed light on a broader context”. The limitations of this “light” are arguably unclear, however the researchers suggest that the transferability of research findings should be determined at the discretion of the individual researcher. While I do feel that the findings from the current study can give some insight into the experiences of women dating with a spinal injury, I also acknowledged that the purpose of IPA as a methodology is to focus on the depth of data, rather than breadth and to report detailed findings, rather than assuming general claims (Smith, 2004).

Secondly, some researchers have suggested that IPA is too dependent on language, requiring participants to be highly articulate in order to communicate the meaning that they make from

their experiences and their experiential understanding (Willig, 2001). This potentially excludes any participants who are less articulate or less educated. On the other hand, this feature of IPA allows researchers to consider the linguistic components of the participants' experiences during analysis, paying attention to the ways in which the participants are communicating their experiences, including their use of certain expressions or emphatic language.

Similarly, IPA has also been criticised for its emphasis on cognition (Willig, 2001).

Researchers have suggested that the emphasis placed on meaning making and the participants understanding of their experience has excluded exploration of the embodiment of their experience (Willig, 2007). However, it is also understood that retrieving this embodiment of experience is almost impossible, as we must engage with cognition and language in order to access a person's experience. In response to this, Smith et al. (2009) suggest that while conducting interviews it is important to attend to the pre-reflexive experiences and not to simply rely on "deliberate, controlled reflection" (Smith et al., 2009, p. 189).

### *Research Design Issues*

The focus of this research, on the experience of dating with an SCI, was appropriate given the paucity of the extant literature in this area, however this fairly broad focus has been both a strength and limitation of the current study. While examining all aspects of dating has allowed me to gain insight into various aspects of the experience and indeed the nature of these experiences as interrelated processes, there has been less opportunity to examine certain issues in more detail. Focusing solely on certain dating experiences, which emerged from the current findings, might have allowed for a deeper experiential understanding (see Opportunities for Future Research).



In addition, the cross-sectional research design has limitations. The current study necessitated carrying out a single interview with each participant, at one point in time that had to be more than two years after the participants' initial injury (see Methodology chapter for rationale). While this is an appropriate structure within IPA analysis and conducting additional interview would have raised time issues, a central finding of the current study was an understanding of the process orientated nature of the experience. The participants' account of their experiences as a process over time indicates that conducting more than one interview would have gained better insight into this change and the nature of this process (see Opportunities for Future Research).

### *Procedural Issues*

As previously discussed, participants were not excluded on the basis of gender, age, sexual orientation, race or nationality due to ethical considerations (see Methodology Chapter). However, they were also accepted to take part on a 'first come first serve' basis. While this was the fairest and most ethically responsible approach, this also meant that the participants who took part effectively selected themselves. Moreover, the characteristics of the participants group might also impose limitations on the current findings.

First, it is possible that the participants differed from the broader spinally injured population in their motivation to take part in the study (Rozmarits & Ziebland, 2004). Participants may be influenced to take part by a particular dating experience, whether positive or negative which might not be common to the broader group. In the context of the current study, three of the participants worked or volunteered within the spinally injured community. This might suggest that they had a stronger motivation for involving themselves in research. However,

while it is impossible to be certain of such motivational issues, during the debriefing process the participants all gave different reasons for their desire to be involved in the current research, including a desire to help others, as a way to give back to the charities that I recruited through, as a way to process and understand their own experiences and out of academic interest.

Secondly, despite the fact that the exclusion criteria for the current study did not preclude men from taking part (see Methodology chapter), no men volunteered to take part. There are many possible reasons for this. First, it could be that the methods and procedures used during the recruitment phase of the project appealed more to women than men, or spoke more to a female mentality. However, I have reviewed my recruitment materials and they do seem to me to be neutral in their presentation of the study information. In addition, these materials were also reviewed by the City University Psychological Research Ethical Committee and gained ethical approval (Reference number: PSYETH (P/L) 15/16 50), which would suggest that this is not the reason for the lack of male interest in this case.

Perhaps a more likely factor could also be that it is generally understood within the research community that men are generally less likely to take part in research than women. This suggests that potential male participants might have been less inclined to contact me about taking part in the current research than their female counterparts. This effect may also have been exacerbated by the intimate and sensitive nature of the research topic. Previous studies have also suggested that women are on average more comfortable discussing more sensitive and emotive issues and talking about their vulnerabilities (Chester & Glass, 2006). Perhaps this effect would have been mediated if I were a male researcher.

Whatever the reason for this lack of male interest, the impact on the current study was that the participant group was composed of six women. This means that the findings can only give insight into the experiences of women with an SCI and not spinally injured men. This can be seen as both a limitation and a benefit of the current study. The inclusion of no male participants means that the study cannot offer no insight into the male perspective or ascertain a divergence between the experience of the male and female participants through comparison. On the other hand, any divergence within these experiences could be seen to imply a lack of homogeneity within the sample group.

I made the decision that the main selection criteria for achieving homogeneity within the sample group should be to recruit participants with a diagnosed SCI that affects movement and sensation in some way. This decision was made on the basis that approximately 2% of the British population have an SCI (Spinal Cord Injury Facts, 2013). This means that the spinally injured population is relatively small compared to the population of the country as a whole and I felt that this characteristic alone was enough to account for the homogeneity of the sample. However, the fact that only female participants took part has increased the homogeneity of the participant group and it could be argued that this has improved the effectiveness of the analysis.

