

**Unemployment in Spinal Cord Injury:  
Understanding the lived experiences of unemployed  
individuals with spinal cord injury and those who  
provide spinal cord injury vocational support in the  
community**

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A thesis submitted in fulfilment of the requirements for the degree of Doctor of  
Philosophy (PhD) in Psychological Sciences

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## **Declaration**

I hereby declare and guarantee that this thesis and the work presented in it are my own and written by myself entirely except where other sources are clearly and identifiably cited.

Wafa Turkistani

**Signature:**

**Date:**

**List of abbreviations and synonyms for key terms in this thesis**

<b><u>Key term</u></b>	<b><u>Abbreviation / synonym</u></b>
<b>Spinal cord injury</b>	SCI
<b>Return to work</b>	RTW
<b>Vocational rehabilitation</b>	VR
<b>Interpretative phenomenological analysis</b>	IPA
<b>Quality of life</b>	QoL
<b>World Health Organisation</b>	WHO
<b>Thesis</b>	Studies 1 and 2
<b>First study</b>	Understanding the lived experience of unemployed individuals with SCI
<b>Second study</b>	Understanding the lived experience of those who provide SCI vocational support in the community
<b>The current researcher / The researcher</b>	PhD candidate – Wafa Turkistani
<b>Academic supervisor</b>	Professor Jonathan A. Smith
<b>Principal investigator</b>	PI
<b>[...]</b>	Editorial elision
<b>...</b>	In a quote, this is an indication of a flowing conversation that has been interrupted by the current researcher to show agreement
<b>p.</b>	Page number in a certain text (e.g. a book or a participant's transcript)

## **Abstract**

Unemployment resulting from spinal cord injury (SCI) is significant for those who experience job loss. A predominantly quantitative approach has typically focused on factors related to return to work (RTW) from the perspective of individuals living with SCI. This thesis sought to add to the qualitative research on the topic by providing contextual and subjective accounts of concrete experience on SCI unemployment.

Moreover, it is important to understand the meaning of employment and/or lack of employment following SCI through the experiences of those providing vocational support to SCI sufferers. The literature on this topic has mainly been explored from the perspective of service providers to reflect on issues related to SCI people and their rehabilitation rather than issues related to the service providers themselves. Hence, this thesis also sought to focus on the experience of SCI vocational support providers in order to understand how they perceived their role.

To achieve the above aims, this thesis comprised two separate studies, where data were collected through semi-structured interviews and analysed using interpretative phenomenological analysis (IPA).

The first study explored the experience of nine men with SCI who became unemployed following their injuries. The findings of the first study demonstrated the mixed feelings of being nostalgic for pre-injury work and at the same time perceiving the self as a victim of SCI for losing work.

The second study explored the experience of five supporters who provided SCI vocational services in the community. Findings demonstrated how those vocational support providers perceived their SCI clients as unique individuals, and how broad the ultimate goals they wanted to achieve with them were.

The findings of the two studies are linked to each other in terms of the importance of support, empathy and customised care after SCI as well as setting comprehensive vocational goals. The two studies are linked to the existing literature through highlighting a particular contribution from an experiential and idiographic perspective. They also suggest different interesting avenues to pursue for future research.

***“If we could look into each other’s hearts and understand the unique challenges each of us faces, I think we would treat each other much more gently, with more love, patience, tolerance and care.”***

Marvin J. Ashton – The Tongue Can Be a Sharp Sword

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## Chapter 1: General introduction

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### Setting the scene

It was only when I finished my secondary school and started my foundation year at university that I ever thought I would be interested in working with individuals with disabilities. During my foundation year, I met Lisa, a Special Education teacher, who came from Venezuela at that time to do her master's degree in the United States. She enjoyed talking about her students with special needs and I used to listen quietly to the stories she used to tell, and maybe sub-consciously think how amazing her job was. I started to be more and more eager to know about this job.

When I was about to finish my foundation year, I had to decide what major I wanted to do at university and I immediately thought of Lisa. At that time, I had to move back to my home country, Saudi Arabia, to start my undergraduate degree and so I applied to the college of Education, where I was offered a place at the Department of Special Education.

During my second year at university, a lecturer was giving a talk during her class about how beneficial it was for us as university students to do voluntary work before completing our undergraduate degrees, and she suggested some names of rehabilitation facilities where university students could volunteer during the summer. I was very enthusiastic about this idea, because I thought that doing voluntary work would prepare me for working with people with disabilities after I graduated.

I signed up as a volunteer in a rehabilitation facility in my home city, which had different wards that cared for patients with disabilities of different ages. Although I was placed in the paediatrics ward, when I walked through the hospital hallways, I was eager to observe adults with disabilities who were also there to receive rehabilitation. I started to ask the staff working there at the time about the different types of therapeutic activities that these adults were being offered at the hospital. It was only then that I knew I was more interested in working with adults with disabilities than any other age.

When I graduated from university, I applied for the same rehabilitation facility I volunteered for and I was offered a job of doing vocational rehabilitation (VR) with adults with different disabilities. When I started working with different cases in different wards, I felt I was being more productive with those with spinal cord injury (SCI). Because I had higher performance with those cases, my manager suggested I work in the ward of SCI exclusively, so I did.

Four years after, I decided to pursue my education in the UK in the area of VR for SCI as my experience revolved around this. Thus, this PhD thesis is dedicated to all my SCI patients, who motivated me, even without knowing it, to pursue it.

### **Preface to the thesis**

The overarching research question for the thesis is:

**What is the meaning and experience of work and/or lack of work for men who have suffered SCI?**

This could be tackled from a number of different angles, and each of which has the potential to shed extra light on the topic. It was decided in this thesis to concentrate on two key aspects:

1. The experience of men who have had a SCI itself and who subsequently became unemployed.
2. The experience of those who offer guidance and support for people with SCI in returning to work (RTW).

At the beginning of the PhD, the focus was very much on the first aspect, which is obviously core to addressing the broader question. Thus, the first study aimed to talk to a group of men who worked before they had a SCI, and who are not currently working subsequently, about their injury and its impact on their experience of job absence.

In analysing and writing up the data for the first study, the researcher considered the main issues arising for the SCI participants in their experiences of being unemployed after

the injury. While participants' accounts illustrated their emotional and social suffering after losing their pre-SCI jobs, participants were mostly eventually able to accept this loss and began to desire a RTW in a different field. At the same time, it was observed that those accounts made no reference to participants being engaged in any professional vocational support in their communities.

It was therefore considered that it would be useful to conduct a second study talking to community vocational supporters who offer advice and guidance to people who have suffered SCI in their attempts to RTW.

The second study, like the first, is written up first in its own terms so that the experiences of the vocational support providers are clear. In a final substantive chapter of the thesis, the results of the two studies are drawn on in order to show how, together, they do indeed help address the main research question of the thesis.

Reflexively, growing up in a well-educated family who have always enhanced their productivity and contribution to society through employment motivated the researcher to conduct this thesis in this topic. Searching for literature that justified undertaking this research, which sought to understand the impact of leaving work after SCI and the importance of providing support to RTW, perhaps did not leave room to question whether work was in fact of value to everyone or not and, subsequently, whether or not the experience of leaving work after SCI was going to be important for participants in the first study.

## **Outline of chapter**

Following on from this introductory chapter, **part (A)** of this thesis includes chapters two to six, which are relevant to the first study.

**Chapter 2** – sets the scene for the first study. Chapter 2's literature review first gives an introduction to SCI in terms of its epidemiology, aetiology, demography and impact, including the impact on community reintegration (in light of the different models of disability). Stemming from this, this chapter then outlines the existing work in the field of SCI employment and social participation in order to support the first study in this thesis.

**Chapter 3** – outlines the methodology of the first study by including an introduction to qualitative research and phenomenology followed by a presentation of the philosophy which underpins IPA. The next section of this chapter outlines a discussion on the rationale behind using IPA in the first study, and when put against the different qualitative and phenomenological methods, its suitability is justified. The final section introduces reflexivity and its demonstration in this thesis.

**Chapter 4** – draws on both Chapters 2 and 3 to give a preface to the first study (i.e., main research question and objectives). This chapter then details the method used in the first study (i.e., ethics, sample, participants, consent, data collection and protection, data analysis and write up).

**Chapter 5** – moves onto the substantive work that the researcher conducted. This chapter presents the findings of the first study, which examines the lived experience of nine unemployed men following SCI.

**Chapter 6** – includes a discussion of how the findings of the first study support and inform the existing literature as well as the study's contribution to knowledge, implications, areas of future research and finally the researcher's reflections and reflexivity notes.



**Part (B)** of this thesis includes chapters seven to 10, which are relevant to the second study.

**Chapter 7** – sets the scene for the second study. Chapter 7’s literature review first gives a brief introduction to VR in terms of its scope, services and providers’ competencies. This chapter then outlines the existing work in the field of disability support provision and social participation in order to support the second study in this thesis.

**Chapter 8** – presents a brief note on the methodology of the second study before it moves to present the preface of the second study and the method it used.

**Chapter 9** – presents the findings of the second study, which examines the personal experience of five support officers working in community organisations to provide vocational services to unemployed individuals with SCI.

**Chapter 10** – includes a discussion of how the findings of the second study support and inform the existing literature as well as the study’s contribution to knowledge, implications, areas of future research and some of the researcher’s reflections and reflexivity notes.

Finally, **part (C)** of this thesis includes chapters 11 and 12, which discuss how studies one and two are linked and how they are validated.

**Chapter 11** – discusses how the two studies in this thesis can be related and how, together, they can answer the overarching research question for the thesis.

**Chapter 12** – is the final chapter, which discusses the validity and quality of both studies in this thesis from the perspective of qualitative and phenomenological research.

## **PART A**

### **Study 1**

# **Understanding the lived experience of unemployed individuals with spinal cord injury (SCI)**

*“I feel as if I have been robbed of my profession  
because of my spinal cord injury”.*

Current participant Henry (p. 34)

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## Chapter 2: Literature review

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### Introduction to this chapter

The experience of unemployment can be significant, especially if it occurs following a life-changing event as significant as sustaining spinal cord injury (SCI). The first study of the current research was interested in exploring the lived experience of those who transitioned from employment to unemployment following SCI in order to understand what it means to go through a phase of unemployment and the impact of this on daily living.

This chapter will present the relevant literature on this topic by starting with a brief introduction to SCI and its diverse impact on individuals, followed by a review of previous research carried out in the particular areas of SCI employment and social participation. In light of this, a discussion on the rationale for conducting the first study in this thesis will take place in the final section of this chapter.

### A brief introduction to spinal cord injury (SCI)

#### **SCI: Problem and impact**

SCI causes damage to the spinal cord and results in changes to the individual's motor and sensory functions (Krstačić, Krstačić, & Gamberger, 2016). In other words, across the sites of damage in the spine, SCI affects the transmission of motor and sensory signals (Maynard et al., 1997). As this devastating event causes permanent dysfunction in several body organs (Hagen, Eide, Rekan, Gilhus, & Gronning, 2010), it leaves its sufferers with reduced physical and psychological health (Craig, Nicholson Perry, Guest, Tran, & Middleton, 2015). SCI is also profound in its impact on personal and societal experiences (Winslow & Rozovsky, 2003), meaning the potential of its influence on community reintegration is significant (Kennedy, Lude, & Taylor, 2006).

Among the significant physical complications following SCI is reduced mobility (Haisma et al., 2007). Often, SCI patients are described as either ‘paraplegics’ or ‘tetraplegics’; paraplegia refers to an impairment of strength or paralysis in lower body parts, whereas tetraplegia refers to an impairment or paralysis in all four body extremities (Figueiredo, Figueiredo, & Resnick, 2013) (Figure 1). According to reports from different countries, such as the UK (Savic et al., 2017), the United States (DeVivo, 2012; Jackson, Dijkers, DeVivo, & Poczatek, 2004), Canada (Thompson, Mutch, Parent, & Mac-Thiong, 2015) and Norway (Hagen et al., 2010), rates of tetraplegia are higher than paraplegia. This result is also supported by early (Wyndaele & Wyndaele, 2006) and recent (Kumar et al., 2018) worldwide reviews published in the literature of SCI. However, regardless of the level of injury, SCI leads to complications in the spine as well as other body parts (Karimi, Omar, & Fatoye, 2014) that require major life changes (Ottomanelli & Goetz, 2016).

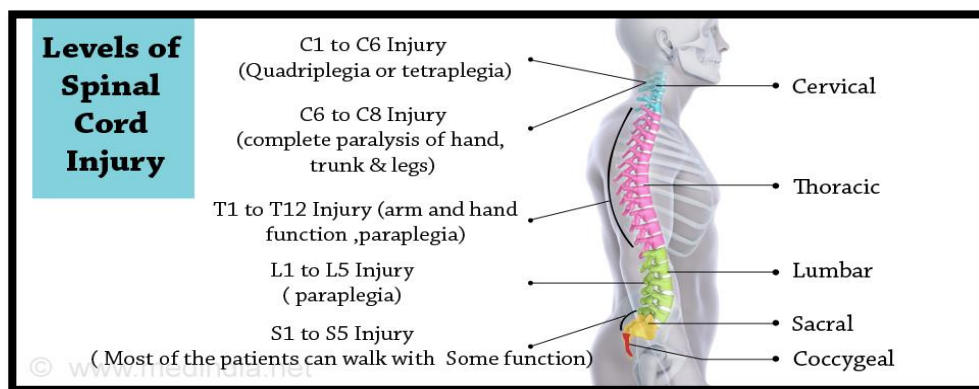


Figure 1. Levels of SCI

Adapted from “Spinal Cord Injury”, 2016 (<https://www.medindia.net/patientinfo/spinal-cord-injury.htm>).

SCI is also associated with a number of psychological problems (Karimi et al., 2014). The mental health of SCI individuals is usually lower than that of the general population (Leduc & Lepage, 2002). The impact of SCI on individuals’ physical ability can be a key factor in those individuals developing depressive symptoms (Peter et al., 2015).

Physical and psychological challenges in SCI can disrupt individuals’ lives as they can negatively affect significant functions, including psychosocial ones (Kennedy et al., 2006);

problems reintegrating into work and the community are common among people with SCI (Buunk, Zurriaga, & González, 2006).

### **SCI: Aetiology and demography**

There are different causes of SCI, which may be traumatic or non-traumatic (Sadowsky, Volshteyn, Schultz, & McDonald, 2002). According to a recent review of the literature, the most common cause of traumatic SCI globally is road traffic accidents (RTAs) (39.5%) followed by falls (38.8%) (Kumar et al., 2018). However, in the UK, falls have been reported as the first cause of traumatic SCI (World Health Organisation & International Spinal Cord Society, 2013). The third most common cause of traumatic SCI globally after RTAs and falls is violence (World Health Organisation & International Spinal Cord Society, 2013). In contrast, non-traumatic SCI is mainly caused by a variety of medical conditions (Guilcher et al., 2010); according to the World Health Organisation and International Spinal Cord Society (2013), the top leading causes for non-traumatic SCI worldwide are neoplastic tumours, degenerative conditions of the spinal column followed by vascular and autoimmune disorders. Although the cause for each non-traumatic SCI case is always coded, the exact onset of most non-traumatic neurological damages in SCI can sometimes be non-instantaneous and it may take weeks or months for the symptoms to develop (such as in the cases of spinal canal stenosis) (New & Marshall, 2014).

Traumatic SCI is most common among young adults (under 30) (Singh, Tetreault, Kalsi-Ryan, Nouri, & Fehlings, 2014) and the elderly (over 60). However, while RTAs, followed by violence, are the most common causes of traumatic SCI among young adults, falls are most common among older age groups. Worldwide, an increase in age correlates with an increase in non-traumatic SCI incidence, which is unsurprising given that an increase in ill health correlates with an increase in age (World Health Organisation & International Spinal Cord Society, 2013).

Overall, due to the aging population and prevalence of falls (Kang et al., 2017), and as a result of osteoarthritis and cervical stenosis causing SCI among the older generation (Ottomanelli & Goetz, 2016), there has been an increase in the average age of adults at

the time of SCI (Kang et al., 2017; Ottomanelli & Goetz, 2016). When looking at the literature systematically, it can be seen that the SCI average age has increased from 35 (Wyndaele & Wyndaele, 2006) to 37 (DeVivo, 2012) and most recently to 39.8 (Kumar et al., 2018). According to the latest UK review, the average age of SCI among the British population was 35.1 (Savic et al., 2017).

In terms of gender, studies have shown that the majority of the SCI population were men (Ottomanelli & Goetz, 2016; Singh et al., 2014). According to recent systematic reviews, the number of SCI male cases was significantly higher than female cases (Kang et al., 2017; Kumar et al., 2018), and the estimated male-to-female ratio worldwide is 2:1 if not higher (World Health Organisation & International Spinal Cord Society, 2013). It has been reported that this higher rate in men is related to gendered behaviour, such as reckless driving, alcohol consumption and involvement in sports with high risk; traumatic SCI caused by sports has been reported as higher in males compared to females after the age of 13 (World Health Organisation & International Spinal Cord Society, 2013).

This can clearly affect the concept of masculinity, where men's identity after SCI can be threatened (Sparkes & Smith, 2002). Loss of adherence to social norms of masculinity after SCI can dramatically affect body image and relationships (Nolan, 2013). However, SCI males may desire a return to this typical masculine identity and so fight to reclaim it (Nolan, 2013; Sparkes & Smith, 2002). Whereas non-adherence to cultural norms of masculinity can negatively affect adjustment to SCI (Burns, Hough, Boyd, & Hill, 2010), adherence in this regard can be linked to SCI life satisfaction (Schopp, Good, Mazurek, Barker, & Stucky, 2007b).

### **SCI: Epidemiology (incidence and life expectancy)**

According to the World Health Organisation (WHO) (2013), the estimated global prevalence of SCI is between 250,000 and 500,000 new cases per year. A more recent systematic review reported that the estimated SCI incidence worldwide varies from 3.6 to 195.4 cases per million (Jazayeri, Beygi, Shokraneh, Hagen, & Rahimi-Movaghar, 2015). According to a recent systematic review, an estimate of 768,473 new SCI cases occurred

annually worldwide between the years 2000 and 2016 (Kumar et al., 2018). Although developing countries have always had higher SCI incidence rates than developed countries (Kumar et al., 2018; Singh et al., 2014), the number of annual SCI cases in Europe, for example, is still considered high. This is because in Western Europe, the SCI epidemiological rate annually is 16 per million (Lee, Cripps, Fitzharris, & Wing, 2014); and in the UK alone, the estimated incidence is between 12 and 16 per million per year (NHS England, 2013).

Despite this high rate of SCI globally, the ability to provide care fluctuates, and so has influenced the number of SCI survival cases (Lee et al., 2014). Statistics from a study in the literature have shown that the average predicted life expectancy for SCI patients aged between 25 and 34 is 38 years post injury (McColl, Walker, Stirling, Wilkins, & Corey, 1997). A more recent statistical study conducted by Shavelle, DeVivo, Brooks, Strauss, and Paculdo (2015) showed that mortality in individuals with SCI did not increase during the period between 2005 and 2012 compared to the period between 1980 and 2004. According to the World Health Organisation and International Spinal Cord Society (2013), while SCI life expectancy tends to depend on the severity and the level of the injury, its rate has increased in developed countries since the 1950s. In the UK, according to a recent review, while life expectancy remains lower for those living with SCI than the general British population, it has been slightly improving since the year 2010 (Savic et al., 2017).