In addition, spinal injury is more common among men than among women, men being four times more likely to sustain an SCI, and therefore it could be argued that findings regarding male experiences would be more applicable to the majority of the spinally injured population. However, claims of applying findings gained through IPA analysis to wider groups should not be overemphasised. As discussed in the Methodology chapter, the quantitative nature of IPA's small sample size means that generalisability is not the goal of findings gained through

this form of analysis. As mentioned previously (see *Methodological Issues* section), Smith et al. (2009) suggest instead that issues of transferability should be left up to the discretion of the researcher. In addition, this larger proportion of men within the spinally injured population has also meant that more research has already been carried out involving male participants and less into women's experiences of SCI. Therefore, it could be argued that this current research has opened up a less well researched field of study.

Thirdly, concern could be raised regarding the participant group's ethnicity. Five of the participants in the current study were of Caucasian descent and one participant was of Asian descent. Additionally, all were British. This is important to keep in mind when evaluating the current findings, as the experiences described in this study are mostly those of Caucasian British participants. This discrepancy is reflected by the extant literature, most of which has been conducted using Caucasian, western participants, particularly university students. Other races and cultures are underrepresented in the literature.

The research which does address the impact of culture on disability attitudes mostly uses American university students in comparison with students from other countries (Anuar & Ghazali, 2015) and focuses on the ethnicity of the non-disabled observer, not the disabled person themselves. Chen et al. (2002) found that American university students held more positive attitudes towards people with disabilities than Asian students in the context of dating and marriage and Hamdy et al. (2011) found that American students' attitudes were more positive than those of Egyptian students. Conversely, Anuar (2013) more recently found that International students held more positive attitudes towards disabled individuals in the context of dating and marriage than American participants. Only one study so far seems to have addressed the impact of race on disability attitudes. Saetermoe, Scattone and Kim (2001)

found that Asian American participants held more negative attitudes towards people with disabilities than European American, Latin American and African American participants. This lack of research has meant that little is known about the generalisability of previously exemplified attitudinal patterns to other cultures (Chen et al., 2002).

It seems likely that cultural beliefs and support structures would impact the perception and understanding of both dating and SCI. The social construction of both concepts has already been explored (see Introduction chapter) and seems to indicate that attitudes towards dating and disability would be constructed differently within different cultural societies. This would inevitably influence the experiences of disabled people from these varying cultural backgrounds, particularly in the context of dating.

Finally, although participants were not excluded from the current study on the basis of their sexual orientation, five of the participants identified as heterosexual and one participant identified as bisexual. There is very little research surrounding the different experiences of disabled people who identify as heterosexual and disabled people within the LGBT community, particularly in the area of romantic relationships. It is therefore unclear what the impact of this characteristic of the participant group will have had upon the current findings. It might be that this lack of representation of LGBT disabled people within the extant literature, and indeed the current research, reflects the fact that the spinally injured population is fairly small compared to the British population as a whole.

### **Opportunities for Further Research**

The current research could be extended by using a variety of methodological approaches, namely a 'mixed methods' approach. Researchers have shown that quantitative methods, such

as surveys, can be effectively linked to qualitative methods, such as interviews or diary keeping (Kvale & Brinkman, 2009; Tindall, 1994). Although this approach to research would take a longer amount of time to complete, this more comprehensive methodology might allow a quantitative measure of some of the findings which have emerged from the qualitative interviews on a larger scale, across age groups and all levels of injury. For ethical reasons, the participants in the current study were not excluded on the basis of age or level and completeness of injury (see Methodology chapter) and, while this was appropriate for the current project and many of the dating experiences seem to be shared by the participants regardless of age or type of injury, a quantitative measure with many more participants might reveal subtle differences between these groups. In this possible future research project, the quantitative data would add to the foundation of the qualitative findings and provide a richer depth of analysis.

Another way to extend the current research, would be to focus more specifically on aspects of the dating experience which have been evidenced by the current findings. Focusing on single aspects such as experiences of control and vulnerability in a dating context, the experiences of sex and intimacy post-injury or perceptions of the importance of sexual health would allow for a richer depth of analysis into those particular experiences and potentially lead to a more detailed understanding of the experience. The areas that I feel are most recent and suffer from a paucity of literature are disclosure and control in dating and romantic relationships. I feel that further research into these areas could lead to further insights and increase our understanding of the nature of these experiences.

As discussed above (see *Research Design Issues*), conducting a longitudinal study might allow a deeper insight into the nature of the experience as a process. This could be conducted

by carrying out a first interview at two years post-injury (see Methodology chapter for rationale) and then potentially two more interviews at intervals of two years. This would allow for an exploration of the impact of dating with an SCI over time and potentially allow for the development stage or process model of the experience, similar to those in the bereavement literature (Worden, 2010). This methodological approach would of course require a much larger time commitment from both a research and the participants and potential drop out rates would be a concern. In addition, while Flowers (2008) stated that multiple contacts such as these, allows the researcher the opportunity to build upon material from an initial interview and to develop a deeper trust with the participants, potentially increasing disclosure, he also warns that conducting multiple interviews can interfere with the open examination of a research topic and instead lure the researcher into focusing purely on issues raised previously. This suggests that the form of secondary or indeed tertiary contact would need to be carefully selected. Supplementing semi-structured interviews with the use of diaries, video recordings or blogs would allow for a spontaneous record of experience.

Finally, the lack of variety within the participant group in terms of ethnicity and sexual orientation (see *Procedural Issues* section) might indicate the need for a more focused exploration of the experiences of LGBT spinally injured individuals or those from varying cultures. This could offer another possible future direction for research. In addition, conducting this research project using a male sample group would allow for examination of the experiences of men with an SCI in the context of dating and might reveal convergent or divergent findings in comparison to the current research.

## **Implications for Counselling Psychology**

The current research makes an original contribution to the field of counselling psychology by answering both a methodological and a knowledge gap in the existing literature. Being a fairly under-researched area, with most of the previous studies being quantitative, this study provides fresh insight into the experiences of the spinally injured population, particularly in the context of dating and relationships. As social attitudes and conventions are constantly and rapidly changing, it is unsurprising that attitudes towards both dating and disability are considerably different to how they were even a few years ago. The findings related to disclosure exemplify this. While dating apps are not considered in the extant literature in relation to disability, they featured highly in the findings from the current study. New and updated research is therefore essential to inform our understanding as counselling psychologists and enable us to effectively meet the needs of our clients and patients.

My dual role as researcher and practitioner has led me to contemplate the ways in which the dating issues, experienced by individuals with an SCI, might be addressed in a therapeutic context. The first consideration is whether therapeutic intervention is necessary for people undergoing these experiences. In line with regarding spinal injury as a form of bereavement, I have reflected upon the bereavement literature, which suggests that, for most people, 'change' is mostly accomplished without external intervention (Parkes, 1970; Worden, 2010).

Furthermore, therapeutic intervention has been found to be most effective in complex grief situations, where the bereaved individual is in greater distress (Stroebe & Schut, 2010). This may suggest that therapeutic support would not be necessary for everyone with an SCI and might be most helpful for those experiencing most difficulty in the context of their dating lives.



However, it is worth noting that, from a phenomenological perspective, the counselling psychologist can be seen as a facilitator for therapeutic change. While this change primarily comes from the client and may have occurred to some degree without intervention, therapeutic intervention can expedite and support this process. As the dating issues and concerns that emerged from the current research were mostly experienced by all of the participants, this suggests that some type of intervention based on these findings, might alleviate or ease dating problems to some degree.

The finding that dating and romantic experiences were not initially important to the current participants, who were instead preoccupied with more practical difficulties in the months after their injury, makes it clear that support regarding dating would not be very beneficial within the hospital setting, during initial rehabilitation. This indicates instead that a facility for later engagement with therapeutic support may be necessary.

These insights have led me to conclude, that while long term therapeutic intervention may not be necessary for everyone in this context, some forms of intervention could be put in place to support single people with an SCI. The findings from the current study have clinical implications, in that they give insight to counselling psychologist and rehabilitation professionals working with spinally injured individuals into how to support their patients through the complex issues that arise surrounding dating. In addition, other clinical applications could be devised.

The LSCIC provides a rolling programme of educational workshops to support newly spinally injured individuals with their recovery. These workshops include information regarding bladder and bowel health, sexual function and relaxation sessions. The current findings could

be applied in this context by developing further workshops to explore self-esteem, body image, sexual health and dating more generally. Although these programmes are generally for the benefit of newly injured individuals who are still undergoing their hospital rehabilitation, these new programmes might be available to individuals who have left hospital and are experiencing the change in their priorities from initially ‘striving’ to ‘thriving’ and being able to consider dating post-injury.

The charity BackUp (see Methodology chapter) which supports people with an SCI runs a mentor programme for spinally injured individuals and their families. They match up a newly injured patient with someone of the same level of injury who can provide them with guidance, support and understanding. Perhaps a similar scheme, which matches people currently struggling with dating issues, to people who have been injured for a longer period of time and have experienced these same dating concerns, could provide this same guidance and support. A further intervention could be the creation of a monthly peer support group for people struggling with dating concerns. This could give single spinally injured individuals a platform to express their fear and concerns as well as allow them to share their negative and positive experiences. This could also allow peers to share advice, guidance and comfort and perhaps ease these the fears and concerns that have been found to arise around dating. These facilities would improve the therapeutic support for single individuals and acknowledge their different but equally important needs and difficulties, rather than dismissing them.

The current findings also suggest the importance for health professionals to gain training in the different needs of single and married spinally injured patients and the different issues that dating with a spinally injury entails. Particularly the issue of sexual health seems to be something that health care professionals in a hospital setting could engage with.

## **Final Considerations of Reflexivity**

This final phase of the research process has brought my own personal reflexivity to an end, the start of which I discussed in the Methodology chapter. Keeping a reflexive diary throughout this research helped me to bracket off my preconceptions and assumptions and explore my influence upon the research process (Finley, 2008). This made clear to me the processual nature of reflexivity itself and developed my understanding of my impact upon the research material and, in turn, its impact upon me.