### **SCI: Community reintegration in light of disability models**

Longevity in the SCI population has been the result of the recent medical advances in both acute care and rehabilitation services (Lidal, Huynh, & Biering-Sørensen, 2007). Rehabilitation, in particular, which has typically focused on managing and improving the physical functioning of people with SCI (Wallace & Kendall, 2014), has only recently broadened its focus to include community reintegration (Nunnerley, Hay-Smith, & Dean, 2013). This development can be seen in light of different models of disability, which will be described below.

### ***The medical model of disability***

Historically, the dominant medical or 'individual' model in the late nineteenth century in Western societies viewed disability as the result of abnormality, disorder or deficiency in the body (Barnes & Mercer, 2010). In other words, the medical or 'individual' model viewed disability as the result of a problem in the human body, whether this was in the form of lacking parts or their improper functioning (Smith & Bundon, 2018). A significant component of this 'individual' model was concerned with medicalising disability (Barnes & Mercer, 2010), meaning its causes and manifestations were internalised (Hartie, 2015).

The medical model of disability has been heavily criticised by policy makers, social researchers, disabled people (Barnes & Mercer, 2010) and academics working on disability studies, because it viewed disability as a physical and psychological tragedy that needs to be overcome personally (Smith & Bundon, 2018). Disabled people themselves argued that their disability is not an 'illness' or 'tragedy' that requires medical treatment, but rather a 'failure of society' to meet their social needs (Oliver, 1999). The medical model of disability has also been criticised for defining 'normality' based on physical assumptions with no considerations of the role of social and cultural forces in constructing this (Smith & Bundon, 2018). The danger with defining able-bodied people as 'normal' while defining disabled people as 'abnormal' was in the assumed authority, superiority and power of the former over the latter (Smith & Bundon, 2018).

### ***The WHO: The International Classification of Functioning, Disability and Health (ICF)***

In an attempt to overcome challenges related to definitions (Oliver, 1996) and following the first national survey by the *Office of Population Censuses and Survey*, the WHO taxonomy of *International Classification of Impairments, Disabilities and Handicaps (ICIDH)* was introduced in the 1980 and included the definition of 'social handicap' as a response to the need to view disability not as an 'impairment' in the body parts, but rather a 'limitation in the functioning' of activities as a result of this impairment (Oliver, 1996). In 2001, The WHO introduced a revised model called '*The International Classification of Functioning, Disability and Health (ICF)*' (Lidal et al., 2007), which was regarded as a result of the



interaction between health, personal and environmental factors (Glässer et al., 2011). This model included the components of body structure, functioning, activity and participation (Whiteneck et al., 2004), where the latter included meaningful activities, such as productive work (Lidal et al., 2007). While the ICF model is considered a 'biopsychosocial' model of disability as it acknowledges the synthesised role of health and environment in understanding disability, this understanding is not based on social theories (Barnes & Mercer, 2010).

### ***The UK social model of disability***

Criticism of the medical model has resulted in the development of a number of social models, such as the Nordic social relative model of disability, the North American social model of disability and the UK social model of disability (Smith & Bundon, 2018). Emerging in 1976 from the political arguments at the *Union of Physically Impaired Against Segregation (UPIAS)*, the UK social model of disability distinguishes between impairment as a limitation in the physical body and disability as imposing an exclusion of impaired people from their societies as a result of their impairment (Shakespeare, 2013). This model views disabled people as being oppressed by their societies (Shakespeare, 2013) due to facing barriers in the structure of their environment (Smith & Bundon, 2018). The UK social model of disability was developed to aid equality practice, where adaptation and change is not for the individual, but rather for the whole society, including non-disabled people (Oliver, 1999). In other words, according to the UK social model, the solution is not to cure the individual's physical impairment, but to eliminate social barriers and develop policies that enable their inclusion (Smith & Bundon, 2018).

However, several criticisms have faced the UK social model of disability in relation to ignoring the role of the body, separating impairment and disability, and overlooking the lived experiences of disabled people and their link to public issues (Smith & Bundon, 2018).

### ***Human rights model of disability***

While the UK social model of disability has been helpful in fighting the discrimination and marginalisation of disabled people in their societies and in enabling them to claim their rights (Smith & Bundon, 2018), for some, it is not a model that provides values, morals or principles that form a policy for disability (Degener, 2016). Thus, the UK social model of disability was not seen as a rights-based model of disability (Degener, 2016).

In 2006, *The United Nation's Convention of the Rights of Persons with Disabilities (UNCRPWD)* was introduced in response to the universal concerns with regards to documenting the human rights of disabled people in their societies (Smith & Bundon, 2018). Unlike the UK social model of disability, the UNCRPWD seeks to provide a disability policy that includes principles (Degener, 2016). As cited in Misener and Darcy (2014), the eight principles of the UNCRPWD are: *“(1) respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons; (2) non-discrimination; (3) full and effective participation and inclusion in society; (4) respect for difference and acceptance of persons with disabilities as part of human diversity and humanity; (5) equality of opportunity; (6) accessibility; (7) equality between men and women; and (8) respect for the evolving capacities of children with disabilities and the right of children with disabilities to preserve their identities”* (p. 3).

The UK signed the UNCRPWD in 2007, and in the latest report by a committee from the UNCRPWD in late 2017, a total of 30 concerns regarding disabled people's treatment and rights in the UK were raised (Haves, 2018). Among these concerns were community inclusion, accessibility, equality and non-discrimination in work and employment (Equality and Human Rights Commission, 2018). In this report, the UNCRPWD committee expressed concerns about gaps in the laws regarding disability anti-discrimination in the UK, lack of accessibility in public facilities and less likelihood of disabled people being in employment and being paid equally to able-bodied people (Equality and Human Rights Commission, 2018). In the conclusion of this report, the committee asked the UK government to provide an update on how its recommendations were going to be implemented, including those related to community inclusion and employment for disabled people (Haves, 2018).

## ***Ableism***

It is hoped that the UK government's response to the above recommendations will make significant changes to the current situation, including fighting ableism. The notion of 'ableism' conceptualises how disabled people are marginalised in their societies (Williams & Mavin, 2012) and refers to the negative views, discussions and decisions regarding physical and mental impairments from the perspectives of able-bodied and able-minded based on their social and professional structures (Ho, 2008). Ableism does not take into consideration the differences in the way people talk, think or feel, and therefore does not accept disability of any kind. It favours abled-bodied over disabled people, because it views disability as a burden on society (Campbell, 2012). In one form of ableism, disabled people are seen as unproductive individuals who are not employable (Jammaers, Zanoni, & Hardonk, 2016).

## **SCI: Employment and vocational support**

Since society can have a role in hindering the participation of disabled individuals, including those living with SCI, it is not surprising to see low employment rates among this population when compared to the general population. In SCI, although studies have varied in terms of how employment rates are calculated due to disparities in samples, demographics, definitions of employment (Chapin & Kewman, 2001), injury onset (Ottomanelli, Sippel, Cipher, & Goetz, 2011) and country of study (Anderson, Dumont, Azzaria, Le Bourdais, & Noreau, 2007), available statistics showed that, unfortunately, the global employment rate among this population is considered low (World Health Organisation, 2013); only 37% of those 68% who had jobs before their SCI actually RTW (Young & Murphy, 2009). In the UK, it is believed that only around one third of working age adults actually return to work (RTW) following their SCI rehabilitation (Kennedy & Hasson, 2016).

Despite employment post-SCI being a sign of successful SCI rehabilitation (Kennedy & Hasson, 2016), and employment being beneficial for both physical and mental health (Multidisciplinary Association for Spinal Cord Injury Professionals, 2017), SCI employment

rates in the UK are believed to be lower than in other European countries (British Society for Rehabilitation Medicine, 2010). Therefore, as part of improving SCI rehabilitation services in the UK, the National Health Service (NHS) England Clinical Reference Group for SCI, in its 2019 five-year plan, will maximise its services to the point where issues of employment will be tackled during the SCI rehabilitation process (Multidisciplinary Association for Spinal Cord Injury Professionals, 2017). Also, the *Craig Handicap Assessment and Reporting Technique (CHART)*, which is an interview tool introduced by the ICF model, will be implemented in the UK as part of the national database for SCI (Multidisciplinary Association for Spinal Cord Injury Professionals, 2017). Completed one, two and five years post SCI occurrence, CHART will measure various life changes following SCI initial rehabilitation, including occupation and the ability to RTW, and will record this in the UK national database (Multidisciplinary Association for Spinal Cord Injury Professionals, 2017).

While this sounds promising, and while a growing body of SCI literature, particularly qualitative research, is being grounded in the social model as well as the human rights model of disability, the influence of the ICF model (which is dominated by the medical model of disability) on the practice and research of SCI community reintegration and employment remains high.

### **Literature review on employment in SCI** **Selection criteria of reviewed papers**

For the purpose of reviewing the literature related to SCI social participation and employment in the first study of this thesis, three separate searches on *PSYCH INFO* database were conducted in November 2015 and were updated in January 2018 then in September 2018. The selected papers for this literature review had the following criteria:

- Both qualitative and quantitative papers, in order to gain a comprehensive knowledge about the work done in the area of SCI employment.
- Papers published between the years 2001 and 2017. This is because work published before this period may have not been influenced by the *2001 ICF* components of participation (mentioned above). However, there was an exception of two studies published in the year 2000 and one published in the year 2018. These studies were included as they addressed

valuable research questions related to the vocational experience of SCI patients and the factors affecting it.

- Papers published in peer-reviewed academic journals, to ensure validity.
- Papers published in English, due to lack of translation facilities.
- Papers with samples of SCI adults aged 18 and above, since the topic in question is employment.
- Papers mainly using SCI patients' reports, such as interviews, surveys or retrospective data.

In applying the above inclusion criteria, the first search used the following set of keywords: (*spinal cord injury, unemploy\*, employ\*, work\*, vocational\**). From 226 hits, the 80 papers which *PSYCH INFO* rated as the most relevant were reviewed, and 28 of these were included. The remaining 52 papers were excluded either because they did not meet the above criteria or for the following reasons:

- Not directly related to the research topic under investigation. For example, papers investigating SCI medical/clinical trials or papers exploring SCI sexual experience.
- Not looking at SCI patients exclusively, meaning the samples in these papers were individuals diagnosed with SCI along with other conditions such as traumatic brain injury.

The second search was conducted to explore literature relevant to the experience of employment, unemployment and RTW, and hence used a different set of keywords: (*spinal cord injury, employ\*, unemploy\*, vocational\*, work\*, return to work, experience*). This search gave a result of 108 hits. Following a review of the 20 papers rated as most relevant by *PSYCH INFO*, eight papers met the selection criteria. Of the remaining 12 papers, two were repeated from the previous search and therefore discarded, while 10 did not meet the selection criteria.

The third search was conducted to ensure that no important papers in the literature were missed. A set of three keywords was used in this search – *paraplegia, tetraplegia and experience* – and 10 hits were noted. Two papers relevant to the research topic were selected as they met the criteria specified above.

**Literature review on employment in SCI:**  
**Emergent themes from reviewed papers**

All papers selected from the three separate searches were reviewed, annotated and thematised as follows: **(1)** Factors influencing and/or influenced by people with SCI's social participation and employment, **(2)** Experiential accounts from people living with SCI relating to community participation and work return and non-return.

**1) Factors influencing and/or influenced by people with SCI's social participation and employment**

The first of these two themes is concerned with what previous studies reported in terms of demographics, and physical, psychological and environmental factors as well as how these could affect people living with SCI's levels of social participation and employment. Also, how employment and social participation after SCI could affect those factors.

**A) Demographics**

*A.1. Gender*

It was interesting to note that in all the reviewed papers, the majority of the sample, if not the entire sample, was composed of male participants. This might have been due to the previously mentioned observation of males being affected more by SCI than females. Anderson and colleagues (2007) reported the same observation in their literature review on determinants of SCI RTW, where most of the studies had male participants.

With regard to SCI employability, work was found to be an important component of male identity (Burns, Boyd, Hill, & Hough, 2010). Although a literature review by Yasuda, Wehman, Targett, Cifu, and West (2002) found no significant correlation between gender and SCI RTW, Anderson and colleagues' review (2007) found that the relationship between gender and post-SCI work was significant. Recent findings by Reinhardt, Post, Fekete, Trezzini, and Brinkhof (2016) supported Anderson and colleagues (2007), where SCI men were more likely to be at work than women.

However, both of these reviews (Anderson et al., 2007; Yasuda et al., 2002) suggested that while SCI men were twice as likely as women to be in paid work, SCI women were more likely to be engaged in homemaking, volunteer work or studying (Yasuda et al., 2002). Perhaps unsurprisingly, men are more likely to have higher earnings following SCI (Krause & Terza, 2006), however, those SCI gender differences could be highly influenced by the availability of financial resources, the nature of work (such as whether it was manual or non-manual), current age and age at injury (Anderson et al., 2007).

### *A.2. Age*

In the majority of the reviewed papers, the average age range of the participants was 18 to 65, which typically represents the working age group for able-bodied people. However, the likelihood of post-SCI employment within this age group varied.

In a large retrospective study comprising participants living with SCI and aged between 18 and 64, age was reported as a significant factor affecting employment, as those younger were more likely to work (Krause, Saunders, & Staten, 2010). Furthermore, while Ottomanelli and colleagues (2011) reported that SCI veterans who were employed were significantly lower in age than those who were not, Lidal, Hjeltnes, Røislien, Stanghelle, and Biering-Sørensen (2009) found that for each year following SCI, the likelihood of early withdrawal from a range of occupations increased. Similarly, Hirsh, Molton, Johnson, Bombardier, and Jensen (2009) examined the relationship between age and employment status for people living with SCI and found that those aged between 45 and 54 were either employed or more likely to be employed than those aged between 55 and 64.

Reasons cited for older SCI persons being less likely to RTW were employers' reduced motivation to hire disabled individuals with a short time left in their professional lives, the decreased ability of older individuals to adapt to their SCI and the reduced desire to do more work after SCI (Anderson et al., 2007). Supporting results showed that SCI participants who were younger worked more hours following their injuries (Reinhardt et al., 2016), while those who were older, although believing in the importance of work in

general, thought that work was not a priority for themselves anymore (Schedin Leiufrud, Reinhardt, Ostermann, Ruoranen, & Post, 2014).

On the other hand, on a small-scale, a contradictory study demonstrated that for 57 SCI individuals with a mean age of 33 years old, age was not significantly related to current work status (Schönherr, Groothoff, Mulder, & Eisma, 2005b). Furthermore, age was not found to be related to quality of life (QoL) and well-being when those successfully rehabilitated into employment were compared with those who were not (Chapin & Holbert, 2010).

### *A.3. Ethnicity*

Previous research has reported the significant relationship between ethnicity and employment for people living with SCI, where SCI Caucasian people were considerably more likely to be employed following their injuries (Anderson et al., 2007; Yasuda et al., 2002), as well as having higher rates of employment and more years of education than other ethnicities (Krause et al., 2010). For instance, in an examination of employment outcomes one year post SCI, although Caucasian people were more likely to be older females with lower functional abilities, they were more likely to have higher educational levels and higher rates of employment than Hispanic people (Arango-Lasprilla et al., 2009). Moreover, a literature review by Ottomanelli and Lind (2009) reported that even after controlling for educational level, Caucasian people with SCI were more likely to be in gainful employment compared to other minority groups. Also, according to a multicentre analysis, while both minority groups and white people had similar employment rates before SCI, people from minority groups were more disadvantaged in terms of employment following SCI (Hess, Ripley, McKinley, & Tewksbury, 2000).

Socioeconomic status could have influenced such findings (Hess et al., 2000). For example, when white Americans were compared to African Americans, the latter had lower scores on economic self-sufficiency and social reintegration regardless of the employment status following SCI (Meade, Lewis, Jackson, & Hess, 2004).



#### *A.4. Education*

Educational attainment was among the well-documented factors affecting life after SCI. For example, education was positively associated with high QoL (Chapin & Holbert, 2010), while in a study looking at QoL and self-esteem among 60 paraplegics living in Brazil, education correlated with all domains of QoL (Blanes, Carmagnani, & Ferreira, 2009). In this study, participants had low educational levels (that is, the majority of participants had finished primary school only) and therefore experienced limited job opportunities. Most participants were forced to rely on social security benefits and also suffered poor QoL.

The role of education in post-SCI employment was noted in a number of reviewed studies, where more years of education were reported as a strong predictor of employment (Schönherr et al., 2005b; Yasuda et al., 2002) and earnings among people living with SCI (Ramakrishnan, Loh, & Omar, 2011). For instance, while Crewe (2000) found that completing community college degrees after SCI was a key to successful employment, Reinhardt and colleagues (2016) emphasised this and additionally reported that those with higher educational levels showed an increase in their working hours following SCI compared to those with lower educational levels.

Anderson and colleagues (2007) summarised key reasons behind the relationship between SCI higher employability and higher educational levels. One of these was that higher educational attainment was linked to higher economic status and therefore greater employment options. Another reason was that most SCI individuals who RTW following their injuries worked in professional, administrative or managerial positions, which required high educational levels. A third reason was that individuals with higher educational attainment needed fewer changes and adjustments to do their jobs than those with lower educational attainment. Finally, people living with SCI who had attained higher education were associated with more involvement in the community as well as more autonomy and motivation than people living with SCI who had lower educational attainment.

Despite this, two papers in the reviewed literature did not find education to be a strong predictor of SCI employment. While Krause and colleagues (2010) reported a moderate

relationship between SCI employment status and education, which varied depending on the severity of the injury, Chapin and Kewman (2001) conducted a qualitative study in which they interviewed both employed and unemployed SCI participants, who generally reported that a lack of education was not a barrier to RTW. Similarly, Ottomanelli and colleagues (2011) reported that more years of education did not predict the employment status of their SCI participants.

#### *A.5. Work experience, nature and intensity*

Factors related to SCI work included three main topics, that is: *pre-SCI work experience*, *type of work* and *work intensity*. Having pre-SCI work experience was found to increase the likelihood of RTW following SCI by 1.3 times (Krause et al., 2010). However, it should be noted that Yasuda and colleagues (2002) found that this was significant only during the first few years following SCI. Further, while returning to a familiar job post SCI was found to facilitate employment (Hay-Smith, Dickson, Nunnerley, & Anne Sinnott, 2013), limited work experience and lack of formal training prior to SCI led to limited expectations of RTW following the injury (Bergmark, Westgren, & Asaba, 2011).

The nature of work was also found to influence employment status following SCI. Murphy and Young (2006) reported self-employment prior to SCI positively influenced RTW following the injury. In a similar vein, Ramakrishnan and colleagues (2011) found that RTW was higher among self-employed people living with SCI as opposed to those with contracted jobs.

Furthermore, SCI participants are more likely to return to non-manual jobs that require less physical involvement. According to Fadyl and McPherson (2010), one of the decisions influencing RTW after SCI is the possibility of finding a suitable job for the current physical condition. Schedin Leiufrud and colleagues (2014) found that those who had done manual jobs before their SCI became interested in office type jobs after their SCI. Interestingly, results from Crewe's (2000) study showed that the largest working group for people living with SCI had started to work in rehabilitation services following their injury.

Finally, in this regard, working full-time versus part-time had an influence on SCI employment. Those who reported excellent health after SCI were usually full-time workers, while those who reported health complications, such as pain and uncontrolled spasticity after SCI, were usually part-time workers (Meade, Barrett, Ellenbogen, & Jackson, 2006).

## **B) Physical health**

### *B.1. Physical ability*

A paper looking at the experience of leaving the spinal unit and returning to the community reported that SCI patients' priority during the first two years following the injury was to improve their physical abilities, which was also something their rehabilitation therapists encouraged (Nunnerley et al., 2013).

With regard to adjustment following SCI, those with less severe secondary complications as well as higher mobility and activity reported higher rates of social participation (Craig et al., 2015) and employment (Ottomanelli et al., 2011). Similarly, a group of people living with SCI who had high functional abilities aimed to find a job (Ottomanelli, Bradshaw, & Cipher, 2009), while a group of SCI individuals with impaired mobility were found to have significant restrictions on daily social activities, including employment (Blanes et al., 2009).

Injury severity (that is, injury level) was also a physical-related variable that influenced SCI social participation and employment; Krause and colleagues (2010) found that less severely injured patients were more likely to go to work following SCI. While quadriplegic people were found to need more help with self-care and domestic activities (Schönherr et al., 2005b), paraplegic people were more likely to be independent and hence go to work (Reinhardt et al., 2016).

### *B.2. Independence*

The literature suggests that going back into the community and having to be independent was viewed as a difficult task to achieve following SCI (Nunnerley et al., 2013). This means that many people living with SCI consider losing independence a challenge to social participation (O'Connor, Young, & Saul, 2004). This is highlighted by the fact that many

healthcare professionals working in rehabilitation programmes do not describe realistic levels of independence to their SCI patients upon their discharge, as they tend to underestimate their value (Nunnerley et al., 2013). Further, social expectations around the importance of autonomy could cause a challenge to social participation for people living with SCI, as they will often face problems with establishing a balance between the need to rely on others and the need to maintain a good social image of being independent (O'Connor et al., 2004).

In terms of employment, while Fadyl and McPherson (2010) found that autonomy was important in the decision to RTW following SCI, Krause (2010) found that there was no significant difference between SCI individuals who were partially independent in mobility and those who were fully independent in mobility in terms of their vocational outcomes.

### *B.3. Injury onset*

Factors related to time since injury were also noted in the literature as having an impact on employment for people living with SCI. Although some studies did not find injury onset as a predictor of employment status following SCI (Hirsh et al., 2009), many others did.

According to a review of the literature, most SCI individuals do not RTW immediately following their hospitalisation (Anderson et al., 2007). Although SCI employment rates increase over time (Reinhardt et al., 2016), the time it takes for people living with SCI to RTW varied in different studies. One example was noted by Chan and Man (2005), where only two out of 16 SCI participants started applying for jobs during hospitalisation, whereas the rest did not start this process until one to two years post hospital discharge. Other examples included participants who RTW in an average of two to three years (Bergmark et al., 2011) and five years (Krause & Pickelsimer, 2008) post SCI. However, for periods longer than these, a number of studies indicated that SCI individuals were less likely to RTW after the first decade post their injuries if they had not already done so (Lidal et al., 2007).

#### *B.4. Medical complications*

Several studies reported that medical complications post SCI could affect the ability to RTW (Lidal et al., 2007). Although a study by Schönherr and colleagues (2005b) reported no relationship between health and SCI employment status, the literature, as will be seen below, was replete with studies specifying the type of medical complications associated with low social participation and RTW rates among the SCI population.

Among those medical complications was chronic pain and fatigue (Schopp et al., 2007a). People living with SCI talked about how they became inactive following their injuries and how chronic pain limited their daily activities (O'Connor et al., 2004). Pain and fatigue were also believed to influence the decision to RTW, as these factors could determine the amount of work that one could do after SCI (Fadyl & McPherson, 2010). In contrast, low levels of fatigue and pain were associated with high levels of SCI social participation (Craig et al., 2015) and RTW following SCI (Wilbanks & Ivankova, 2015).

Another medical complication associated with unemployment for people living with SCI was the difficulty with bowel and bladder control and its scheduling. Results from a focus group showed that in both stages of job consideration and job maintenance, bowel and bladder management and scheduling were considered barriers for SCI individuals returning to work (Chan & Man, 2005). Supporting results from O'Connor and colleagues (2004) showed that as part of their day-to-day tasks for work preparation, people living with SCI found that bowel and bladder management needed a long time. Hence, this overall need for prolonged procedures for preparing to go to work were seen as barriers to SCI employment (Hay-Smith et al., 2013).

### **C) Psychological health**

#### *C.1. The ability to reintegrate into community*

Generally, the ability to reintegrate into the community following SCI could affect the ability to RTW. Losing companionship with other SCI persons after being discharged from hospital caused feelings of insecurity, isolation and loneliness (Dickson, Ward, O'Brien,

Allan, & O'Carroll, 2011). This could be because SCI individuals identify more with each other than with able-bodied individuals (O'Connor et al., 2004), since similar capabilities could help form or modify beliefs about personal potential for success (Fadyl & McPherson, 2010).

### *C.2. Self-esteem*

Motivation was found to contribute to employment for people living with SCI (Crewe, 2000; Wilbanks & Ivankova, 2015). Similarly, Chan and Man (2005) found that employed SCI individuals regarded self-esteem as an important factor in their decision to RTW.

### *C.3. Self-efficacy*

In addition, self-efficacy predicted employment status (Umucu et al., 2016) and social participation following SCI (Craig et al., 2015). Chapin and Kewman (2001) found that those who were working post SCI had high self-efficacy in terms of tasks they were able to accomplish. On the other hand, those who were unemployed post SCI were less confident in their physical abilities if they were to RTW (Chapin & Kewman, 2001) and described difficulties in designing specific plans for their future and having control over them (Bergmark et al., 2011). Finally, self-perception of poor health was seen as a barrier to employment for people living with SCI (Krause & Pickelsimer, 2008), where unemployed SCI individuals seemed anxious, fearful and worried about letting their employers down (Chan & Man, 2005).

### *C.4. Coping*

Coping was also a psychological variable affecting SCI employment. Kent and Dorstyn (2014) suggested that effective coping was significantly related to being engaged in post-SCI vocational activities. As an illustration, Chapin and Kewman (2001) found that coping helped SCI individuals go to work, adjust readily to their jobs after the injury and embrace changes, while lack of coping resulted in SCI individuals having some issues with their employers, which reduced the possibility of staying or advancing in their jobs. Yasuda and

colleagues (2002) found similar results in their review, where termination of employment after SCI was related to declines in coping with the injury.

### *C.5. Hope*

Hope is a psychological variable that could influence SCI employment. In papers by Lohne and Severinsson (2004) and O'Connor and colleagues (2004), hope was related to physical aspects, where a barrier to work was related to SCI participants wanting to go back to their pre-injury life of standing and walking. However, hope facilitated the process of post-SCI employment in a number of studies (e.g., Blake, Brooks, Greenbaum, & Chan, 2017; Hay-Smith et al., 2013), and predicted its continuity for a five year-period (Krause & Pickelsimer, 2008).

### *C.6. Satisfaction*

Life satisfaction has been found to be one of three main domains that are clinically important for employment for people living with SCI (Kent & Dorstyn, 2014), meaning satisfaction and SCI employment status are positively correlated (Yasuda et al., 2002). When applying this correlation to field observations, those with SCI who were unemployed felt more dissatisfaction over their perceived choices in regard to employment-related needs (Schopp et al., 2007a), while those who were employed were more satisfied (Kent & Dorstyn, 2014) and reported good psychological health (Chapin & Kewman, 2001).

### *C.7. The value of work*

Work had different meanings for different SCI individuals. To many, being employed meant having good self-esteem (Schedin Leiufrud et al., 2014), being independent (Chan & Man, 2005), communicating with others (Schedin Leiufrud et al., 2014), contributing to society (Wilbanks & Ivankova, 2015), returning to a 'normal' life (Hay-Smith et al., 2013) and having an income (Chapin & Kewman, 2001).

The vocational value of work also had an influence on the RTW process following SCI. Fadyl and McPherson (2010) found the value of work to be among the main components

contributing to the decision to RTW after SCI, whereas Crewe (2000) found it among the main facilitators to achieving SCI RTW. Further, those who had already RTW following SCI, when asked to rate the importance of work in their lives, reported higher scores than those who had not yet RTW (Chan & Man, 2005).

## **D) Environmental factors**

### *D.1. Environmental accessibility*

Different environmental factors had a positive association with social participation and employment for those living with SCI. Among those factors was environmental accessibility; while Löfvenmark, Norrbrink, Nilsson Wikmar, and Löfgren (2016) reported lack of accessibility as a barrier to day-to-day activities, Babamohamadi, Negarandeh, and Dehghan-Nayeri (2011) reported it as a barrier to social participation and autonomy for those living with SCI. The environmental accessibility of the workplace was reported to influence the decision to recommence work after SCI (Fadyl & McPherson, 2010), where it could be either a hindrance (Blanes et al., 2009) or a facilitator to achieve this decision (Wilbanks & Ivankova, 2015).

### *D.2. Transportation*

Other environmental factors included transportation. While some research (Anderson & Vogel, 2003) indicated that community transportation was among the domains enabling the highest levels of satisfaction for people living with SCI, other work (Lidal et al., 2007) indicates that challenges with transportation were ranked the number one barrier to SCI RTW.

### *D.3. Community resources*

Two studies reported that rehabilitation programmes primarily focused on physical care, offering limited resources for psychological care and vocational training (Nunnerley et al., 2013; O'Connor et al., 2004). Psychological resources were found to significantly relate to SCI vocational outcome (Kent & Dorstyn, 2014), where emotional support could play an



important role in the decision to RTW following SCI (Fadyl & McPherson, 2010). Social support and networking in the community were also found to help SCI individuals manage their psychological well-being (Babamohamadi et al., 2011), and therefore predicted (Anderson et al., 2007) and facilitated SCI employment (Murphy & Young, 2006).

Other studies (Schedin Leiufrud et al., 2014), indicated that SCI patients complained about being offered meaningless jobs by the welfare system that did not match their capabilities or qualifications. Similarly, a group of SCI individuals reported being on welfare benefits because there were limited job opportunities for people with disabilities offered by their communities (Blanes et al., 2009). Many of those who did manage to RTW following SCI withdrew from work due to limited community resources in terms of training and support (Anderson et al., 2007).

The awareness of people living with SCI of community resources can also play an important role in their RTW process. Ottomanelli and colleagues (2009) emphasised the relationship between awareness of community resources and SCI RTW, where those who showed more awareness were more likely to RTW. Supporting results showed that when comparing Caucasian and Hispanic SCI individuals, the latter were less likely to RTW due to lack of vocational information in their community (Arango-Lasprilla et al., 2009).

#### *D.4. Financial aspects*

Factors related to finance could have an impact on post-SCI employment. According to Anderson and Vogel (2003), those who RTW following SCI were usually dissatisfied with their low income. Ramakrishnan and colleagues (2011) identified differences in earnings among 76 participants with SCI and found that only a minority were earning more after SCI compared to what their earnings were prior to SCI.

In contrast, when comparing those who RTW following SCI with those who were on social benefits, the latter had a lower average yearly income (Ottomanelli et al., 2011) and merely wanted to make ends meet through the disability allowance (Chapin & Kewman, 2001). Thus, relying on the disability allowance could be seen as a disincentive to RTW following SCI (Ottomanelli et al., 2011) due to the fear of losing social benefits (Anderson et al.,

2007). Supporting results showed that among the reasons some veterans with SCI did not want to RTW following their injuries was that they were not in need of the income from work (Ottomanelli et al., 2009).

#### *D.5. Vocational rehabilitation (VR) services*

Getting individuals back to work following SCI is considered one of the goals of the vocational services provided during rehabilitation. However, this can be challenged by a lack of awareness about the availability of such services among SCI individuals (Ottomanelli et al., 2009). It can also be challenged by the limited availability of these VR services for SCI individuals (Anderson et al., 2007), which may be regarded as a barrier to post-SCI employment. A third challenge is related to how these services were provided; for example, rehabilitation specialists in Nunnerley and colleagues' (2013) study had a pre-determined hospital discharge check-list, which only matched the SCI individual's level of injury regardless of his or her personal needs.

Despite these challenges, other studies reported that VR specialists could provide different types of support to facilitate RTW for people living with SCI (Anderson et al., 2007). Furthermore, these specialists can contribute to further vocational development (Crewe, 2000) by recognising the unique needs of SCI individuals and tailoring rehabilitation programmes accordingly (Hay-Smith et al., 2013). VR specialists could also provide a bridge between SCI individuals and employers, taking a partnership approach to providing vocational support, encouragement and guidance (Hay-Smith et al., 2013). Finally, VR specialists could play a fundamental role in securing jobs for SCI individuals (Lidal et al., 2007), assisting them with regaining their stamina for work, suggesting and applying modifications in the workplace (Wilbanks & Ivankova, 2015) and helping in job maintenance through different interventions (O'Hare & Murphy, 2017).

#### *D.6. Social stigma*

Many SCI individuals face social stigma in their communities; for example, many able-bodied people mistakenly think that SCI causes mental impairment along with physical

impairment, which is a judgment that makes people with SCI feel worthless and inferior (Dickson et al., 2011). SCI individuals are usually seen as either invisible or overly visible, which can serve to make them feel like outsiders who are different to others (O'Connor et al., 2004).

Employers, in particular, can stigmatise people with SCI. The negative image and attitude of society towards employing people with SCI (Babamohamadi et al., 2011), mostly illustrated in the misconception about their capabilities to work, could be a barrier to RTW after SCI (Hay-Smith et al., 2013). In Chan and Man's (2005) study, for instance, SCI participants had their job applications accepted, but were rejected by employers after appearing with their disabilities at interviews.

#### *D.7. Employers*

Even employers who do not intend to discriminate against people with SCI or to stigmatise them could influence post-SCI employment in different ways. Murphy and Young (2006) identified the central role of employers in adjusting the environment to meet the physical requirements of people living with SCI and preparing a healthy organisational climate. However, Anderson and colleagues (2007) argue that the limited knowledge or limited authority of some employers could decrease their ability to accommodate SCI employees in the workplace, which in turn decreases the likelihood of SCI RTW. On the other hand, supportive and understanding employers were reported by Hay-Smith and colleagues (2013) as facilitating RTW for their employees following SCI.

#### *D.8. Work accommodations*

Stemming from the above, it can be seen that the need for work accommodations can either facilitate or hinder post-SCI employment. Effective forms of adjustments to the SCI workplace include flexible hours and tasks (Murphy & Young, 2006) as well as installation of assistive devices, such as computers and dictation software (Wilbanks & Ivankova, 2015). Lacking such necessary accommodations for the SCI individual could deter the process of RTW (Chapin & Kewman, 2001).

However, since changes in appearance and the need for special equipment could affect how able-bodied colleagues perceive SCI individuals, this was reported as a major deterrent to take the decision to RTW following SCI (Fadyl & McPherson, 2010). Some SCI individuals felt embarrassed to ask for help from their colleagues at work when they needed to (Chan & Man, 2005) as they did not want to come across as a burden to others (Dickson et al., 2011).

## **2) Experiential accounts from people living with SCI relating to community participation and work return and non-return**

The second main theme in this literature review consisted of six studies which aimed at exploring the experience of people living with SCI in relation to social participation and employment, whether this was about RTW or work absence. All six studies used a qualitative design, where data were analysed inductively.

All six studies were experiential and thus emerged in this literature review as the consequence of the aim to try to say something about how SCI individuals made sense of their return to the community, employment and/or unemployment following SCI.

In order to explore these experiential studies, two sub-themes will be introduced. The first of these looks at the experience of people living with SCI in terms of social participation during the period of transition from hospital to home. The second looks at the vocational experience from the perspective of those living with SCI who already RTW following the injury as well as those who did not.

### **A) The social experience of transitioning from hospital to home for people living with SCI**

This first sub-theme included two studies that explored the meaning of going back to the community following SCI hospital discharge. While the first study gave an insight into the positive experience of SCI social participation, the second did the opposite.

*A.1. The seemingly positive experience of social participation after hospital discharge for people living with SCI*

The first study was by Van de Velde, Bracke, Van Hove, Josephsson, and Vanderstraeten (2010), who used a grounded theory (GT) approach and semi-structured interviews to understand perceived experiences of transitioning to home among 11 male paraplegic people two months after their hospital discharge. All participants used to work prior to their injury.

The findings of this study suggested that it was vital for SCI participants to be occupied by activities, even if those activities were meaningless and just “to kill time”. They believed that these activities could clear their minds and give them the feeling of being human:

*I always wanted to play the guitar [...] now I took the opportunity to learn [...] music is inside everyone, I just use it to feel I am alive (P5-D13, as cited in Van de Velde et al., 2010, p. 351).*

Furthermore, performing more meaningful activities and having a sense of achievement were perceived as important forms of social participation, enabling people living with SCI to feel like valuable members of their society (Van de Velde et al., 2010).

Participants’ experiences in this study were also influenced by the amount of control they regained over their environmental conditions and by performing activities that helped them find individuals who could estimate the importance of their actions. To elaborate, contributing to society and getting involved in activities that made participants with SCI feel important, such as the feeling of being needed, were fundamental features of their experience and also enhanced their social participation (Van de Velde et al., 2010).

*A.2. The seemingly negative experience of social participation after hospital discharge for people living with SCI*

On the other hand, Dickson and colleagues (2011) explored the challenges experienced by SCI individuals when transitioning from hospital to home and used semi-structured interviews and interpretative phenomenological analysis (IPA) to illustrate this. The

researchers reported the negative experiences their participants had in adjusting to their new lives after leaving the spinal unit. While friendship with other people living with SCI at the hospital seemed to facilitate the ability to cope with injury, as a result of being surrounded by people in similar situations, being discharged from hospital and the ensuing feelings of isolation, vulnerability and insecurity seemed to hinder the process of coping:

*Oh, it was strange; I didn't want to leave them [fellow patients]. I mean that sounds terrible (Lucy, as cited in Dickson et al., 2011, p. 466).*

Dickson and colleagues (2011) reported that their participants had feelings of belonging to the spinal unit, where they received “first-class” care and support. After being discharged, those SCI participants could not sustain their physical fitness nor handle their depression. They felt disappointed about support services outside the hospital:

*I'm quite sure I'm not the first person to get depressed after finding out you're crippled for the rest of your life. But what I'm surprised about is the fact that routinely there's not some sort of follow-up (Colin, as cited in Dickson et al., 2011, p. 468).*

Another challenge for SCI participants in this study was the difficulty of living with able-bodied individuals at home. Although SCI participants experienced a sense of guilt for relating to their SCI ‘family’ at the hospital more than with their own families, they were daunted by the transition from living with fellow SCI patients to living with able-bodied individuals. This was due to the negative emotions (such as being inferior and worthless) that those SCI participants had as a result of others’ reaction to their injury. Participants talked about embarrassment over being a burden on others and described how this resulted in feelings of loneliness and isolation (Dickson et al., 2011).

## **B) The vocational experience of transitioning from employment to unemployment and vice versa for people living with SCI**

A more specific goal for people living with SCI than the ability to socially participate in the community is the ability to work. Four studies aimed to understand the lived experiences

of SCI individuals who were employed prior to their injuries and who either RTW or did not afterwards. The following is a description of those findings:

### *B.1. The experience of RTW*

Wilbanks and Ivankova (2015) collected their data using semi-structured interviews and photographs of assistive technology devices, then analysed them using Morse and Richard's coding technique (2012). The researchers investigated the experience of RTW among individuals with SCI, 24 to 37 years following their injuries.

Those SCI participants who were employed expressed positive feelings towards the vocational and medical care they received when they were first injured, which influenced their ability to find and maintain employment later on. They also expressed their satisfaction with the support they received in the work environment, including the support from their employers and the benefits of using assistive devices at work:

*This desk in my office was specially made for me. I had it made higher and narrower so I could have more room in my office (G-man, as cited in Wilbanks & Ivankova, 2015, p. 742).*

Motivation was also part of these participants' positive experiences of post-SCI employment, where rehabilitation professionals and other people were considered role models who influenced the RTW path:

*I wanted to be a teacher, and then met people in the rehab program and I liked them so much that it made me want to go into their program and get a degree (Sally, as cited in Wilbanks & Ivankova, 2015, p. 744).*

Participants in this study described the decision to RTW following SCI as coming naturally and intrinsically. They also described their ambitions to continue working and fight social stigma, and how overwhelmingly positive this experience was.