My understanding of reflexivity as a process perhaps reflects the findings from the current study regarding the process orientated nature of experience. These findings prompted me to reflect on the concept of process itself and the phenomenological nature of experience. My clinical experience, together with previous research, has taught me that person-centered techniques are generally the most appropriate approach to supporting those who have suffered a bereavement and consequently a recent traumatic spinal injury (Worden, 2010). I therefore use the person-centered approach a great deal in my therapeutic practice. This may be what in turn drew me to the IPA methodology for this research.

These research-practice links perhaps indicate that my own understanding of process, within a therapeutic context, has influenced my understanding of process within a research context. I have been left wondering whether this understanding has influenced my analysis of the data or whether the findings regarding process reflect the use of a phenomenological methodology. Despite this, although IPA acknowledges that a researcher cannot fully separate themselves from the research process, I was careful to bracket off this understanding and perception while conducting this research and I believe that these findings capture the participants' experiences.

In addition, at this stage of the research process I have reflected further on my position as a non-disabled researcher. I found that the open-ended structure of the research interviews allowed the participants to unrestrainedly explore aspects of their experience and gave voice to the participants as the experts of their own experience (Smith et al., 2009). The broad nature of the research questions, and indeed the broad range of findings, may indicate my lack of personal experiential knowledge regarding being spinally injured. However, this also reflects my desire not to impose my own assumptions on the research process and to bracket off my own preconceptions.

I also feel that the current findings have given greater coherence to my own dating experiences. I found that I related to many of the participants' dating experiences, particularly the dating issues which they felt were the same as those experienced prior to their injury and their experiences of using dating apps. Although I separated my own dating experiences from the research process during the interview and analysis stage, reflecting on the current findings has prompted me to reflect on my own experiences in relation to the current research.

## **Conclusion**

In this manuscript, I intended to explore the experience of dating with an SCI and to show, through a phenomenological lens, the importance of this research area. I attempted to provide valuable insight into the processes of coping and adjustment and the explorations of meaning which women with a spinal injury face, from the time of their injury, until they are ready to enter the dating world again and beyond. I have attempted to highlight the gaps in the existing literature and emphasise the need to offer more focused counselling support to single spinally injured people. By providing a space for the participants to openly explore their thoughts and feelings, I endeavoured to allow them give voice to experiences which are not fully

understood by the rest of the spinally injured community, healthcare professionals and the wider population.

I have attempted to demonstrate the importance of this research to the field of Counselling Psychology, particularly the research-practice links which have clinical applications that could benefit spinally injured patients in the future. I hope that this research will raise awareness of the issues faced by single people with a spinal cord injury within the Counselling Psychology community and will provide insight for both research and therapeutic practice into how to understand and support individuals through these experiences.

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## Appendix I: Recruitment Advertisement



### Department of Psychology City University London

#### **PARTICIPANTS NEEDED FOR RESEARCH INTO *BEING SINGLE AND DATING WITH A SPINAL CORD INJURY.***

We are looking for volunteers to take part in a study on the experience of single people with a spinal cord injury, who are currently dating or want to be in a romantic relationship.

You would be asked to: take part in an interview with a researcher.

Your participation would involve 1 session,  
which is approximately 90 minutes.

For more information about this study, or to take part,  
please contact:

**Charlotte Airey** (Supervisor: Julianna Challenor)

Psychology Department  
at

██████████ or  
Email: ██████████

Or ██████████

This study has been reviewed by, and received ethics clearance  
through the Psychology Research Ethics Committee, City University London  
Ethics approval code: PSYETH (P/L) 15/16 50

If you would like to complain about any aspect of the study, please contact the Secretary to  
the University's Senate Research Ethics Committee on ██████████ or via email:  
██████████

## **Appendix II: Interview Schedule**

- 1). Could you give me a brief history of your experiences of dating with an SCI?
- 2). Could you describe your expectations of dating after your injury?
- 3). Could you describe your recent dating or romantic experiences, either in person, online or with potential partners?
- 4). What is it like for you when you are on a date? (Prompt: How do you feel when you are on a date or talking to a potential partner (physically, emotionally, mentally)?, What do you think about when you are on a date or talking to a potential partner?
- 5). How did you feel that your expectations compare to your experiences?
- 6). How do you feel that your experiences of dating with an SCI compare to your dating experiences before your injury?
- 7). What are your experiences or expectations of physical intimacy/sexual contact with an SCI?
- 8). What do you imagine potential partners want or expect from you when dating?
- 9). Are there any social pressures you have experienced around dating or any societal expectations you have felt?
- 10). Do you think that other people's expectations of you dating are influenced by your gender/sex?
- 11). What are your future hopes (for dating)?

## Appendix III: Information Sheet



### **The lived experience of single people with a spinal cord injury who are currently dating or want to be in a romantic relationship**

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

#### **What is the purpose of the study?**

The aim of this research is to develop an understanding of the lived experience of dating with a Spinal Cord Injury (SCI). Previous research has mainly focused on the impact of SCI on marriages and relationships and less research has explored the experiences of single people. People have reported practical limitations to dating, such as inaccessible homes and public places, transport issues and in some cases reliance on carers. Another factor that has been reported more recently is the idea of "disclosure". In recent years dating has moved into the online arena and "blind dates" with people met on dating websites have become common. Several studies have also found that disabled people experience negative attitudes from able-bodied people when dating. Despite these findings, the experiences of people with SCI who are single have not been examined thoroughly and this study aims to understand these experiences. This study is being undertaken as part of a doctoral research degree program.