Participants in this study cited improvements in physical fitness, state of mind and financial stability as benefits of RTW (Wilbanks & Ivankova, 2015).

However, despite those benefits, participants also described challenges they faced as part of their SCI RTW experience. According to them, it was difficult to maintain good stamina and a regular schedule whilst also fighting prejudice at work when employers and colleagues underestimated their capabilities to perform well (Wilbanks & Ivankova, 2015).

A more recent study was by Holmlund, Hultling, and Asaba (2018), who similarly explored the experiences of those who RTW following their SCI. In this study, participants' injury onsets ranged from three to 10 years, and all had managed to return to paid work at some point after their injuries. For the purpose of conducting this study, participants met together for eight weekly sessions to share stories and photos that they had taken with their smartphones that reflected their feelings and views about work. Holmlund and colleagues (2018) used photovoice methods and narrative analysis (NA) to collect and analyse data from those participants.

Initially, participants viewed RTW as the only way to re-normalise life after SCI and make a difference in their society. However, this depended on how much they felt welcomed and understood by employers in terms of their personal needs:

*I just want to blend in, I do not want to make a lot of noise, it would have been so nice to just be able to get my own coffee mug and my lunch*  
(Participant, as cited in Holmlund et al., 2018, p. 6).

Further, when they wanted to negotiate their potential to RTW, participants were unclear as to where to go to for support or what the responsibilities for certain stakeholders were:

*No, I would really like to see that there were ... guidelines and like, a certain sequence, what steps that should be taken when one has, like, suffered a spinal cord injury, instead of the Employment Service and the SSIA trying to agree with each other, based on their guidelines that are not at all relevant for the type of situation that we find ourselves in*  
(Participant, as cited in Holmlund et al., 2018, p. 7).



However, the support was better when they began to work, as most participants felt similar to everyone else and competent to complete tasks; they believed that their colleagues did not view them as disabled or prone to have low performance. Asking for help was not an issue apart from sometimes being challenged to decide how much help to ask for without drawing too much attention (Holmlund et al., 2018).

Overall, participants felt that they were responsible for finding solutions that could help them integrate into their everyday work. Those solutions came in the form of strategies related to their health, such as the type of wheelchair they could use at work and so on (Holmlund et al., 2018).

### *B.2. The experience of work non-return*

Bergmark and colleagues (2011) explored the vocational experience of individuals living with SCI from the perspective of those who were on sick leave following their injuries. The authors explored the expectations around RTW for those SCI individuals through semi-structured interviews and constant comparative analysis.

Participants in this study talked about their personal experience of regaining control over their bodies, understanding the adjustments needed after the injury and the time it took to re-learn, prioritise and conduct day-to-day detailed tasks post SCI. However, they were not motivated to be rushed to RTW while they were still not fully able to. Instead, they tried to fill their day with activities that they considered “*meaningful*” and that could prepare them to RTW in the future. The only challenge with this, however, was their expectations around how long they would be doing these activities, which they thought would only be for a short period. These participants doubted their ability to maintain productivity for long periods if they officially RTW:

*Still trying to keep up my physical training, and so on, fairly regularly, so as to maintain all these small things that one has to consider anyway when one goes to work or school, a type of schedule for an ordinary day (Participant, as cited in Bergmark et al., 2011, p. 2555).*

Although all participants in this study had a strong desire for work, not all of them had positive expectations to RTW in the labour market. This was either due to limited academic background, lack of previous work experience or low expectations of being able to maintain employment (Bergmark et al., 2011).

### *B.3. The vocational experience from the perspective of both work returners and non-returners*

Hay-Smith and her colleagues (2013) explored the personal experience of RTW from the perspective of different groups of people. This study included those SCI individuals who pursued work following their injuries, those who were job seekers and those who were unemployed. The study also explored the same experience from the perspective of VR professionals working with the SCI participants in rehabilitation programmes.

A total of 12 relatively young SCI individuals (23-56 years old) between two to three years post injury and six VR professionals participated in this study. In order to understand the personal accounts of paid work in all participants, semi-structured interviews and IPA were used to collect and analyse data respectively (Hay-Smith et al., 2013).

In this study, employed participants went back to their previous employers, while job seekers experienced disappointment over not being able to meet their ambitious employment outcomes. On the other hand, unemployed participants thought work was not a priority for them, as they wanted to improve their physical abilities before looking for work. Furthermore, two of the VR professionals participating in this study were diagnosed with SCI, and therefore believed that they were able to be *“inside”* the experience of SCI employment and bring a lot to the VR programme (Hay-Smith et al., 2013).

Unemployed participants regarded RTW as a return to ‘normal’ life after SCI; they felt work would come at a later stage, after they improved other aspects of their lives after SCI. In other words, RTW was not a high priority, but rather *“the icing on the cake”* and *“the final piece of the puzzle to fit in”* (Hay-Smith et al., 2013).

On the other hand, while job seekers and unemployed SCI participants believed that *“being occupied throughout the day”* was important in structuring their lives and increasing their sense of contribution and productivity, employed participants believed that paid work contributed to an increased sense of self-worth, especially for male participants who emphasised the necessity of having an income and supporting their families as *“breadwinners”* (Hay-Smith et al., 2013).

Finally, where continuing with employment was unquestionable among employed participants, job seekers and unemployed SCI participants were hopeful but at the same time cautious about whether they were able to work or not. Particularly those unemployed viewed their SCI as a *“grieving process”*, which required a lot of adjustment, and because of the physical barriers caused by SCI, employment was something only to hope for (Hay-Smith et al., 2013).

### **Summary of the literature review**

As seen above, research has suggested that SCI can significantly affect social participation, including work, and thus employment rates following SCI remain low. However, with the right support, facilitation and capabilities, more people with SCI can RTW.

The area of SCI employment and social participation is a wide-ranging one, which includes discussions on various life aspects that can facilitate or hinder RTW and social activities following SCI, as well as discussions on successful and unsuccessful experiences of community reintegration and RTW following SCI.

### **Rationale for the first study based on the above review of the literature**

Although a small number of experiential studies explored topics relevant to SCI employment and social participation, more research is warranted to tackle issues related to the particular experience of SCI unemployment.

Further, over the past two decades, research has focused mainly on factors determining work re-entry after SCI. In the literature review above, the first main theme described aspects that could either facilitate or hinder the process of going to work following SCI. For

example, previous studies showed that age was a demographic factor that affected the likelihood of post-SCI employment, meaning the younger the SCI person was, the more likely he or she was to RTW post SCI and vice versa. Another example was lack of wheelchair accessibility in the workplace, which was identified as a barrier to SCI work. Hence, there seemed to be a sense of saturation in the SCI literature in terms of focusing on RTW factors, which were usually illustrated in lists of facilitators, barriers or predictors to this process without going deeply into how this was experienced and interpreted by people living with SCI. Thus, it is warranted to conduct further research that allows more space for participants to talk openly about how they could make sense of their experiences of leaving work and how they generally view them.

Many of the reviewed studies focused on aspects related to SCI RTW or the experience of unemployment for the purpose of understanding the process of RTW after SCI. This resulted in little attention being paid to the sole experience of unemployment and what it means to go through this significant stage, regardless of whether RTW was a current aim or not. Due to the significance of the experience of SCI unemployment, research in this area is warranted; it can be argued that the impact of unemployment would be expected to be more significant for SCI individuals who used to have a job before the injury but stopped working permanently afterwards than those who have plans to RTW.

While the first study in this thesis aimed to fill the above gaps in the literature, it also aimed to contribute to the knowledge of professionals working in the field of VR regarding the experience of SCI work absence, in order to help tailor rehabilitation programmes according to the needs and the expectations of SCI individuals. Ultimately, on a larger scale, understanding the personal accounts of unemployment for people living with SCI may contribute to the increased rates of RTW among this population, which, in turn, can help decrease the economic burden on society.

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## Chapter 3: Methodology

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### Introduction

The topic of unemployment following spinal cord injury (SCI) is an extensive one that can be looked at from different angles. **Interpretative phenomenological analysis (IPA)** (Smith, Flowers, & Larkin, 2009) was chosen as the research approach for exploring the meaning of the particular lived experience of men who left their jobs after acquiring SCI. This chapter aims to justify this choice and its suitability for the above topic; however, before doing this, it is important to introduce qualitative and phenomenological research in psychology as well as the theoretical framework of the chosen method of IPA.

### Qualitative research in psychology

#### **Qualitative research versus quantitative research in psychology**

Quantitative psychologists have been influenced by the school of 'positivism' in that they have an interest in using empirical research in order to either confirm or reject hypotheses (Ashworth, 2015; Howitt, 2010). However, qualitative psychologists work in a different way (Howitt, 2010), as they warrant their findings through their philosophical stances rather than testing assumptions (Chamberlain, 2015).

Quantitative psychology is limited in the ways in which it can address issues of everyday living (Flick, 2014); many qualitative researchers felt that they needed to get closer to the phenomenon under study and that if they were to explore human experiences, natural settings instead of laboratories were more appropriate to do so (Eisner, 2003).

The constant movement and expansion in the field of qualitative research is seen in the engagement of its intellectuals and scholars in community practice (Smith & Sparkes, 2016). However, it is worth drawing on pioneering work in qualitative research to see how

it initially offered an approach that was different from the predominant quantitative paradigm.

## **Pioneering work in qualitative psychology research**

### **The idiographic orientation**

The work of Gordon Willard Allport (1897-1967) is admired for its concern with the uniqueness of the experience and the behaviour of the individual (Ashworth, 2015). Allport's development of a 'theory of personality' viewed human personality as the individual's unique patterns of traits, attitudes and formations (DeCarvalho, 1991). His idiographic approach to research in psychology considered the self and its meaning and highlighted the importance of how factors specific to the individual can be formed and patterned in his or her life. Therefore, Allport's work is considered pioneering in qualitative psychology as a result of his use and analysis of personal documents and self-reports for the aim of understanding the individual (Ashworth, 2015).

### **The constructionist orientation**

Constructionist George Kelly (1905-1967) believed that individuals' acts are based on their construction of the world rather than a fixed, absolute version of the world. He saw individuals as being knowledgeable enough to categorise events happening in their world into constructs or 'interpretations', which they can modify depending on their own experiences. Thus, Kelly could be seen as a personal constructionist, because he viewed individuals' constructs as unique to them and did not prioritise the role of social basis when it comes to self and thought (Ashworth, 2015).

The early social constructionist George Herbert Mead (1863-1931), on the other hand, introduced 'symbolic interactionism', which was important for emphasising the production of the mind and the self through social interaction (Ashworth, 2015). Central to Mead's work was language, where he argued that the meaning of linguistic symbols is shared socially and not individually (Ashworth, 2015). Qualitative research in psychology is influenced by Mead's work in that it looks at the person first as a member of society then

as an individual in the contexts of both linguistic symbolic systems and embedded forms of cultural activities and practices (Ashworth, 2015).

While Mead and Kelly, as constructionists, argued that qualitative psychology is an attempt to make sense of reality through constructs or interpretations, those with a perceptual orientation viewed qualitative psychology as an attempt to investigate the 'lifeworld'. This division between construction and perception is similar to the one between the descriptive and interpretative phenomenologies of Husserl and Heidegger (Ashworth, 2015), as will be seen below.

### **Phenomenological research in psychology**

#### **A brief history of phenomenology**

'Phenomenology' is a Greek-origin term which means 'appearance', and therefore phenomena, as defined by philosophers, are 'things as they appear' as opposed to 'things as they are in reality' (Spinelli, 1989). Influenced by the work of its founder Edmund Husserl (1859-1938), phenomenology aims to study the human experience; it commits to the idea of understanding what it is like to experience the world (Smith et al., 2009). This commitment of phenomenology to the human experience has been of interest to researchers in psychology (Willig, 2008b), and particularly those in qualitative psychology (Elliott, Fischer, & Rennie, 1999).

Although the basis of phenomenology was established by Husserl, it would be wrong to consider his approach the sole one to phenomenology (Spinelli, 1989); Martin Heidegger (1889-1976) was a student of Husserl and had an influential approach that many researchers have embraced (Willig, 2008b). Heidegger criticised Husserl's phenomenology for being too theoretical and abstract, and argued that it is not possible to view any knowledge without an interpretative lens (Smith et al., 2009). While Husserl was concerned with general processes of psychology, such as perception and consciousness, Heidegger was more concerned with the inquiry into the ontology and conceptualisation of existence as well as with the actual activities that present the world to us in a meaningful way (Smith et al., 2009).

Heidegger's existential phenomenology argues that an individual's existence is directly related to creating meaning for his or her experience, and that this meaning is the result of the individual's choice (Spinelli, 1989). His phenomenology aims to start with events that take place existentially, meaning the self and the situation both exist in one structure (Kugelmann, 2004).

Other figures in existential phenomenology, such as Maurice Merleau-Ponty (1908-1961) and Jean-Paul Sartre (1905-1980), have contributed to its development by emphasising the lifeworld (Ashworth, 2015). While Heidegger introduced the concept of 'worldliness', Merleau-Ponty introduced the subjective concepts of 'embodiment' and our relationship with the world (Smith et al., 2009). In other words, Merleau-Ponty emphasised that not being able to entirely capture the experience of the 'other' does not mean we should ignore it (Smith et al., 2009), but rather consider that: *"my perception of 'other' always develops from my own embodied perspective"* (Smith et al., 2009, p. 19).

On the other hand, Sartre's concern is about the future self rather than the present self, meaning the concern is always about what the self will become rather than what the pre-existing self is. This is also related to Sartre's concept of 'nothingness', which sees that one's perceptions about the self and the world are influenced by both absent and present things (Smith et al., 2009).

The work of Heidegger, Merleau-Ponty and Sartre moves away from the descriptive phenomenology established by Husserl and calls for an interpretative stance for phenomenology that allows us to become involved with the world and with others rather than being isolated creatures (Smith et al., 2009).

### **Doing phenomenological research in psychology**

Phenomenological psychologists have a common interest in researching the experience and typically access that experience through verbal accounts (Larkin, 2015), which requires choosing the correct method to do so (Keen, 1975). One of the more widely used methods in the field today is 'interpretative phenomenology' (Langdrige, 2007).



## **Interpretative phenomenology**

The theory of interpretation is referred to as 'hermeneutics' (Willig, 2008b), while the circularity in which humans engage when they try to understand something through interpretation or 'meaning-making' is referred to as the 'hermeneutic cycle' (Schleiermacher, as cited in Willig, 2008b). This means that there is a relationship between the whole and the part of a phenomenon, where each one of them is required to understand the other (Smith et al., 2009).

An early writer in hermeneutic phenomenology in its general form was Friedrich Schleiermacher (1768-1834), who offered a holistic view of the process of interpretation. Schleiermacher viewed the interpretation process as being, on one hand, concerned with the meaning of the text and, on the other, concerned with the individuality of the author or the analyst in interpreting the text (Smith et al., 2009).

Articulating a case for hermeneutic phenomenology was an aim of Heidegger, who was also concerned with examining something that is hidden in order to help bring it to light as well as examining what is manifest to uncover the ways it is connected to the hidden (Smith et al., 2009). Heidegger argued that interpretation is always a process of inevitably looking at new stimuli with the lens of previous experiences and preconceptions (Smith et al., 2009).

Following Heidegger and Schleiermacher, Hans-Georg Gadamer (1900-2002), an important writer in hermeneutics (Langdrige, 2007), agreed with Heidegger in that when we try to read and understand a text, we become engaged in a dialogue between the first understanding (i.e., the past), and the text per se (i.e., the present) (Smith et al., 2009). Therefore, central to the interpretative process of Gadamer is the importance of both history (Smith et al., 2009) and language, which are tools that can help reveal the historical context of the individual (Langdrige, 2007). It can be said then that both Gadamer and Heidegger, as hermeneutic phenomenologists, gave an insight into the dynamic relationship between the past (that is, the initial understanding) and the present (that is, the new phenomenon that is being investigated) (Smith et al., 2009).

## **Interpretative phenomenological analysis (IPA)**

IPA is the chosen qualitative and phenomenological method for the first study; its founder, Jonathan A. Smith, argued for a psychological approach that captures experiential accounts (Smith et al., 2009) from the perspective of individuals themselves (Willig, 2008b). Being widely utilised in psychology and relevant disciplines today, IPA is able to address a variety of research issues relevant to the human experience (Smith & Osborn, 2015). For example, IPA is used in research carried out in health psychology (Smith & Rhodes, 2015) and organisational psychology (Ahn, Dik, & Hornback, 2017). IPA is also used in relevant disciplines, such as in health education (Bennett, Harden, & Anstey, 2018), nursing (Young, 2009) and sociology (Osafo, Hjelmeland, Akotia, & Knizek, 2011).

IPA theoretically adheres to the connection between individuals' talk, thinking and emotions, and to the idea that this can be a complicated connection, meaning there is a possibility that some people find it hard to share their thinking and emotions. In these cases, the IPA researcher uses individuals' talk to interpret their thoughts and emotion (Smith & Osborn, 2015).

### **Theoretical foundations of IPA**

IPA has its roots in phenomenology (i.e., the study of the lived experience), hermeneutics (i.e., the interpretations of both the participant and the researcher) and idiography (i.e., the analysis of each particular case) (Smith, 2011). Those three areas of philosophy of knowledge (i.e., phenomenology, hermeneutics and idiography) constitute the theoretical foundations of IPA (Smith et al., 2009).

#### **A) Phenomenology**

IPA is aligned with Husserl in seeing that research in phenomenology aims to reflect the experience of everyday living; whether this experience is an activity or a response to an activity (Smith et al., 2009). Thus, IPA is concerned with examining the subjective lived experiences of humans. However, as research in IPA is always "*experience close*", it always examines "*the subjective experience of something*" (Smith et al., 2009, p. 33).

IPA mainly aims to analyse lived experiences (Smith et al., 2009), and mostly focuses on experiences that are of great existential importance to individuals (Smith, 2011). IPA also aims to explore, through personal reflection (Smith et al., 2009), how individuals perceive those experiences and what they particularly mean to them (Langdridge, 2007). That is, whereas IPA is concerned with everyday experiences, the meaning-making and sense-making by individuals of such experiences are what make them important (Smith et al., 2009).

IPA is phenomenological in that it allows this exploration to be conducted with no pre-defined categories, but rather with a freedom of expression (Smith et al., 2009). IPA researchers, in line with researchers in human and health science, aim to explore the human experiences of 'others' rather than their own, and therefore face the challenge of coherently collecting, analysing and interpreting personal accounts of a third person (Smith et al., 2009).

## **B) Hermeneutics**

Influenced by Heidegger's and Gadamer's hermeneutic phenomenology, IPA is always concerned with interpretation (Smith et al., 2009); IPA researchers tend to engage in a 'double hermeneutic process', where participants try to interpret and make sense of their personal experiences, while researchers try to interpret and make sense of the participants' accounts (Smith, 2004). In other words, IPA researchers have a dual role; they require the same personal and human skills as their participants, but at the same time they are required to employ those skills in a more self-conscious, systematic way that allows them to enter their participants' personal accounts of the experience under investigation (Smith et al., 2009).

IPA can also employ a 'double hermeneutic' in that it combines 'empathy' with 'questioning' (Smith et al., 2009). This means that IPA, in part, encourages the researcher to adopt the approach of being an 'insider' and try to understand the participant's view by standing in his or her shoes, while and at the same time asking the participant questions, and so stepping back and looking at him or her from a distance (Smith et al., 2009).

Thus, in IPA, phenomenology and hermeneutics are combined; the phenomenological stance allows the IPA researcher to get as close as possible to the experience of the participant, and without the hermeneutic stance that encourages the interpretation of both the researcher and the participant, this would be impossible (Smith et al., 2009).

### **C) Idiography**

Since experience is embodied and uniquely perceived, it can be approached idiographically. IPA has a commitment to idiography, or 'the particular', which operates at two levels (Smith et al., 2009). Firstly, IPA's commitment to the particular means that it aims to collect and analyse detailed and nuanced data, which are also rich and deep, and tends to adopt reflective, imaginative and creative designs in order to achieve this aim. In other words, IPA tends to use data collection methods that allow participants to tell their stories in a reflective way and express their feelings and concerns in as much detail as possible (Smith et al., 2009).

Secondly, IPA is committed to offering detailed analysis of particular events happening in particular contexts from the perspective of particular individuals (Smith et al., 2009). Hence, IPA researchers use small, purposive and homogeneous samples; IPA's idiographic stance means that it aims to produce case-by-case examination of the experience (Smith & Osborn, 2015).

However, IPA's idiographic commitment also means that it is possible to move from patterns found in each case to shared patterns, convergences and divergences between cases (Smith et al., 2009). This is to say, IPA researchers tend to identify emergent patterns (or themes) within the single case and subsequently identify them across multiple cases (Smith et al., 2009).

As the first study in this thesis used the method of IPA to conduct an individual-case analysis for each of its participants followed by a cross-case analysis, the following section will explain the rationale for this choice.

## **Rationale for using IPA in the first study**

### **The suitability of a qualitative design for the first study**

The first study aimed to explore what it was like to become unemployed following SCI, how this experience was perceived, how SCI individuals faced different consequences from leaving work as a result of their injury, and what they thought about return to work (RTW) in the future. Quantitative methods would have struggled to achieve this aim. Although it might seem difficult to categorically draw a distinction between qualitative and quantitative approaches (Smith, 2015), quantitative methods are usually concerned with transforming verbal data into numbers and producing statistical accounts (Smith, 2015). In other words, quantitative approaches rely on predictions to generalise findings and reach objectivity (Harwell, 2011), and therefore are not concerned with meanings and issues around everyday living (Flick, 2014). On the other hand, investigating the detailed personal account of one's life is usually done through qualitative methods (Ashworth, 2015), as these methods have an interest in understanding an experience (Rohleder & Lyons, 2015) and viewing a phenomenon from a subjective perspective, especially when the concern is with perceptions and beliefs (Yardley, 2015).

In addition, quantitative studies often use tools such as surveys and questionnaires to test assumptions (Harwell, 2011), and eventually transform words or images into numbers (Bernard, 2006). By contrast, the data in qualitative studies is typically participants' own reports of personal and social experiences, such as interviews; researchers are then concerned with interpreting what those data mean (Smith, 2015). Hence, studying personal experience is considered one of the empirical methods to interpret the meaning of a phenomenon in qualitative research (Smith & Sparkes, 2016).

Where qualitative researchers try to convey the deep meaning of their data to their audience (Bernard, 2006), they do this through interacting with their participants (Harwell, 2011). Thus, *“as Smith, Harré and Van Langenhove (1995a) have argued, this [qualitative research in psychology] involves a shift from measurement to understanding, from*

*causation to meaning, and from statistical analysis to interpretation” (Murray & Chamberlain, 1999, p. 7).*

Finally, the use of a qualitative design in the first study of this thesis is informed by chapter two’s literature review, where the number of studies adopting qualitative methods was lower than those adopting quantitative methods when exploring the topic of SCI employment and social participation. Also, as can be seen in Table 1 below, despite the existing body of qualitative literature in this area, focusing on experiential accounts of particularly unemployed individuals still receives little attention.

Table 1

*Review of qualitative literature exploring the experience relevant to SCI social participation and employment*

	Study 1	Study 2	Study 3	Study 4	Study 5
<b>Studies</b>	Van de Velde, Bracke, Van Hove, Josephsson, & Vanderstraeten (2010)	Dickson, Ward, O'Brien, Allan, & O'Carroll (2011)	Wilbanks, & Ivankova (2015)	Bergmark, Westgren, & Asaba (2011)	Hay-Smith, Dickson, Nunnerley, & Anne Sinnott (2013)
<b>Qualitative methods</b>	GT	IPA	Morse and Richard's coding technique	Constant comparative analysis	IPA
<b>Areas of exploration</b>	The experience of transitioning from hospital to home following SCI	The difficulties with adjusting to SCI life following hospital discharge	The experience of RTW following SCI	The expectations of unemployed SCI individuals on work return	The experience of RTW from the perspective of post-SCI employed, unemployed and job seekers
<b>Identified gaps</b>	<i>Experiential: SCI Social participation (no direct reference to employment/unemployment)</i>		<i>Experiential: SCI employment (no particular focus on the sole experience of becoming unemployed)</i>		

### **The commitment of the first study to the theoretical framework of IPA**

Qualitative research in general (Rohleder & Lyons, 2015), and IPA research in particular, are usually interested in gaining knowledge about people’s experience with certain health conditions. The early work of IPA (Smith et al., 2009) and the vast majority of its published

papers are in the area of health psychology (Brocki & Wearden, 2006). The first study in this thesis was committed to a qualitative and experiential (i.e., phenomenological) design, which served to achieve its aim of understanding the subjective experience of unemployment as a consequence of the health condition of SCI.

The first study in this thesis was also committed to IPA in that it was hermeneutic and idiographic. It aimed to gain detailed accounts of the experience of SCI unemployment from the perspective of SCI individuals, and emphasised the joint role of the researcher and the participants in interpreting these accounts (i.e. double hermeneutics).

### **The approach of IPA versus other qualitative and phenomenological approaches in psychology**

Another justification for using the approach of IPA in this thesis is its suitability for the aims of the research compared to other approaches. Although qualitative and phenomenological methods in psychology are similar to each other and can sometimes overlap (Smith, 2015) in terms of their aim to enhance an understanding of the phenomenon rather than to verify previous assumptions (Elliott et al., 1999), they can differ in their theoretical emphasis (Lyons, 2007).

The following will give a sense of some of those approaches in order to clarify how they are different from the current study's chosen approach of IPA. As each approach is discussed, the reasons why IPA was the most suitable for the current study will unfold.

#### **A) IPA versus discourse analysis (DA)**

Discourse analysis (DA) is a qualitative method that aims to understand the use of language and its functions (Brown & Yule, 1983). This is to say that DA is not concerned with linguistics, but rather with studying social texts in order to gain a good understanding of social life (Potter & Wetherell, 1987).

The two major approaches to DA (i.e., discursive psychology & Foucauldian DA) differ in their theoretical underpinnings and the research questions they ask. While discursive

psychology is concerned with people's discourse practices and therefore asks 'what people do with their talk', Foucauldian DA is concerned with discursive resources and therefore asks 'how subjectivity and objectivity are constructed by discourses' (Willig, 2008a). However, both of these two approaches have their grounds in social constructionism (Smith et al., 2009), that is, in the role of language in constructing social reality (Willig, 2008a).

IPA research questions explore the understanding of individuals' orientation towards their world (Smith et al., 2009), as opposed to social interactions explored by DA research questions (Potter, 2003). As such, IPA seemed more suitable for the current research questions.

IPA, although theoretically committed to understanding people's mental and emotional states through their talk, emphasises that the researcher's interpretation is important when people are not able to self-disclose certain emotions (Smith & Osborn, 2015). In other words, although IPA can still be seen as an inquiry into the social positions and discourses used by its participants, the participant and the underlying meaning of his or her experience, rather than discursive representations, are the main units of the analysis in IPA (Smith et al., 2009).

Overall, the first study in this thesis was committed to the approach of IPA, which resonated with its aim of understanding how SCI participants made sense of their experience of work absence rather than how they drew on linguistic resources to construct accounts of meaning to this experience, as a DA study might have done.

### **B) IPA versus narrative analysis (NA)**

In narrative analysis (NA), the focus is on the story (Smith, 2016). NA researchers look at an unexpected and incomprehensible event in an individual's life that might be positive or negative (Parker, 2005), and use this as a tool for the person to express his or her actions and experience of everyday living (Widdershoven, 1997).



Thus, NA, as a qualitative method, resonates with IPA in its interest in understanding the lived experience through studying the content of the narrative (Smith et al., 2009). However, while NA is an inquiry into how our culture and our relationships with others construct our stories, including the experience and its meaning (Smith, 2016), IPA is explicitly committed to the inquiry into the experience and its openness to interpretation (Hartie, 2015).

Further, although overlapping, while NA in one form is experience-centred, in another, it is event-centred (that is, the focus is on “*the spoken recounting of particular past events that happened to the narrator*”) (Squire, Andrews, & Tamboukou, 2013, p. 5). Thus, NA, in one of its divisions, focuses on the story as a specific form of discourse (Smith, 2016). With its concern with language (Widdershoven, 1997), NA shares some commonalities with DA in being interested in the structure of the narrative and what this structure offers as well as what it limits in terms of the exploration of the human experience (Smith et al., 2009).

In contrast, IPA is exploratory, because its research is conducted inductively and framed openly, meaning it can digress from its original aim depending on the data collected (Smith et al., 2009).

Hence, it can be said that IPA’s stance of inductivity as well as its commitment to produce subjective accounts of an experience, as opposed to being impacted by narrative resources available to the researcher (Hartie, 2015), both go hand in hand with the first study’s aim of gaining in-depth understanding of the experience of SCI unemployment.

### **C) IPA versus grounded theory (GT)**

Grounded theory (GT) aims to develop a theory inductively, that is a theory that derives from the data and not from tested assumptions (Payne, 2016). In one of its forms, GT concentrates on the phenomenon of study and places priority on the interpretative aspect of it. This form is known as ‘constructivist GT’, where data and analysis are created from experiences and relationships with participants (Charmaz, 2006). It views the generated theory as an interpretation (Bryant; Charmaz, as cited in Charmaz, 2006), emphasises the

role of the researcher's view when analysing data (Charmaz, 2006; Willig, 2008b), and holds a clear epistemological position (Smith et al., 2009).

By contrast, an alternate form of GT is known as 'objectivist'. This derives from the positivist tradition and therefore considers neither the role of the researcher in the interpretation process nor the social context where data emerge (Charmaz, 2006). Instead, objectivist GT assumes an objective reality to social events that the researcher can only observe and record (Hartie, 2015), meaning the researcher needs to find existing data in order to discover theory from them (Charmaz, 2006).

Although GT is similar to IPA in that it is able to understand the phenomenon and its process, GT is seen more as a conceptual approach (Charmaz, 2006). Also, while GT aims to build a theory from studying large, heterogeneous samples (Hartie, 2015; Smith et al., 2009), IPA aims to be idiographic and therefore uses small, purposive and homogeneous samples to study what it means for each particular person to be in a particular situation (Smith et al., 2009), with no initial aim to produce general claims (Smith & Osborn, 2015). This idiographic approach of IPA, which sees each case as unique, seemed more suitable than the approach of GT for exploring the topic of SCI unemployment.

#### **D) IPA versus thematic analysis (TA)**

Researchers using thematic analysis (TA) start by identifying an important moment in their data, coding it and finally interpreting it (Boyatzis, 1998). Nevertheless, the role of TA in categorising data into patterns and themes is stronger than its role in interpreting them (Howitt, 2010). Conversely, IPA has a pure commitment to hermeneutics, which complimented the epistemological position of the current researcher.

A significant feature of TA is its flexibility, which is manifested in the absence of a clear theoretical framework (Braun & Clarke, 2006). IPA, on the other hand, is theoretically committed and philosophically informed by the three key areas of phenomenology, hermeneutics and idiography (Smith et al., 2009), and therefore, as a methodologically explicit approach to understanding the personal experience in great detail, better suited the aim of the first study in this thesis.

### **E) IPA versus Giorgi's approach to phenomenology**

Centred around Husserl's classic method (Langdridge, 2007), Giorgi's approach to phenomenology is descriptive (Van Manen, 1997), because it uses language to articulate and analyse an experience (Giorgi, 2012). In contrast, IPA is an interpretive approach to phenomenology (Smith et al., 2009), which allows the researcher to gain an inside perspective on the phenomenon studied through recognising his or her interpretative role in the research process (Smith & Osborn, 2015).

Furthermore, as Giorgi's approach is concerned with building up a general structure of the phenomenon studied, it focuses on analysing the common accounts of the experience (Giorgi & Giorgi, 2008; Smith et al., 2009). By contrast, because IPA is concerned with the idiography of the phenomenon, and so focuses on analysing both commonalities and differences between the accounts of the experience (Smith et al., 2009). Here, IPA seemed to better fit the aim of the researcher in capturing the richness of the experience of SCI unemployment through identifying commonalities and differences between the participants.

While Giorgi's phenomenological approach aims to produce generalisation, IPA's focus is narrowed to the detailed analysis of the personal experience (Smith et al., 2009) among a particular group, with no intention to make general claims (Smith & Osborn, 2015).

Finally, while Giorgi's phenomenological approach aims to maximise the variation of its samples by recruiting participants with similar experiences but different demographic variables, IPA is keen not to have those significant variations in its samples (Langdridge, 2007). This idiographic stance of IPA fitted the aims of the first study in this thesis, which was concerned with individually examining the lived experience of a small, purposive sample of unemployed male individuals living with SCI.

## Reflexivity

Reflexivity is an important element when doing qualitative research in general (Palaganas, Sanchez, Molintas, Visitacion, & Caricativo, 2017), and experiential studies in particular, where the previously mentioned equal roles of researchers and participants in the research is crucial (Shaw, 2010). To elaborate, reflexivity is important for enhancing the credibility and trustworthiness of research outcomes through acknowledging the beliefs, biases, values and knowledge of the researchers (Berger, 2015). This means that the inevitable role of these factors needs to be documented (Willig, 2013).

Reflexivity is about directing the researcher's critical gaze inwards and conducting a self-evaluation of their work, thus distinguishing this process from reflections (Shaw, 2010). According to Finlay (2002), while reflexivity and reflections can each be seen as located at two ends of the same continuum, reflexivity is more active and more able to produce general understandings, insights and interpretations than reflections. Freshwater and Rolfe (2001) summarised this by saying: "*whereas reflection gives a central place to communication, reflexivity provides an extension of communication into the deeper domains of human experience*" (p. 530).

Reflexivity is a process that interpretative researchers undertake in their research (Dowling, 2006). Unlike mere reflections, in which researchers find a connection between something they did in the research and its consequences (Oliver, Serovich, & Mason, 2005), reflexivity aims to enable those researchers to acknowledge how the entire process of research was informed by their experiences, environment, feelings and thoughts (Etherington, 2004). In other words, while reflections come towards the end of research and refer to researchers' discussion of speculations of the effect of certain relevant aspects of the research outcomes, reflexivity is an on-going process of critically evaluating the subjectivity of the researcher on the design of the research, collection and analysis of data, and presentation of outcomes (Gough, 2003).

Hence, reflexive researchers must, for example, be aware of those questions they emphasised and those that they avoided, as well as how they reacted, felt and thought

during interviews and how personal sensitivity impacted the reporting of the analysis (Berger, 2015).

In this thesis, both reflections and reflexivity were present; while brief reflections are presented at the end of each study, the reflexivity of the researcher is demonstrated throughout.

The researcher utilised four different types of reflexivity throughout this thesis (i.e. personal, critical, epistemological and feminist). Those types, which are described below, were identified in light of the work of Palaganas and colleagues (2017).

### **A) Personal reflexivity**

Looking inward, personal reflexivity occurs when researchers are aware of how their position, perspectives and presence can impact their research (Finlay, 2003). In other words, personal reflexivity is about the choices researchers make, which are informed by their personal response to their position in the research (D’Cruz, Gillingham, & Melendez, 2007), as well as their personal experiences and values (Palaganas et al., 2017). According to Jootun, McGhee, and Marland (2009), *“reflexivity, characterised by an ongoing analysis of personal involvement, helps to make the process open and transparent”* (p. 45).

Research questions, for example, beside their scientific importance, need to relate to a passion that the researcher is eager to explore (Maso, 2003). As mentioned in chapter one, this IPA thesis, which focuses the primary research question on the meaning of employment and/or lack of employment for people living with SCI, was mainly the result of the researcher’s personal belief that work is incontrovertibly an important aspect of any adult’s life.

When doing personal reflexivity, Gough (2003) suggests letting a colleague look at, for example, the research question in order to provide a different lens from that of the researcher, and to encourage that colleague to challenge it and/or suggest alternatives.

In this thesis, the academic supervisor worked closely with the researcher in designing the research, including the creation of the aforementioned research question.

### **B) Critical reflexivity**

Looking outward to social and cultural factors that shape personal practices and inward to critically evaluate how to make sense of those practices (White, 2001), critical reflexivity examines social and political constructions that shape the process of research (Dowling, 2006) and enhances knowledge based on political and ethical questions raised by researchers (Palaganas et al., 2017).

For example, a main motive for conducting the first study of this thesis was to tackle the issue of the unheard voices of unemployed SCI individuals and their neglected experiences in both research and rehabilitation settings (more on this in the next chapter).

### **C) Epistemological reflexivity**

To enhance the transparency of their research, qualitative researchers need to be explicit about their role in how knowledge was constructed in their research (Finlay, 2002). Epistemological reflexivity encourages those researchers to ask themselves questions related to how the research question, study design and method of analysis helped understand the studied phenomenon and shaped the findings of the research (Dowling, 2006). Assumptions about the knowledge created in the research challenge notions of objectivity, since reflexive researchers acknowledge that they cannot produce knowledge that is entirely free of subjectivity (Palaganas et al., 2017).

One way of doing epistemological reflexivity is for the researcher to conduct critical thinking by taking a theoretical position in order to present the personal value of the research (Gough, 2003). In line with this, in this thesis, epistemological reflexivity was demonstrated according to methods that will be described below.

The researcher in this thesis personally preferred to use IPA because she believed that knowledge is better understood through extensively listening to individuals rather than asking them to evaluate their feelings or experiences using numbers or filling short forms. The researcher's first degree in special education, a humanitarian subject, followed by her master's degree in qualitative health psychology had certainly re-enforced this view of knowledge creation.

However, while the researcher believed that IPA was the most suitable approach for the topic of her thesis, she occasionally felt that using this approach was overwhelming as she had occasional concerns that some participants, especially those who showed an interest in her work background and how she developed a passion to explore the thesis topic, could perceive her as someone who could offer vocational help. To elaborate, the researcher was sometimes unconsciously hesitant to ask further questions when participants talked about their history of work and the plans to RTW, as she felt that this could be an indication that some kind of support (e.g. therapeutic) was going to be offered.

#### **D) Feminist reflexivity**

Feminist reflexivity is about the researcher's awareness of his or her gendered values, perceptions and beliefs that may impact the process of the research (Dowling, 2006). In addition, feminist reflexivity, within different stages of the research, emphasises differences in power and how gender differences can shape the research process (Palaganas et al., 2017). It emphasises reciprocity in the relationship between researchers and participants, in which both become reflexive (Dowling, 2006), but where this reciprocal relationship is not suggested to be intimate (Palaganas et al., 2017).