#### **Why have I been invited?**

People with a diagnosed SCI, which affects movement and sensation are being asked to take part. Only people who have been injured more than a year ago will be asked to take part. All levels of injury will be included. Eight participants will be asked to take part in the study.

#### **Do I have to take part?**

Participation in the project is voluntary, and you can choose not to participate in part or all of the project. You can withdraw at any stage of the project without being penalised or disadvantaged in any way.

It is up to you to decide whether or not to take part. If you do decide to take part you will be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time, without giving a reason, until the write up of the research begins.

#### **What will happen if I take part?**

- You will be offered a pre-interview meeting, to meet the researcher and to discuss the research process. This is not essential if you would rather or are only able to meet once.
- You will take part in an interview with the researcher, approximately 90 minutes long.
- These interviews will be audio-recorded.
- The interview will be based on prepared questions but there will be opportunity to discuss your individual experiences in detail.
- The interview and pre-interview meeting will take place at Aspire, SIA or Wheelpower.
- The interviews with the eight participants are planned to be conducted within six months of first contact.

**What do I have to do?**

You will be asked for a convenient date and time to attend an interview. You will be asked to answer the researcher's questions, during an approximately 90 minutes interview. The questions will be open-ended so that you can guide the focus of the interview and explore your personal experiences.

**What are the possible disadvantages and risks of taking part?**

With all spinal injuries there is the possibility of psychological trauma, whatever the circumstances of the injury. Although the questions will focus on dating, it is possible that exploring your experiences may focus on aspects of your life that you find distressing. If at any time you feel upset and wish to stop the interview you can and contact numbers of places to go to for support will be provided for you.

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

There are no direct benefits to taking part, except that this research could lead to potential benefits for future patients and contribute to existing knowledge. Many people also report that talking to a researcher about their experiences can be beneficial.

**What will happen when the research study stops?**

Participants' interviews will be anonymised with pseudonyms used to conceal the identity of participants. No identifiable data will be used. The recordings and transcripts will be kept on a password-protected laptop and the recordings deleted from the Dictaphone as soon as they have been uploaded to the laptop. After analysis is complete, the recordings and transcripts will be kept for five years, in line with data protection standards. After this the recordings will be deleted and the transcripts destroyed.

**Will my taking part in the study be kept confidential?**

- Only the main researcher will have access to the data; data will not be shared with any other researcher.
- Audio recordings of interviews will only be kept until they have been transcribed, they will then be deleted.
- Records of personal information will be kept separately from all interview data, which will be anonymised.
- Confidentiality will only be broken if you report intending to cause harm to yourself or others, during the interview. In this case the researcher will inform her supervisor and will attempt to provide you with appropriate sources of support.
- After the research has been completed and submitted the recordings will be deleted and the transcripts destroyed.

**What will happen to the results of the research study?**

The results of the study will be used in a doctoral thesis and may possibly be published in psychological publications. The data will remain anonymous. If you would like to receive a summary of the results then please inform the researcher after your interview.

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

You are free to withdraw from the study up until the write up of the research begins, without being penalised or disadvantaged in any way.

**What if there is a problem?**

If you have any problems, concerns or questions about this study, you should ask to speak to the researcher. If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: *The lived experience of single people with a spinal cord injury who are currently dating or want to be in a romantic relationship.*

You could also write to the Secretary at:  
Anna Ramberg  
Secretary to Senate Research Ethics Committee  
Research Office, E214  
City University London  
Northampton Square  
London  
EC1V 0HB  
Email: [REDACTED]

City University London holds insurance policies, which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

**Who has reviewed the study?**

This study has been approved by City University London Psychology Research Ethics Committee, Ethical approval code:

**Further information and contact details**

Charlotte Airey: [REDACTED]

Julianna Challenor (Research Supervisor): [REDACTED]

Psychology Department City University: [REDACTED]

**Thank you for taking the time to read this information sheet.**

## Appendix IV: Consent Form



Title of Study: ***The lived experience of single people with a spinal cord injury who are currently dating or want to be in a romantic relationship.***

Ethics approval code: PSYETH (P/L) 15/16 50

Please initial box

1.	<p>I agree to take part in the above City University London research project. I have had the project explained to me, and I have read the participant information sheet, which I may keep for my records.</p> <p>I understand this will involve:</p> <ul style="list-style-type: none"> <li>• being interviewed by the researcher.</li> <li>• allowing the interview to be audiotaped.</li> </ul>	
2.	<p>This information will be held and processed for the following purpose(s): <i>To answer the research question stated above.</i></p> <p>I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party. No identifiable personal data will be published. The identifiable data will not be shared with any other organisation.</p>	
3.	<p>I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project, until the write up of the research begins, without being penalized or disadvantaged in any way.</p>	
4.	<p>I agree to City University London recording and processing this information about me. I understand that this information will be used only for the purpose(s) set out in this statement and my consent is conditional on the University complying with its duties and obligations under the Data Protection Act 1998.</p>	
5.	<p>I agree to take part in the above study.</p>	

Name of Participant	Signature	Date

Name of Researcher	Signature	Date



## Appendix V: Debrief Form



### *The lived experience of single people with a spinal cord injury who are currently dating or want to be in a romantic relationship*

#### DEBRIEF INFORMATION

Thank you for taking part in this study. Now that it's finished we'd like to tell you a bit more about it.