Seeking active aid in developing and designing the research from someone with the same gender as the participants is suggested as one way of doing feminist reflexivity (Gough, 2003). In this thesis, the researcher, as a female, sought aid and advice from a male colleague, who was living with SCI himself and who conducted research in a similar area, during the design of the first study, which recruited nine men (more on this in the next chapter).

## **Summary**

To recap, this chapter shed light on qualitative and phenomenological research in psychology as methodologically guiding the first study in this thesis. The chapter then introduced IPA as the chosen approach for the first study and highlighted its relevance to the topic of ill-health. The differences between IPA and other existing qualitative and phenomenological approaches in psychology were then explored, demonstrating that IPA is the most suitable method for answering the current research question. Finally, as an important element of undertaking IPA research, this chapter discussed reflexivity and its demonstration in this thesis.

Overall, the experiential, double hermeneutic and idiographic stances of IPA, as well as its openness to experiences presented by the participants themselves (with those participants being the core of the analysis), are well suited to the first study.



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## Chapter 4: Method

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This chapter will draw on the substantive work completed in the first study. It will start by presenting the main research question and objectives, and will then move to outlining the process for gaining ethical approval, recruiting and consenting participants, collecting, analysing, writing up and protecting the data of the first study.

### Main research question

The first study in this thesis asked: **how do individuals with spinal cord injury (SCI) make sense of their personal experience of transitioning from employment to unemployment following their injury?**, which corresponds to Smith and colleagues' (2009) definition of an interpretative phenomenological analysis (IPA) research question; the above question was open and exploratory (i.e., it asked **how**), phenomenologically directed (i.e., it asked about the **experience**) and focused on meaning (i.e., it asked how individuals **make sense** of their experience).

The justifications for this research question were theoretically and methodologically discussed in chapters two and three. In addition, this research question went hand in hand with the researcher's passion to give voice to those who became unemployed following SCI. This is to say that not only in existing literature, but also in the researcher's own experience of working in rehabilitation, those who were unemployed following SCI were usually neglected. When the researcher previously worked with SCI patients in rehabilitation, she always felt that therapeutic attention was given to those who showed a desire or a potential capability to return to work (RTW), while those who were struggling to do so were significantly given less attention by vocational rehabilitation (VR) professionals. Even those receiving VR support following SCI were usually not given the opportunity to reflect on their experiences of leaving their jobs after their injuries; the researcher typically had to go through checklists and fill in quantitative forms designed by the rehabilitation

facility when collecting patients' information during vocational support sessions; these forms and checklists focused only on therapeutic goals.

Therefore, the motivation to conduct the first study of this thesis was derived from the researcher's aim to focus on the impact of SCI unemployment by using an individual lens and by getting close to the experience while outside institutional walls.

### **Objectives**

Stemming from this, the main objectives of the first study were to answer the following:

1. How do people living with SCI describe the impact of leaving work on their quality of life (QoL)?
2. What perspectives do unemployed people living with SCI have on work, work absence and RTW?

### **Ethics**

Initially, it seemed to the researcher that recruiting participants for the first study through community organisations in the UK that provide support to individuals living with SCI was going to be an accessible process that would allow her to interview unemployed SCI individuals outside institutional walls (as opposed to her previous experience of working with patients in rehabilitation). However, establishing connections with the research teams at those SCI community organisations turned out to be a challenge, as the researcher was newly in the UK and had limited connections in the field of SCI there.

However, the academic supervisor of the researcher was willing to establish contacts with the head of the Clinical Psychology Department at the National Spinal Injuries Centre (NSIC) Stoke Mandeville Hospital in the UK, who offered to support the first study of this thesis. While recruiting participants through a National Health Service (NHS) Trust might have impacted the research process and outcomes (see chapter 6), this was an opportunity for the researcher to recruit participants and overcome the challenges of her first choice of approaching SCI community organisations.

As a result of the above, this first study received ethical approval from the NHS in the UK through a process that consists of three main stages. In October 2015, the head of the Clinical Psychology Department at the NSIC agreed to provide clinical supervision for the study, and therefore became the Principal Investigator (PI). Based on this, the researcher signed an honorary contract with Stoke Mandeville Hospital to recruit participants who were former service users of the Clinical Psychology Department at the NSIC.

In January 2016, the researcher started to develop a thorough research protocol document in light of the guidance from the Health Research Authority (HRA) within the NHS. The researcher then completed an NHS ethics application form on the Integrated Research Application System (IRAS) website, which contained information about the research design and purpose, risks, ethical issues, procedures, benefits, recruitment, consent, confidentiality, management and publication of the study. The application was reviewed by the research team (that is, the PI at Stoke Mandeville Hospital, the researcher's academic supervisor and the sponsor's representative of the study at Birkbeck, University of London), and was then submitted to a Proportionate Review Research Ethics Committee (REC) within the NHS. This committee reviewed the proposal in April 2016. The Proportionate Review REC transferred the application to a Full Review REC, since the topic of the research was considered sensitive and needed to be reviewed more thoroughly. Bloomsbury NRES Committee conducted a full review of the research application in May 2016 and approved it in July 2016 (Appendix 1).

The researcher then applied for HRA approval for the study, which required information about the delegation tasks for Stoke Mandeville Hospital and a schedule of events. HRA approval was gained in August 2016 (Appendix 1). Based on this, a request for confirmation of capacity and capabilities was then sent to the Research and Development (R&D) office at Stoke Mandeville Hospital. After gaining confirmation from the R&D office (Appendix 1), it was planned that recruitment would be initiated in September 2016, but due to circumstances beyond the researcher's control, the PI of the study had to be changed. Thus, an HRA amendment approval had to be sought, and recruitment was re-initiated in October 2016.

Although the overall process of applying for ethical approval for this study was an exhaustive and lengthy one, it was a unique experience that allowed the researcher to be trained to write an extensive research protocol document and consider different ethical issues and challenges. Also, having had support from a fellow PhD student who had recruited participants for his SCI study from the same department at Stoke Mandeville Hospital made it easier for the researcher to undertake the process of applying for NHS ethics. As a British male, the researcher's PhD fellow was more familiar than she was with the culture and with working with SCI men in the UK, and therefore helped her to gain a better understanding of some of the relevant issues and potential risks that had to be considered in her NHS ethics application.

### **Eligibility criteria of the sample**

The following were the inclusion and exclusion criteria of participants in the first study:

#### **1) Inclusion criteria**

To be included in the first study, participants had to be:

- Males
- Aged 20-55 years
- Of British nationality
- Able to read, write and speak English fluently
- Able to verbally express themselves
- Diagnosed with SCI
- Having an SCI onset of one year or more
- Previous service users of the Clinical Psychology Department at the NSIC – Stoke Mandeville Hospital
- Currently based in the UK
- Identified as having a job prior to SCI
- Currently unemployed

#### **2) Exclusion criteria**

Participants were excluded from the first study if they did not meet the inclusion criteria or if they met the following condition:

- Diagnosed with a significant cognitive deficit

### **Justification of eligibility criteria**

The above inclusion criteria were defined by elements the researcher was able to control and justify, mainly through reference to the literature. However, while the researcher believed in the importance of controlling for additional criteria, such as injury level, the recruitment team at Stoke Mandeville Hospital, who have experience and knowledge in this area, advised that controlling for the injury level in the first study would reduce the number of potential participants.

In terms of justifying the agreed criteria above, in order to achieve participant homogeneity in this first study, only those British nationals with English language fluency in reading, writing and speaking were included. This was due to two reasons: firstly, as this study used IPA to analyse its data, which is a method that depends on participants' verbal expressions and the researcher's interpretation of those expressions, language was an important factor. Therefore, if participants spoke a different language to the researcher, then her interpretation of their expressions might not have been accurate when translating them to English. Secondly, this study lacked resources to provide interpreters for participants with any language other than English.

The first study focused on male participants. This was because men typically comprise the majority of SCI cases – a mean of 80 to 85% of people living with SCI are male (Wyndaele & Wyndaele, 2006). In addition, as cited in the literature review chapter, men living with SCI are more likely to RTW than women (Anderson et al., 2007; Yasuda et al., 2002). According to Anderson and colleagues (2007), work was an important part of identity for SCI male individuals.

When combined, these factors warrant a study exploring how males make sense of their experience of leaving work due to SCI. Finally, focusing on SCI male individuals was related to the use of IPA. Since all participants were the same gender, this fits in with IPA's homogeneity requirement (Smith et al., 2009).

Based on the latest figures noted in the literature, which indicated that the mean age of people with SCI in the UK was 35.1 (Savic et al., 2017), it was decided to include

participants aged between 20 and 55 years. In addition, influenced by her cultural background and work experience in Saudi Arabia, which might differ from practices in the UK, the researcher felt that interviewing participants younger than 20 would mean that those participants would have been less likely to have had sufficient pre-injury work experience to reflect on, while interviewing those older than 55 would mean that they would have been close to retirement and therefore less impacted by becoming unemployed.

Participants had to be one year or more post SCI. The World Health Organisation and International Spinal Cord Society (2013) state that it may take people living with SCI up to one year to gain functional recovery, deal with their medical needs and adjust to their return to family and home. In addition, as mentioned in the literature review, the mean time before resuming work is around one year (Bergmark et al., 2011; Krause & Pickelsimer, 2008). Findings by Hancock, Craig, Dickson, Chang, and Martin (1993) demonstrated the tangible reality of psychological upsets, including depression and anxiety, during the first year of SCI. Lohne and Severinsson (2004) examined patients' experiences of hope during the first year of SCI and found common feelings of disappointment among participants. These factors guided the decision to speak to participants who were a year or more post SCI.

Individuals who had been diagnosed with a significant cognitive deficit were excluded from the first study. Unlike the researcher's previous experience in rehabilitation, where a multidisciplinary team of psychiatrists and clinical psychologists was present and on-call at all times when SCI patients were seen for VR, there was a lack of ability to provide such appropriate support for the participants in this study at interview settings, should it ever be needed. In addition, this IPA study required participants to be cognitively healthy in order to be able to independently and clearly express their views on the experience of work non-return.

## Sample homogeneity and size

### **1) Sample homogeneity**

As demonstrated in the literature review, almost all the reviewed qualitative studies used samples which were not homogenous in terms of their gender, employment history or status. To elaborate, two of the reviewed studies (i.e. Bergmark et al., 2011; Hay-Smith et al., 2013) that looked at experiences relevant to SCI unemployment had discrepancies in their sampling criteria. In Hay-Smith and colleagues' (2013) study, researchers aimed to explore the experience of employment following SCI. They targeted four different groups: employed people with SCI, unemployed people with SCI, job seeking SCI participants and VR professionals. They also targeted both male and female individuals with SCI, where the number of men was always slightly higher in the four groups above (i.e., employed = 4 [men = 3, female = 1], unemployed = 5 [male = 4, female = 1] & job seeking = 3 [male = 2, female = 1]).

Similarly, the study by Bergmark and colleagues (2011) looked at experiences and perceptions of work after SCI from the perspective of unemployed SCI participants who were both with and without pre-SCI work experience. The sample in this study (n= 8) varied in terms of gender, where the majority were males (n=6).

Those two studies, with the variety in their samples, were purposive and able to capture a wide picture of the experience they were investigating. However, the first study of this thesis, in line with the approach of IPA, recruited a more specifically homogeneous sample than those two studies, which comprised male participants with SCI who were all employed before the injury but became unemployed subsequently. This sample was selected in order to closely understand participants' particular perspectives on unemployment following their injuries.

### **2) Participant group size**

The first study recruited a total of nine participants. This was in light of Smith and colleagues' (2009) suggestion to use a small number of cases in IPA studies in order to

allow the development of meaningful similarities and differences, where the focus remains on the quality rather than the quantity. To elaborate, recruiting a small, homogeneous sample as opposed to a larger sample in this study would allow the researcher to pay attention to the meaning of the details in each participant's account and subsequently compare them with the details of other participants' accounts in terms of where they converge and where they diverge. This above process is referred to by Smith and colleagues (2009) as *"the development of subsequent micro-analysis of similarities and differences across cases"* (p. 52).

### **Recruitment**

All participants in the first study were identified and accessed through the Clinical Psychology Department at the NSIC Stoke Mandeville Hospital in the UK. The hospital PI for this study delegated the task of recruitment to an assigned assistant psychologist at the department, who screened for potential participants in light of the inclusion and exclusion criteria, identified potential participants and made initial contact with them.

According to Willig (2013), qualitative researchers are ethically bound to provide participants with full information about the study and its procedures as well as seeking and gaining their consent to take part before data collection commences. In this study, the assigned assistant psychologist sent all potential participants invitation letters (Appendix 2), participant information sheets (Appendix 3) and informed consent forms (Appendix 4) by post. Participants were asked to read the information sent to them and sign their consent forms within one week. Those whose signed consent forms were not received within two weeks were re-contacted by the assigned assistant psychologist to ask if they were still interested in taking part in the study. As per the research protocol, no further contacts were made after the second time with any potential participant.

Those who returned their signed consent forms to the hospital, by post, were made known to the researcher through the assigned assistant psychologist. The researcher then contacted those participants by phone and arranged a time for the interview.



## **Consent**

Staff at the Clinical Psychology Department at the NSIC Stoke Mandeville Hospital took responsibility for sending informed consent forms to the nine participants by post, receiving the signed forms and filing them. Original copies of the signed informed consent forms were kept by the assigned assistant psychologist at an allocated site file for the study at Stoke Mandeville Hospital. The hospital made photocopies of all signed informed consents and sent them to the researcher by post, where she kept them in a controlled-access file at Birkbeck, University of London.

All participants signed their informed consent forms and returned them to the hospital except for one participant who, upon his request, gave consent to the researcher on the same day of the interview. Due to his high-level injury, this participant provided his verbal rather than his written consent prior to starting the interview, which the researcher audio-recorded. The participant's personal assistant was a witness to the verbal audio-recorded consent and signed a form to this effect, which was forwarded by the researcher to Stoke Mandeville Hospital to keep in the allocated site file.

Participants in this study were not remunerated for taking part.

Qualitative researchers have an ethical responsibility to give participants the right to withdraw from the study with no fear of being punished (Willig, 2013). Therefore, both the participant information sheet and the informed consent form specified that participants had up to two weeks after the interviews to request for their interviews to be withdrawn from the study. However, no withdrawal requests from any participant were received.

## **Participants**

The nine participants who were identified and consented to take part and be interviewed in the first study were all males aged between 30 and 55 years (mean age = 43.8). The injury onset of those participants at the time of the interviews ranged between two and nine years (mean injury onset = 4.5 years). All participants were Caucasian-British except

for one participant who was African-British. Three participants did office work prior to the injury; two of them had master's degrees. Four participants did manual work and two did a combination of manual and office work prior to their injuries. Seven participants were paraplegics and two were quadriplegics.

Detailed demographic information about the participants is in Table 2.

Table 2

*Demographics of participants in the first study*

<u>Name (pseudonym)</u>	<u>Gender</u>	<u>Age</u>	<u>Race</u>	<u>Higher education</u>	<u>Type of previous work</u>	<u>Injury onset</u>	<u>Injury level (figure 1)</u>
<b>Chris</b>	M	30	Caucasian	No	Manual	2 years	T10
<b>Simon</b>	M	34	Caucasian	Yes	Office	5 years	C4
<b>William</b>	M	55	Caucasian	No	Manual/Office	5 ½ years	C4
<b>Henry</b>	M	45	Caucasian	Yes	Office	9 years	C2
<b>Mark</b>	M	42	African	No	Office	3 ½ years	C4
<b>Andy</b>	M	55	Caucasian	No	Manual	4 years	C2
<b>Jack</b>	M	39	Caucasian	No	Manual	3 years	T3
<b>Mathew</b>	M	53	Caucasian	No	Manual/Office	6 years	T2
<b>Jeff</b>	M	42	Caucasian	No	Manual	2 ½ years	T6

Table 3 summarises the demographics of participants in the first study.

Table 3

*Summary of participants' demographics in the first study*

<u>Gender</u>	<u>Age</u>	<u>Ethnicity</u>	<u>Educational Level</u>	<u>Previous work</u>	<u>Injury onset</u>	<u>Level of injury</u>
Male = 9 out of 9	Mean = 43.8	Caucasian = 8 out of 9	Higher education = 2 out of 9	Manual = 4 out of 9	Mean = 4 ½ years	Paraplegia = 7 out of 9
-	-	African = 1 out of 9	-	Office = 3 out of 9	-	Quadriplegia = 2 out of 9
-	-	-	-	Manual/Office = 2 out of 9	-	-

### Data collection

It is vital that the method of data collection generates data that matches the research question (Willig, 2013). As the research question in this first study is suitable to the approach of IPA in that it is experiential, interpretative and idiographic, semi-structured, one-to-one interviews, which are the most common data collection method for IPA (Smith et al., 2009), were used.

Conducting IPA interviews is often described as engaging in a conversation for the ultimate purpose of answering the research question. However, IPA researchers tend not to directly ask their participants the research question, but rather come at it “*sideways*” (Smith et al., 2009, p.58).

The following will explain how the interview schedule of the first study was devised as well as where, when and how the nine interviews were conducted before pen portraits of participants will be highlighted:

## **1) Interview schedule**

IPA researchers usually develop an interview schedule (Smith et al., 2009), which does not produce hypothesised data (Smith, 2004), but rather data that are elicited from participants' feelings, thoughts and stories (Smith et al., 2009).

The interview schedule in the first study was developed based on gaps in the literature; predominantly in light of the identified gaps in the results of the five qualitative studies mentioned in Table 1.

Although it was a challenge for the researcher to balance between being naive (that is, not having any assumptions) and being informed by the existing literature when devising the interview schedule, carefully reading the relevant studies in the literature allowed her to identify gaps that the first study could help fill, and to think about new interview questions that were directly and particularly related to the current research question.

However, the researcher was cautious not to include questions in the interview schedule about masculinity and the impact of SCI on this, especially in relation to the impact of losing work on the identity of fathers and/or breadwinners. This was mainly because the researcher, as a female, felt that she was unfamiliar with the significant and personal definition of masculinity for each participant in particular as well as generally for those operating in a Western culture as opposed to her own culture. Thus, she chose not to include such questions in the interview schedule and rather leave it open for participants to draw on the issue of masculinity if they felt it was something they wanted to talk about.

Conversely, an important set of questions that the researcher wanted to ensure was included in the interview schedule of the first study related to participants' plans to RTW. This was firstly because the literature heavily explored this in different areas relating to SCI employment, and secondly because the researcher was eager, as a vocational service provider, to know about her participants' plans to RTW after SCI. In more detail, while the topic of plans to RTW following SCI was usually essential in any existing literature

relevant to SCI employment, it was also an essential part of the VR therapeutic programmes that the researcher previously provided to her SCI patients in rehabilitation.

Questions in IPA interview schedules are kept open to allow participants to speak at length, and so offer as much information as possible. This is to say, for most of the interview, the IPA researcher listens, while the participant talks (Smith et al., 2009).

Semi-structured interviews were used to give participants the opportunity to talk, in great detail, about different elements of the lived experience of becoming SCI sufferers in the first place, but more importantly about becoming unemployed as the result of their injury.