The main aim of this study is to develop an understanding of the lived experience of dating with an SCI. We are looking at participant's expectations of dating and how these compare with their experiences. Further aims are to explore how participants perceive society's attitudes towards their dating experiences and whether men and women experience dating differently.

The questions asked in the interview were designed to attempt to answer these aims and improve understanding of dating with an SCI. We are interested in the individual experiences of participants and therefore we do not have particular expectations of the results. Despite this we feel that there may be a difference in the way men and women experience dating with an SCI.

If this research has raised any concerns for you and you feel you would like some support please contact your GP or the hospital in which you were treated and ask for an appointment with psychologist. Alternatively, you could contact one of the support charities below:

#### Disability Support

**SIA:** Call the free advice line 0800 980 0501 or visit the advice chat room <http://www.spinal.co.uk/forums/>

You could also visit <http://www.spinal.co.uk/how-we-help/telephone-counselling/> to arrange a telephone counseling session with a volunteer counselor or visit <http://www.spinal.co.uk/how-we-help/peer-support-service/> to speak to a member of the peer mentoring scheme.

**BackUp:** Call 0208 875 1805 for advice and telephone support or visit <http://www.backuptrust.org.uk/what-we-do/mentoring> to arrange to speak to a peer mentor.

**Aspire:** For advice call 0208 954 5759 or for peer support visit <http://www.apparelyzed.com/organisations>

#### General Counselling and Mental health Support:

**Samaritans:** Call 0845 790 9090 or email [jo@samaritans.org](mailto:jo@samaritans.org) or visit <http://www.samaritans.org/branches> to find your local Samaritans branch.

**BPS:** The British Psychological Society offers information about different types of counselling and which treatments may benefit different people. Visit their directory of psychologists <http://www.bps.org.uk/psychology-public/find-psychologist/find-psychologist> to find a psychologist that is right for you.

**BACP:** The British Association for counselling and Psychotherapy offers information about different kinds of therapy and provides a list of accredited counselling professionals. Visit [http://www.bacp.co.uk/seeking\\_therapist/right\\_therapist.php](http://www.bacp.co.uk/seeking_therapist/right_therapist.php) to find a therapist near you.

**Counselling Directory:** Search for counsellors who specialise in relationships, sexual issues and disability. Visit <http://www.counselling-directory.org.uk/internet-addiction.html> to search for your nearest counsellor.

### Relationship Support

**Relate:** For relationship counselling and advice call 0300 100 1234 or visit <http://www.relate.org.uk> to find your nearest Relate service.

You could also visit “Ask Amanda” at <http://www.relate.org.uk/blog/topics/relationship-help> to ask anonymous relationship advice from a trained Relate counsellor.

There are also anonymous advice blogs and chat rooms to address specific topics:

Divorce and Separation: <http://www.relate.org.uk/blog/topics/divorce-and-separation>

Family and Parenting: <http://www.relate.org.uk/blog/topics/family-life-and-parenting>

Health and Wellbeing: <http://www.relate.org.uk/blog/topics/health-and-wellbeing>

Older people: <http://www.relate.org.uk/blog/topics/older-people>

Relationships and Society: <http://www.relate.org.uk/blog/topics/relationships-and-society>

Sex and Sexuality: <http://www.relate.org.uk/blog/topics/sex-and-sexuality>

Relate also offer sex therapy; visit <http://www.relate.org.uk/relationship-help/help-sex/sex-therapy> to book an appointment or to watch a video explaining the process of sex therapy.

**TLC trust:** Call the sex and disability helpline on 0707 499 3527 for advice on sexual issues specifically for disabled people or their health professionals and care staff. The advice line is open from 11am – 7pm weekdays.

**BASRT:** The British Association for Sexual and Relationship Therapy offers a list of accredited relationship therapists all over the country. Visit [www.basrt.org.uk](http://www.basrt.org.uk) for find a therapist near you.

**CORST:** The College of Relationship and Sexual Therapists offer specific advice on sex and disability. Visit <http://www.cosrt.org.uk/information-for-members-of-the-public/sex-and-disability/>

### Psychosexual Counselling

Chelsea and Westminster Hospital: <http://www.chelwest.nhs.uk/services/hiv-sexual-health/clinics/56-dean-street/psychosexual-therapy>

Let's talk about it:

<http://www.letstalkaboutit.nhs.uk/page.asp?fldArea=2&fldMenu=9&fldSubMenu=0&fldKey=342>

Couple Works: <http://www.coupleworks.co.uk/london-based-sex-psychosexual-therapy/>

**Simon Parritt:** Disabled psychosexual relationship therapist, based in South London. Call 020 8542 2994 or email: [simon.parritt@talktalk.net](mailto:simon.parritt@talktalk.net)

**Steve Shears:** Psychosexual Therapist at Headway, the brain injury association and Relate, relationship counselling. Also in Private Practice.

Email: [steveshears@btinternet.com](mailto:steveshears@btinternet.com)

#### Gender and Sexuality Organisations

**London, Lesbian and Gay Switchboard:** Offers support for lesbian, gay, bisexual and transgendered communities in the U.K. Call 0300 330 0630 (Open daily 10am-11pm) or Visit <http://www.llgs.org.uk> where an online instant messaging service is also available.

**The Lesbian and Gay Foundation:** Offers support for lesbian, gay, bisexual and transgendered individuals. Call 0845 330 3030 or email [helpline@lgf.org.uk](mailto:helpline@lgf.org.uk)  
Alternatively visit <http://www.lgf.org.uk> for details of groups, one-to-one services, clinics and police help.

**The Gender Trust:** For support for transsexual, gender dysphoria, transgender, or gender identity issues, email [info@gendertrust.org.uk](mailto:info@gendertrust.org.uk)

#### Sexual Health Advice

**NHS Sexual Health:** Offers confidential advice about sexual health and centres for Sexually Transmitted Infections. Call 0300 123 7123 (lines open Monday - Friday 9am - 8pm, Weekends 11am - 4pm).

**Brook:** Offers sexual health advice and education and free contraception. Visit <http://www.brook.org.uk>

**Wide Way Clinic:** Offers information on sex and reproductive health. Also provides free pregnancy testing, sexual health testing, abortion referral and sexual assault services. Call 0203 458 5200 for telephone advice or to make an appointment. Wide Way Medical Centre, Wide Way, Mitcham, CR4 1BP. Open 3pm - 7pm on Mondays.

**Epsom and St Helier University Hospital:** Offers testing and advice and support. Walk-in Clinic: Open Monday - Friday 9am - 11:15am (Doors open at 8.15). Appointment sexual health clinics: Monday 2pm - 4pm, Tuesday 4pm - 6pm, Thursday 2pm - 4pm. Same day HIV testing takes place on Thursday mornings. Call 0137 273 5735.

**FPA:** Offers online sexual health advice and a STI and contraception clinic finder, to help you find your nearest clinic. Visit <http://www.fpa.org.uk>

Alternatively you could visit the following links to popular lifestyle and support blogs written by people with spinal injuries:

<http://www.spinalcordinjury-paralysis.org/blogs/20>

<http://lifeparalyzed.blogspot.co.uk>

<http://www.spinalcordinjuryzone.com/tag/personal-story>

<http://arashrecovery.com>

We hope you found the study interesting. If you have any other questions please do not hesitate to contact us at the following:

Charlotte Airey: [REDACTED]

(Research supervisor Julianna Challenor: [REDACTED])

Ethics approval code: PSYETH (P/L) 15/16 50

## Appendix VI: Letter of Ethical Approval



Psychology Research Ethics Committee  
School of Arts and Social Sciences  
City University London  
London EC1R 0JD

28<sup>th</sup> October 2015

Dear Charlotte Airey

**Reference:** PSYETH (P/L) 15/16 50

**Project title:** The lived experience of single people with a spinal cord injury who are currently dating or want to be in a romantic relationship

I am writing to confirm that the research proposal detailed above has been granted approval by the City University London Psychology Department Research Ethics Committee.

### Period of approval

Approval is valid for a period of three years from the date of this letter. If data collection runs beyond this period you will need to apply for an extension using the Amendments Form.

### Project amendments

You will also need to submit an Amendments Form if you want to make any of the following changes to your research:

- (a) Recruit a new category of participants
- (b) Change, or add to, the research method employed
- (c) Collect additional types of data
- (d) Change the researchers involved in the project

### Adverse events

You will need to submit an Adverse Events Form, copied to the Secretary of the Senate Research Ethics Committee ([anna.ramberg.1@city.ac.uk](mailto:anna.ramberg.1@city.ac.uk)), in the event of any of the following:

- (a) Adverse events
- (b) Breaches of confidentiality
- (c) Safeguarding issues relating to children and vulnerable adults
- (d) Incidents that affect the personal safety of a participant or researcher

Issues (a) and (b) should be reported as soon as possible and no later than 5 days after the event. Issues (c) and (d) should be reported immediately. Where appropriate the researcher should also report adverse events to other relevant institutions such as the police or social services.

Should you have any further queries then please do not hesitate to get in touch.

Kind regards

Hayley Glasford  
Student Administrator  
Email: [REDACTED]

Katy Tapper  
Chair  
Email: [REDACTED]

**Appendix VII Example of Initial Note-taking (Participant 2: Alexandra)**

1. and the chair as ugly. I think with a lot of people it is *emphatic language*
2. always, you know, you hate the chair so much because you've *emphatic*
3. got to be in it and you do not want to be in it but you have *Relationship with chair  
lack of control*
4. to get in it because that is the only way you can sort of
5. function day to day. *loss (of mobility)  
control  
freedom*
6. Then as for relationships, that is probably the last
7. thing on your mind. You do not even think about that because *Initially nels. not important/  
not priority.  
emphatic*
8. you think, oh, nobody will be interested now because you are
9. disabled, you are ugly and you sit in an ugly chair and *repetition self esteem/  
self worth*
10. initially you cannot see beyond your disability. All the *Initially cannot see beyond  
disability*
11. physical aspects of a relationship is kind of ended because *loss (of sex life/  
intimacy)*
12. you are now paralysed. So, surely you can't do anything. But *emphatic*
13. you kind of, what's the word, you kind of imagine or think, *searching for meaning*
14. like, whether you can feel any more, you know, if you were to
15. have a sexual relationship with somebody. *will sex/pleasure  
be the same  
Uncertainty*
16. Then, you know, you ask, you think about all these
17. things like whether sex would be the same as before or whether *Changes before/  
after/  
questioning  
Sex. Uncertainty*
18. you can't feel anything. Then there is, if you are high
19. level, the autonomic dysreflexia, you worry about that. These *level of injury  
fear?*
20. are the things that you kind of learn I suppose along the way *medical language  
learning process?  
over time*
21. when you become involved with somebody, but it is the initial
22. bit of getting involved and having the confidence to do that. *confidence  
growing confidence?*
23. Then I suppose with time your confidence does come back
24. and things do get better. Then I suppose you become a bit *emphatic  
Hopeful / positive  
improving over time*
25. like, because, I mean, especially me, I have a certain type of