Interview schedules in IPA usually contain between six and 10 questions, as well as some probes (Smith et al., 2009). In keeping with this, the interview schedule of the first study included a total of 10 questions with probes (Figure 2):

- 1. Could you give a brief history of your SCI?**  
*(Probes: how did the injury occur? what happened during and after your SCI?)*
- 2. Could you describe your typical day prior to the injury?**  
*(Probes: how did you use to spend your day?)*
- 3. Could you describe your typical day now (post-injury)?**  
*(Probes: what activities have you been doing since the injury?)*
- 4. How can you describe your absence from work since the injury?**  
*(Probes: what happened regarding your job after your SCI? how do you feel about being away from work at the moment?)*
- 5. How does work absence affect your everyday life?**  
*(Probes: which areas of your life do you feel have been most affected by leaving work?)*
- 6. What does your job (pre-injury) mean to you and what does having a job in general mean to you?**  
*(Probes: is work related to having an income? is it also related to feelings of productivity and contribution to society?)*
- 7. What does RTW mean to you?**  
*(Probes: is RTW related to being able to do certain activities?)*
- 8. How much do you think about RTW?**  
*(Probes: often? is it among your current priorities to RTW?)*
- 9. What could influence your decision to RTW?**  
*(Probes: what could determine whether you will RTW or not?)*
- 10. How do you envisage yourself working?**  
*(Probes: how do you imagine yourself going back to work?)*

Figure 2. The interview schedule of the first study

As Figure 2 shows, in IPA, the researcher usually starts to ask broad questions then gradually narrows them in order to gain detailed accounts of the experience in question (Howitt, 2010). This is known as the funnelling approach. In other words, IPA researchers typically start their interviews with questions that are descriptive in order to capture a general sense of the experience before moving to more evaluative questions, where participants can be more analytic about their experience (Smith et al., 2009). Moreover, it was believed that by using this approach, the interview schedule would be able to move from emotionally less difficult questions about the physical history of the injury to more complicated and sensitive questions about work absence and the meaning of that to the participants.

In this thesis, this funnelling approach helped the conversation to flow and rapport to be established, which was something that Smith and colleagues (2009) emphasised in order for IPA researchers to obtain good data.

The first question was relevant to participants' history of the injury as well as the time they spent in rehabilitation and recovery. The next question was related to participants' life before the injury, followed by a set of questions related to their life after the injury, including work absence. The following question took the participants back to thinking about the value of work before the injury as well as after the injury. The last set of questions was relevant to how participants perceived their future vocational lives after the injury. Table 4 summarises this:

Table 4

*Interview schedule of the first study - areas of exploration*

Area of exploration	Question number
History of the injury	1
Life and work before the injury	2
Life and work absence after the injury	3, 4, 5
The perceived meaning of work	6
Future vocational life	7, 8 9, 10

The interview schedule was not followed strictly, but rather helped guide the interviews. By using this semi-structured approach, interview questions can be modified based on the responses of the participants (Smith & Osborn, 2015). This also allows both the researcher and the participant to engage in a conversation, in which the researcher can inquire about interesting data as they arise (Smith & Osborn, 2015). Ultimately, conducting this type of interview in a one-to-one format allows in-depth data to emerge as participants are given the opportunity to be heard (Smith et al., 2009).

It was vital for the researcher to listen attentively to the participants and follow up on points that the participants raised. This ensured that interviews were participant-led and aimed to uncover rich aspects that participants felt comfortable sharing. This meant that there was a balance between the input of the researcher and the participants in each interview, where neither of them felt in charge of the whole situation.

Extended moments of silence allowed most participants in this study to talk more about their experience, but when participants felt they had little to say, the researcher's questions and probes came as an aid to help them think about what they wanted to say next.

In addition, some feedback from the participants, such as *"oh, that is a good question"* boosted the researcher's confidence and motivation during the interviews. Similarly,

feedback and small gestures from the researcher to participants' answers, such as "*oh, that is interesting*" worked as signs for the participants that what they were saying was valuable.

## **2) Interview Settings**

All nine participants were interviewed by the researcher in their homes, which was their preferred choice. The interviews were conducted on dates and times that were convenient to the participants. The researcher conducted all interviews during November and December 2016. All interviews were audio-recorded. Each interview was arranged and conducted as the researcher received the signed informed consent of the participant.

## **3) Pen portraits of participants**

Below are brief pen portraits of the nine participants in the first study:

**Chris-** seemed a positive and an active young gentleman. His injury was invisible to others, which might have impacted his acceptance of it. Although it felt positive and less demanding to have the first interview with a participant who did not need any assistive device for mobility, the researcher was less able to feel that Chris was an SCI sufferer and she therefore had to change some terms in the interview questions to make them seem more relevant to Chris's high functional abilities.

Chris was keen to talk about his injury, and he liked to use metaphors and expressions when describing his feelings and perspectives on things.

The researcher enjoyed talking to Chris; he was cheerful and gave her a boost to carry out the rest of the interviews for this study.

**Simon-** had quite a high-level injury. He appeared on his power-wheelchair when he welcomed the researcher to his home. He had a personal assistant who accompanied him until the start of the interview.

Simon was very quiet, but not shy. He was highly educated and came across as an open-minded person. However, he spoke in a low and possibly sad voice. Although Simon



hardly changed his facial expressions, the researcher was aware that some questions might have the potential to upset him and thus had to re-word them.

**William-** was a respectful middle-aged man, who used to have a high-profile job in aircraft industrial engineering. He was involved in two court cases; one because of the motorbike accident which caused his SCI, and the other against his previous employer for discriminating against him following his SCI. At the time of the interview, William was still awaiting verdicts.

Although his injury was almost invisible, William seemed fully aware of his own physical limitations. Therefore, although he could ambulate without an assistive device, he referred to his injury as a 'disability'.

When William was talking, he was more descriptive than emotional; he usually spoke about his feelings in an indirect way and used expressions that did not directly reflect how he perceived his experience of leaving work. The researcher found it more challenging, compared to the previous interviews, to elicit information from William on his perspective about his injury and work.

**Henry-** was very friendly and motivated to participate in the research. He was a teacher before the injury and he held a master's degree in education. Therefore, he felt that his work was on a similar level to the researcher's. This made both Henry and the researcher feel at ease and led to a feeling of satisfaction with the flow of the interview.

**Mark-** was keen to share his experience in-depth. During the interview, he spoke slowly and clearly, and always offered to explain what he meant by certain expressions.

Mark talked extensively about how he acquired his SCI and described the traumatic moments of his family trying to save his life, which was moving for the researcher. His motivation to overcome the challenges of his injury and start a new career were inspiring.

**Andy-** was a friendly man who, with his partner Susan, welcomed the researcher to their home. He had a smile on his face even when he spoke about critical moments and sad events in his life.

Andy asked for his partner to be with him in the interview; he seemed attached to her and spoke repeatedly about how she helped him with most of his daily activities both inside and outside the house. The researcher noticed that when Andy spoke during the interview, he sometimes referred to himself as 'we' instead of 'I', perhaps due to his strong emotional attachment to his partner, whom he perceived to share the ups and downs of his injury.

**Jack-** and his wife welcomed the researcher to their home. Jack was happy to offer his time to talk about his experience of SCI and work because he wanted his story and his suffering to be heard.

Jack seemed emotional throughout the interview, and when his wife left the interview for a couple of minutes while he talked about his struggles with work after SCI, he started crying. Although this was a little overwhelming for the researcher, she tried to acknowledge Jack's emotions and asked him if he needed a break. At the end of the interview, after providing the debriefing form, the researcher asked Jack if he wanted to speak to a clinician from the Clinical Psychology Department at Stoke Mandeville Hospital for support, but he said he was feeling better and that he did not need it.

**Mathew-** was on his power-wheelchair when the researcher visited him in his house. Although he was friendly, he seemed quiet and avoided eye contact most of the time. He spoke with a low voice and often paused for a long time before answering questions.

As Mathew did not feel energetic, the researcher asked if he was feeling tired and wanted to take a break before proceeding with the interview. Although he was enthusiastic about the interview and wanted to proceed, he told the researcher that he was on a medication that sometimes lowered his energy. As a result of this, the interview was cut short, although most of the questions were covered.

**Jeff-** When the researcher went to interview Jeff, his house was busy as many of his family members were there, plus builders who were doing some work in the kitchen. It was therefore a bit challenging for the researcher to focus on the interview.

However, Jeff was friendly and seemed kind; he was generous in his answers. He was also inquisitive about the work of the researcher and was keen to know how he could contribute.

### **Support and debrief**

An essential part of constructing the research protocol for the first study was to make sure that psychological support was available to participants through the Clinical Psychology Department at NSIC Stoke Mandeville Hospital. The researcher also had a plan in place for how to manage situations if a participant got distressed either during the interview or afterwards. Also, a lone worker policy was constructed to ensure the researcher's safety at the interview sites.

All interviews went smoothly with no issues, except of the previously mentioned small incident of Jack. At the end of each interview, the researcher thanked the participants, reminded them about the purpose of the study and provided them with a debrief form that included information on resources for psychological and vocational support in the community that they may have found useful (Appendix 5).

### **Data Analysis**

In IPA, collecting data through interviews usually requires recording the conversations on audio or video media and then transcribing them verbatim. When transcribing IPA interviews, it is important for the researcher not to take short cuts (Howitt, 2010) as this could lead to missing a variety of important interpretative social interactions in the transcript (Smith et al., 2009).

In this study, all nine interviews were audio-recorded and transcribed verbatim before the IPA analysis.

Smith and colleagues (2009) describe the process of IPA as follows:

1. Closely analysing line-by-line each participant's concerns, understandings and experiential accounts.
2. Identifying emergent themes, which means that the researcher needs to look for patterns (e.g., convergences and divergences) within the data of a single case before looking across different cases.
3. Engaging in an interpretative account of the data, meaning that the researcher needs to develop a dialogue with his or her coded data and psychological background in order to understand his or her participants' concerns.
4. Developing a structure to illustrate the connection between the identified themes.
5. Organising all analysed material.
6. Developing a complete narrative by taking the reader through themes and offering evidence from the transcripts (i.e., extracts).
7. Reflecting on the researcher's own experience of conducting the study (e.g., his or her own perceptions).

Following Smith and colleagues' (2009) guidance for doing IPA, the analysis of this study followed the above sequential steps, whilst moving back and forth in a hermeneutic cycle.

The next sections will explain, in detail, how the researcher took those analytical steps.

### **1) Individual-case analysis**

Each case was analysed individually. Therefore, the description below shows how each individual participant's interview was analysed separately before moving to the next one.

Each interview was carefully listened to while reading its transcript line by line in order to gain familiarity with the data and get a sense of the narrative as a whole.

The next stage involved re-reading the transcript and starting to write informal comments by closely engaging with the data. As guided by Smith and colleagues (2009), for each individual case, a table of two columns was initiated, where the transcript was

on the left side and comments were on the right. Microsoft Word comments feature was used to conduct this step of the analysis, where a small paragraph, a few sentences or sometimes one sentence (depending on the richness of the data) was highlighted and commented upon.

This annotation process aimed to capture important observations (Smith et al., 2009), and was rather open-ended, meaning there were no requirements about which data to comment on or the length of each comment. This exploratory task enabled openness around what to write as well as the inclusion of personal feelings. Almost every line was commented on in the individual transcripts in order not to miss any potential gems in the data.

While this is not a prescriptive task, Smith and colleagues' (2009) suggestion in annotating IPA data was followed, where comments were divided into three main types: descriptive, linguistic and conceptual. The descriptive comments (written in normal text) focused on the content that shaped participants' thoughts, whereas linguistic comments (*written in italic*) focused on how participants used language to convey certain messages, such as metaphors or repetition of words. Conceptual comments (underlined) focused on the interpretation of the data, including the personal reflection of the researcher's own understanding, experiences and knowledge.

Comments were first written for each highlighted element in the individual transcripts and were then re-visited to decide which type of comment each one was. This helped check whether, for example, most comments were descriptive and therefore whether a more interpretative lens was needed.

In Table 5 below, an example from participant Simon's raw data demonstrates how initial comments were created on the transcript. In this example from the first quarter of his interview, Simon was giving a detailed answer to a question about his life before the injury and what a typical day at work was like for him. Here, Simon talked about the nature of his pre-injury job, as well as how he felt about it.

Table 5

*An example from participant Simon’s transcript of how initial comments were created – Study 1*

Transcript	Comments
<p><b>Simon:</b> So, at the time of my injury, I have been in (<i>African country 2 – name omitted</i>) for almost a year and a half doing a very very intense job, it was extremely pressurised, it was extremely stressful, it involved a lot of travel around (<i>African country 2 – name omitted</i>); I was living out of a suitcase, and I was only in my home, you know, the place where I stayed in (<i>African country 2 – name omitted</i>) a week every two months or something. Other than that I was just on the road and I am [unclear 00:09:45] and stuff. And I loved it, I mean it stressed out my mind; the work, you know, but I was... I loved the organisation I worked for, I was proud of my achievements, and the project I was involved with I really liked, it was very exciting; in terms of research and things like that. So, that is what I did, actually.</p> <p><b>Simon:</b> I was research and evaluation advisor for this massive governor’s programme across the eastern (<i>African country 2 – name omitted</i>). So, I was in charge of overseeing an impact evaluation, which was a randomised control trial done by Colombia University in America. Erm, it was just a huge operation to... it was a... long story short, it was a huge evaluation I was overseeing with a lot of staff; about eighty people, and training them to go out in the field, collect data, you know!</p>	<p><u>Simon described his job before the injury in an interesting way. He first started describing the intensity of the job and the challenging side of it and how he felt about that (it was a very stressful job). He then went to describe the positive feelings about the job, his desire to do that job and the excitement associated with this.</u></p> <p><i>When Simon talked about his positive feelings, he used a consistent language of nostalgia, sentiment and longing. He was speaking about his feelings in the past tense.</i></p> <p><i>The terms he used “I loved it”, “I was proud of my achievements”, “the project I was involved with I really liked” and “it was very exciting” were very powerful in conveying the message that he misses his previous work. He talks about it with a lot of passion.</i></p> <p>Simon is describing his nature of work, which involved traveling, training and doing paperwork.</p>

The Microsoft Word comments feature was used for convenience during analysis. However, to add clarity for the reader and ensure that examples of the analysis were easy to read, comments have been inserted directly into a fresh column ('comments'); the content of the comments is identical, however.

As can be seen from Table 5, descriptive comments were typed with normal text adjacent to Simon's straightforward description of his pre-injury job. Conceptual comments (underlined), however, reflected elements of the transcript where Simon was more emotional, such as when describing his pre-injury job as well as the researcher's interpretation of his pride in such a job that, while stressful, was full of achievements. Finally, linguistic comments (*written in italic*) reflected the use of some of Simon's words and expressions which showed his passion for this job in a nostalgic tone, especially when using the past tense.

The next step involved transforming initial comments into '*emergent themes*' by condensing the meaning of each comment and concisely expressing its experiential import, as interpreted by the researcher. For this, a third column was added to the table alongside the transcript and annotations; *emergent theme(s)* stemming from each comment were on the left side.

Table 6 shows an example from Simon's annotated transcript of how *emergent themes* were created from annotations.

Table 6

An example from participant Simon’s idiographic analysis of how emergent themes were created – Study 1

Emergent themes	Transcript	Comments
<p><b>A demanding yet an interesting job</b></p> <p><b>Passion for a proudly-done job</b></p> <p><b>Paperwork, teamwork and training formed the nature of the work</b></p>	<p><b>Simon:</b> So, at the time of my injury, I have been in (<i>African country 2 – name omitted</i>) for almost a year and a half doing a very very intense job, it was extremely pressurised, it was extremely stressful, it involved a lot of travel around (<i>African country 2 – name omitted</i>); I was living out of a suitcase, and I was only in my home, you know, the place where I stayed in (<i>African country 2 – name omitted</i>) a week every two months or something. Other than that I was just on the road and I am [unclear 00:09:45] and stuff. And I loved it, I mean it stressed out my mind; the work, you know, but I was... I loved the organisation I worked for, I was proud of my achievements, and the project I was involved with I really liked, it was very exciting; in terms of research and things like that. So, that is what I did, actually</p> <p><b>Simon:</b> I was research and evaluation advisor for this massive governor’s programme across the eastern (<i>African country 2 – name omitted</i>). So, I was in charge of overseeing an impact evaluation, which was a randomised control trial done by Colombia University in America. Erm, it was just a huge operation to... it was a... long story short, it was a huge evaluation I was overseeing with a lot of staff; about eighty people, and training them to go out in the field, collect data, you know</p>	<p><u>Simon describes his job before the injury in an interesting way. He first started describing the intensity of the job and the challenging side of it and how he felt about that (it was a very stressful job). He then went to describe the positive feelings about the job, his desire to do that job and the excitement associated with this.</u></p> <p><i>When Simon talked about his positive feelings, he used a consistent language of nostalgia, sentiment and longing. He was speaking about his feelings in the past tense.</i></p> <p><i>The terms he used “I loved it”, “I was proud of my achievements”, “and the project I was involved with I really liked”, “it was very exciting” were very powerful in conveying the message that he misses his previous work. He talks about it with a lot of passion.</i></p> <p>Simon is describing his nature of work, which involved traveling, training and doing paperwork.</p>



After looking at the whole individual transcript and identifying *emergent themes* from all initial comments, all identified *emergent themes* were pulled out of the transcript and a list of them was created (as seen in a sample in Figure 3 below).

**A sample of *emergent themes* from Simon's idiographic analysis:**

- The lost sense of belonging
- Cutting all ties with the past
- The battle to reintegrate
- Work pressure was an excitement
- A demanding yet an interesting job
- The injury has called it off
- The mixed feelings of denial and acceptance
- Passion for a proudly-done job
- Nostalgia to joyful plans that the injury interrupted
- Paperwork, teamwork and training formed the nature of the work
- A whole life that was left behind
- Initial denial and shock following the injury
- It felt like a dream
- The uncertain self

*Figure 3.* An example from participant Simon's data of how *emergent themes* were pulled out of the annotated transcript and listed for clustering - Study 1

Each *emergent theme* was then written on a small piece of paper and all pieces of paper were then placed on a large surface. The next task involved clustering the *emergent themes* according to patterns of connection. Since there was a large number of *emergent themes* in each participant's transcript, it was difficult to cluster them under '*superordinate themes*' immediately (*superordinate themes* in IPA are presented as the highest level of themes and the final stage of the individual-case analysis). To elaborate, if *emergent themes* from the transcript were to be clustered under *superordinate themes* immediately, the analysis would either create too many *superordinate themes* or have too many *emergent themes* under a *superordinate theme*. Therefore, a step of creating '*second-order themes*' was conducted in order to cluster *emergent themes*; later, those *second-order themes* were grouped under *superordinate themes* (*second-order themes* were larger than *emergent themes*, but smaller than *superordinate themes*).

*Emergent themes* were arranged and re-arranged into groups using strategies suggested by Smith and colleagues (2009). In Figure 4 below, the researcher used the following strategies in Simon's idiographic analysis:

- **Contextualisation:** in which *emergent themes* were grouped together because they told a narrative or were related to a temporal moment.
  
- **Function:** in which the focus was on how *emergent themes* functioned in the transcript and how they could serve the participant to present the self in a distinct way.

An example of *emergent themes* grouped together under *second-order themes* based on the strategy of *contextualisation*:

❖ **Chaotic moments**

- *Initial denial and shock following the injury*
- *It felt like a dream*
- *The uncertain self*
- *The mixed feelings of denial and acceptance*

An example of *emergent themes* grouped together under *second-order themes* based on the strategy of *function*:

❖ **Work was a life that was fully embraced**

- *Paperwork, teamwork and training formed the nature of the work*
- *Doing a job that was always the desired job*
- *Sophistication of previous work was a plus*
- *A proud worker of a unique job*
- *Passion for a proudly done job*
- *Work pressure was an excitement*
- *A demanding yet an interesting job*
- *A socially fulfilling job*

*Figure 4.* Examples from participant Simon's idiographic data of how the work of clustering *emergent themes* under *second-order themes* was done – Study 1

In the first example in Figure 4, the four *emergent themes* (bulleted in black squares) were interpreted as illustrating Simon's feelings during the acute stage of his injury, although some of those themes were more long-lasting than others. The four *emergent themes* described the 'Chaotic moments' that Simon lived at that time, when he could not fully comprehend the full impact of the injury on his life and he was oscillating between accepting the injury and denying it.