**Appendix VIII Example of Identifying Emergent Themes (Participant 2: Alexandra)**

1. and the chair as ugly. I think with a lot of people it is
2. always, you know, you hate the chair so much because you've
3. got to be in it and you do not want to be in it but you have
4. to get in it because that is the only way you can sort of
5. function day to day.
6. Then as for relationships, that is probably the last
7. thing on your mind. You do not even think about that because
8. you think, oh, nobody will be interested now because you are
9. disabled, you are ugly and you sit in an ugly chair and
10. initially you cannot see beyond your disability. All the
11. physical aspects of a relationship is kind of ended because
12. you are now paralysed. So, surely you can't do anything. But
13. you kind of, what's the word, you kind of imagine or think,
14. like, whether you can feel any more, you know, if you were to
15. have a sexual relationship with somebody.
16. Then, you know, you ask, you think about all these
17. things like whether sex would be the same as before or whether
18. you can't feel anything. Then there is, if you are high
19. level, the autonomic dysreflexia, you worry about that. These
20. are the things that you kind of learn I suppose along the way
21. when you become involved with somebody, but it is the initial
22. bit of getting involved and having the confidence to do that.
23. Then I suppose with time your confidence does come back
24. and things do get better. Then I suppose you become a bit
25. like, because, I mean, especially me, I have a certain type of

LOSS

Initially vs  
Later  
(process)

LOSS

Sex &  
Intimacy

emphatic language  
emphatic  
Relationship with chair  
lack of control  
loss (mobility)  
control  
freedom  
Initially feels not important/  
emphatic not priority.  
repetition  
self esteem/  
self worth  
Initially cannot see beyond  
disability  
loss (of sex life/  
emphatic intimacy)  
searching for meaning  
will sex/pleasure  
be the same  
Uncertainty  
Changes before/  
questioning after  
Sex  
Uncertainty  
level of injury  
fear?  
metaphorical language  
learning process?  
over time  
confidence  
growing confidence?  
emphatic  
Hopeful/positive  
improving over time

### Appendix IX Extract from Master Table of Themes

The Role of Gender	Ref.	Quote
	P8L5	<i>“I think it could be different with males and females about disability. I think it’s easier for disabled men to find partners than females I think.”</i>
	P8L12	<i>“I always find males are more to do with, um, appearance, you know, the external rather than what’s inside, so I thought, especially, I think I have noticed it a lot on a dating site, you know, that males don’t approach you because you are in the chair because they are kind of afraid of it.”</i>
	P27L10	<i>“Men in wheelchairs I find are a lot bolder in approaching able-bodied females. They are quite sort of cheeky and they kind of win them over with, I suppose, the cheekiness and charm and their disability. So there is a difference in how men and women behave in dating after a spinal injury. Definitely men are bolder, I think, well, the ones I have come across anyway. But women are more, they shy away from it and it is a lot to do with self-esteem [ ] females are a bit more cautious.”</i>
	P14L20	<i>“I think there is something in women that makes them more nurturing and more like “oh, he is in a wheelchair, I can look after him” and what not.”</i>
	P16L3	<i>“I do know a lot of guys, good looking guys in chairs who get a lot of attention from woman. I do not know if it is because woman are seen as the more caring sex, you know, looking after people. I do not know. But men who are in a chair may feel emasculated, that they feel they need to be, this is all very old fashioned, the protector and the bread winner and the one who does the handy, the DIY stuff and you know, picks the woman up. I do not know, all these things they feel emasculated maybe because they are now using a wheelchair.”</i>
	P25L3	<i>“Yeah, it’s easier for blokes to find women because women are more caring and accepting. They sort of look for different qualities, especially in my age bracket as well.”</i>
	P25L10	<i>“He was like “yeah, well, you know blokes, yes, well, we can pick up women really easily because women are really nice but, yes, blokes, yeah, they’ve got not sympathy, yeah, women do not get blokes if they have got an injury”, and I was like “mate, I am a girl” and he went, “whoops” (laughs) so my immediate expectation was that it was going to be harder for me as a woman, for a bloke to be understanding basically.”</i>
	P37L6	<i>“Sometimes I talk to people who are dating paralysed men and what I find really interesting is that they have had some sort of abuse or something happen in the past and they feel they are safe with their paralysed man. They are safe because they are not going to get thrown around or jumped on when they don’t want to”.</i>



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