In the second example in Figure 4, it was believed that all listed *emergent themes* (bulleted in black squares) functioned in Simon's account as looking at previous work as 'the life', because of all the excitement, positivity, pride, success and achievements that were associated with the job he was doing before his SCI.


At this stage, as *second-order themes* were attracting *emergent themes*, some *emergent themes* were thoughtfully put aside as they did not fit the growing patterns.

After producing a final set of *second-order themes* similar to those in Figure 4 (i.e. *Chaotic moments* & *Work was a life that was fully embraced*), all *second-order themes* were written on small pieces of paper (each with its relevant *emergent themes* written under it) in order for them to be clustered under the highest level; that is, under *superordinate themes*. To create those *superordinate themes*, connections between *second-order themes* (with the aid of the latter's *emergent themes*) needed to be identified; the *emergent themes* under each *second-order theme* reflected its content (i.e. position, function and meaning in the transcript), and therefore helped it be clustered under the most appropriate *superordinate theme*.

Strategies which were both similar to and differed from those mentioned earlier were used to group themes at this stage. In Figure 5 below, the following strategy, suggested by Smith and colleagues (2009), was used to cluster *second-order themes* under a *superordinate theme*:

- **Abstraction:** in which like with like themes were put together.

An example of *second-order themes* being clustered under a *super-ordinate theme* using the strategy of *abstraction*:

 **In the haze of SCI**

❖ **Chaotic moments**

- *Initial denial and shock following the injury*
- *It felt like a dream*
- *The uncertain self*
- *The mixed feelings of denial and acceptance*

❖ **Focusing on the present**

- *The solo focus on physical recovery following the injury*
- *Cutting all ties with the past*
- *Dissociating self from reality*

Figure 5. An example from participant Simon's idiographic data of how *second-order themes* were clustered under *superordinate themes* – Study 1

In Figure 5, both *Focusing on the present* and *Chaotic moments* were *second-order themes* that reflected Simon's dilemma. Simon's struggle to initially face and accept reality after his injury was a vague process that was full of uncertainties and mixed feelings, and which continued in the present. When Simon wanted to forget the past, he was still detaching himself from current reality.

However, in rare cases in the individual analysis process, *second-order themes* could occasionally stand alone with their *emergent themes* and without being further clustered. These themes therefore worked as *superordinate themes*; that is, they were upgraded from *second-order* to *superordinate themes* which attracted *emergent themes*. According to Smith and colleagues (2009), this strategy of theme upgrade in IPA is called '**subsumption**'; the forthcoming Table 7 included two examples of those rare cases of *subsumption*.

The careful investigation of *second-order themes* while being clustered under *superordinate themes* meant that some were put aside as their material did not fit the identified patterns.

Finally, a table of *superordinate themes* was created for each individual participant's case (Simon's analysis is presented as an example in Table 7 below), in which those *superordinate themes* were presented in the best way to tell an idiographic narrative. In Table 7 below, each *superordinate theme* was numbered (**1, 2, 3 and so on**), while each *second-order theme* under a *superordinate theme* was alphabetised (**a, b, c and so on**) and each *emergent theme* under a *second-order theme* was bulleted (in black square) and written in normal text.

As can be seen in Table 7 below, while all three levels of themes (*superordinate, second-order* and *emergent*) were presented in a column on the left side of the table, keywords from the transcript corresponding to each *emergent theme* (since these were the closest themes to the transcript) were presented in a middle column, and page numbers from the transcript for those keywords were provided in a column on the right side of the table.

Table 7

An example of a table of superordinate themes for an individual case (Simon) – Study 1

<u>Themes</u>	<u>Key words</u>	<u>Page number</u>
<p><b>1. Work was a life that was fully embraced*</b></p> <ul style="list-style-type: none"> <li>▪ <i>Paperwork, teamwork and training formed the nature of the work</i></li> <li>▪ <i>Doing a job that was always the desired job</i></li> <li>▪ <i>Sophistication of previous work was a plus</i></li> <li>▪ <i>A proud worker of a unique job</i></li> <li>▪ <i>Passion for a proudly done job</i></li> <li>▪ <i>Work pressure was an excitement</i></li> <li>▪ <i>A demanding yet an interesting job</i></li> <li>▪ <i>A socially fulfilling job</i></li> </ul>	<p><i>I was research and evaluation advisor</i></p> <p><i>That is what I always wanted to do in my life</i></p> <p><i>Even my family and my fiends could not relate to</i></p> <p><i>Novel</i></p> <p><i>I love it</i></p> <p><i>Life was exciting</i></p> <p><i>It stressed out my mind [...] but [...] I loved the organisation I worked for</i></p> <p><i>Your colleagues are your friends and your housemates</i></p>	<p>11</p> <p>9</p> <p>26</p> <p>13</p> <p>10</p> <p>28</p> <p>10</p> <p>13</p>
<p><b>2. In the haze of SCI</b></p> <p><b>a. A huge interruption to a smooth life</b></p> <ul style="list-style-type: none"> <li>▪ <i>Nostalgia to joyful plans that the injury interrupted</i></li> <li>▪ <i>Blaming work for partially causing the injury</i></li> <li>▪ <i>The injury has called it off</i></li> </ul> <p><b>b. Chaotic moments</b></p> <ul style="list-style-type: none"> <li>▪ <i>Initial denial and shock following the injury</i></li> <li>▪ <i>It felt like a dream</i></li> <li>▪ <i>The uncertain self</i></li> <li>▪ <i>The mixed feelings of denial and acceptance</i></li> </ul>	<p><i>A little holiday, which I was really looking forward to</i></p> <p><i>It was one factor leading to my spinal injury</i></p> <p><i>So the spinal injury happened, I lost all of that; my friends, my work and my home were all abroad</i></p> <p><i>That really did not really daunt me until further down the line</i></p> <p><i>It was not real</i></p> <p><i>Limbo</i></p> <p><i>Dilemma</i></p> <p><i>I just tried to stay positive, but I was just despondent</i></p>	<p>4</p> <p>14</p> <p>26</p> <p>5</p> <p>27</p> <p>37</p> <p>37</p> <p>31</p>

<p><b>c. Focusing on the present</b></p> <ul style="list-style-type: none"> <li>▪ <b>The solo focus on physical recovery following the injury</b></li> <li>▪ <b>Cutting all ties with the past</b></li> <li>▪ <b>Dissociating self from reality</b></li> </ul>	<p><i>Maximise whatever physical recovery</i></p> <p><i>I never look at photos</i></p> <p><i>Switching my mind off</i></p>	<p>17</p> <p>37</p> <p>30</p>
<p><b>3. The daunting experience of rehabilitation*</b></p> <ul style="list-style-type: none"> <li>▪ <b>Physical challenges at rehabilitation</b></li> <li>▪ <b>Disappointments during the rehabilitation period</b></li> <li>▪ <b>Blame for rehabilitation neglect and unfairness</b></li> <li>▪ <b>Patient education versus high expectations</b></li> </ul>	<p><i>I have got two bolts literally stretching my spine out to relieve the pressure</i></p> <p><i>It wore down my optimism about the future bit by bit</i></p> <p><i>Disheartening</i></p> <p><i>It seems very very good</i></p>	<p>7</p> <p>7</p> <p>5</p> <p>9</p>
<p><b>4. Self versus others</b></p> <p><b>a. The challenges with relying on others</b></p> <ul style="list-style-type: none"> <li>▪ <b>The challenge with losing independence and privacy</b></li> <li>▪ <b>The deep and indescribable feelings of losing the independent self</b></li> <li>▪ <b>The narrowed space for independence</b></li> <li>▪ <b>Privacy meant a lot but it was lost</b></li> </ul> <p><b>b. The battle to reintegrate</b></p> <ul style="list-style-type: none"> <li>▪ <b>The struggle with accommodation when back to the community</b></li> <li>▪ <b>The lost sense of belonging</b></li> <li>▪ <b>Social isolation following the injury</b></li> </ul> <p><b>c. Difficult, but gradually learning to live with it</b></p> <ul style="list-style-type: none"> <li>▪ <b>Self-underestimation as a result of leaving work</b></li> <li>▪ <b>The active tringle consisting of the injury, the lack of self-confidence and the difficulty of RTW</b></li> </ul>	<p><i>Those were the two hardest aspects of my life to lose; independence and privacy</i></p> <p><i>But now I am going to be reliant on someone else</i></p> <p><i>The rhetoric is verbal independence for quadriplegics</i></p> <p><i>I lost a lot; I lost my privacy</i></p> <p><i>They did not have anywhere for me to live</i></p> <p><i>I did not have a home in England</i></p> <p><i>My neighbours were really anti-social</i></p> <p><i>I hate talking about myself</i></p> <p><i>My self-confidence ...it has taken a big hit from the spinal injury</i></p>	<p>30</p> <p>39</p> <p>30</p> <p>30</p> <p>15</p> <p>18</p> <p>26</p> <p>35</p> <p>35</p>

<ul style="list-style-type: none"> <li>▪ <b>Exaggerating productivity works as a defence mechanism</b></li> <li>▪ <b>Coming to terms with other's negative reactions to current jobless self</b></li> <li>▪ <b>The combat for social acceptance in relation to work</b></li> <li>▪ <b>Accommodating the workplace to special needs as an embarrassment</b></li> <li>▪ <b>The helplessness feeling associated with RTW as a disabled</b></li> <li>▪ <b>Selectivity of work mode as a sign of awareness about physical limitations</b></li> </ul>	<p><i>I sort of finding myself exaggerating what I do voluntarily a little bit</i></p> <p><i>I am just trying to sound busier than I am</i></p> <p><i>It is a way that they are trying to quickly understand who you are</i></p> <p><i>They have not met someone like me</i></p> <p><i>I hate being disabled</i></p> <p><i>I was also worried that going back to work full-time was going to be too much for me</i></p>	<p>33</p> <p>36</p> <p>36</p> <p>36</p> <p>32</p> <p>34</p>
<p><b>5. It is not working</b></p> <p><b>a. Absence of good luck</b></p> <ul style="list-style-type: none"> <li>▪ <b>Failed attempts in finding an alternative to previous work</b></li> <li>▪ <b>Lack of work opportunities as a disappointment</b></li> <li>▪ <b>Eagerness for work and education was faced with neglect and rejection</b></li> <li>▪ <b>The agony associated with failure to get a job</b></li> <li>▪ <b>Appreciation matters</b></li> </ul> <p><b>b. Internal versus external complications to hinder work return</b></p> <ul style="list-style-type: none"> <li>▪ <b>Lack of wheelchair accessibility as an obstacle for work</b></li> <li>▪ <b>Lack of modifications by employers as an obstacle for work</b></li> <li>▪ <b>Medical complications to hinder work</b></li> <li>▪ <b>The shame of losing work-related skills</b></li> <li>▪ <b>The strive to excel is an obstacle to RTW</b></li> <li>▪ <b>It is not the same anymore</b></li> </ul>	<p><i>I do not think it was going so well either</i></p> <p><i>It is not nice to not be successful</i></p> <p><i>I had quite high hopes that life was going to be different</i></p> <p><i>The course facilitator was not very... was not very kind or encouraging</i></p> <p><i>I was a bit taken for granted in a bit</i></p> <p><i>Unfortunately, they were not ready for me</i></p> <p><i>They were more hands-on [...], so that was a shame</i></p> <p><i>I was just not up to it at the time</i></p> <p><i>I do not use my mind much anymore</i></p> <p><i>I do not want people to expect less of me</i></p> <p><i>I find it hard keeping up; I was extremely productive</i></p>	<p>34</p> <p>25</p> <p>25</p> <p>32</p> <p>21</p> <p>19</p> <p>22</p> <p>22</p> <p>22</p> <p>23</p> <p>37</p>



<p><b>6. The push that keeps the current flow</b></p> <p><b>a. The real motive to RTW</b></p> <ul style="list-style-type: none"> <li>▪ <b>Financial reward from work is not a priority</b></li> <li>▪ <b>The deeply missed psychological rewards of work</b></li> </ul> <p><b>b. Sharing is caring</b></p> <ul style="list-style-type: none"> <li>▪ <b>Partner as a significant source of emotional support</b></li> <li>▪ <b>An encouraging partner</b></li> <li>▪ <b>The sacrifices of a working partner</b></li> <li>▪ <b>A comfortable life with partner</b></li> </ul> <p><b>c. The light at the end of the tunnel</b></p> <ul style="list-style-type: none"> <li>▪ <b>RTW training as a sign of enthusiasm</b></li> <li>▪ <b>Striving for sense of achievement</b></li> <li>▪ <b>A determined spirit to achieve productivity</b></li> </ul>	<p><i>I do not need to work</i></p> <p><i>I do miss that sense of purpose and that sense of team and accomplishment</i></p> <p><i>I was just despondent. But I had Stephany with me and my family are very encouraging</i></p> <p><i>She often wants to invite me along</i></p> <p><i>Stephany (name changed) was already working, she was just commuting</i></p> <p><i>I mean we are okay without that income</i></p> <p><i>It was nice, it was actually really helpful</i></p> <p><i>It was rewarding</i></p> <p><i>I will try, I will keep on trying</i></p>	<p>40</p> <p>40</p> <p>31</p> <p>35</p> <p>24</p> <p>40</p> <p>34</p> <p>19</p> <p>38</p>
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(\*): Subsumption

## 2) Cross-case analysis

Having produced nine individual tables of *superordinate themes* for the nine participants in this study, the next task was to conduct a cross-case analysis. The first stage of this involved pulling out all *individual superordinate themes* from individual participants' tables, writing each of them on a small piece of paper (with its *second-order themes* and the name of participant to whom the theme belonged) and reviewing them. The purpose of reviewing *individual superordinate themes* at this stage was to cluster them and so find patterns of connection across cases (that is, convergences and divergences between participants' cases).

Therefore, *individual superordinate themes* (with their *second-order themes*) were clustered under '*group themes*'. Creating those *group themes* was done using some of Smith and colleagues' (2009) strategies mentioned earlier. In Figure 6 below, an example from the cross-case analysis utilised the earlier mentioned strategy of *abstraction*, in which similarities between the data were identified.

An example of clustering *individual superordinate themes* under *group themes* based on the strategy of *abstraction*:

❖ **Pre-injury work: looking back with nostalgia**

- **Simon**
  - Work was a life that was fully embraced
  - “That is what I always wanted to do in my life”.
- **William**
  - It was a job full of motivations
  - “Just found it more and more interesting”.
- **Henry**
  - Emotional attachment to previous work
  - “I think that the job itself was interesting”.
- **Mark**
  - The positive pre-injury career life
  - “I had a very successful career, I learnt a lot”.
- **Andy**
  - Perceiving previous work as meaningful
  - “I think if you have got a job that you enjoy doing then it is not so much of a chore”.
- **Jeff**
  - The passion of doing pre-injury work
  - “I loved it [...]. It was an eye opener”.

Figure 6. An illustration of clustering *individual superordinate themes* under *group themes* – Study 1

In the example in Figure 6, *Pre-injury work: looking back with nostalgia* was a *group theme* that attracted a number of *individual superordinate themes*, since those themes had similar meanings relating to nostalgia and the longing for a successful, enjoyable pre-injury job. *Individual superordinate themes* are bulleted in black squares with evidence from the individual transcripts.

Following the same pattern as before, each *group theme* was written down on a small piece of paper along with the name of the participants to whom it belonged. All these *group theme* papers were placed on a large surface, and were then clustered under the highest group of themes, known as ‘*master group themes*’. Strategies that were both similar and different to those described before were used during this process. In Figure 7 below, *group themes* were clustered under a *master group theme* (i.e. *The bittersweet feeling about work*) utilising the following strategy:

- **Polarization:** in which the focus was on differences in the data rather than similarities.

An example of clustering *group themes* under *master group themes* based on the strategy of *polarization*:

❖ **The bittersweet feelings about work**

❖ **Pre-injury work: looking back with nostalgia**

- **Simon**
  - Work was a life that was fully embraced
  - *"That is what I always wanted to do in my life"*.
- **William**
  - It was a job full of motivations
  - *"Just found it more and more interesting"*.
- **Henry**
  - Emotional attachment to previous work
  - *"I think that the job itself was interesting"*.
- **Mark**
  - The positive pre-injury career life
  - *"I had a very successful career, I learnt a lot"*.
- **Andy**
  - Perceiving previous work as meaningful
  - *"I think if you have got a job that you enjoy doing then it is not so much of a chore"*.
- **Jeff**
  - The passion of doing pre-injury work
  - *"I loved it [...]. It was an eye opener"*.

❖ **Victimised workers by their own injuries**

- **Henry**
  - Emotional detachment from previous work
  - *"I feel as if I have been robbed of my profession because of my spinal cord injury"*.
- **Mark**
  - Dealing with the emotional trauma of leaving work
  - *"I felt very resentful because I felt pushed out of my career"*.
- **Simon**
  - It is not working
  - *"I find it hard to keep up; I was extremely productive"*.
- **Andy**
  - Feelings of being a victimised worker by the injury
  - *"Well it takes your whole life away really"*.

Figure 7. An illustration of clustering *group themes* under *master group themes* – Study 1

In the example in Figure 7, *polarization* was not between participants' accounts, but rather their two different feelings about work. Both nostalgia and victimisation were feelings that many participants had towards their pre-injury jobs. However, in the above example, while nostalgia worked as a positive aspect, victimisation worked as a negative one. This divergence showed how participants had a mixture of bitter and sweet feelings about their work before and after the injury.

Next, the recurrence of each *master group theme* was measured as suggested by Smith and colleagues (2009). A judgement was made that to be included, a *group master theme* needed to be present among at least five out of the total nine participants. Figure 9 is an example of how the calculation was done in the first study.

An example of identifying recurrence in <i>master group themes</i> :								
<b>A master group theme:</b>								
The bittersweet feelings about work								
<b>Chris</b>	<b>Simon</b>	<b>William</b>	<b>Henry</b>	<b>Mark</b>	<b>Andy</b>	<b>Jack</b>	<b>Mathew</b>	<b>Jeff</b>
No	Yes	Yes	Yes	Yes	Yes	No	No	Yes
<b>Present in at least 5/9 of sample?</b>								
Yes								

Figure 8. An example of identifying recurrence in *master group themes* – Study 1

A total of four *group master themes* were identified in this study, which were: **(1)** In the haze of SCI; **(2)** Reflecting on dynamics of social interaction following SCI; **(3)** The bittersweet feelings about work; and **(4)** Achieving inner peace and moving forward.

Finally, similar to a final table of *superordinate themes* for an individual participant (see an example in Table 7 above), a table of *master group themes* was created (see Table 8 below) to capture the core of the lived experience of becoming unemployed following SCI for the nine participants.

The final version of the table (see Table 8 below) included four *master group themes* (**numbered 1, 2, 3 & 4**), each with its *group themes* under it (**lettered 1.a, 1.b and so on**). Each *individual superordinate theme* was illustrated with extracts from participants' transcripts and with the corresponding page numbers. Finally, to aid comprehension, some *group themes* were annotated with sub-headings (such as '**Critical moments**') to cluster closely allied material.

Table 8  
 Table of master group themes – Study 1

Themes	Participant, individual superordinate theme, <i>corresponding extracts</i>	Page
1. In the haze of SCI	-	-
1.a. The initial moments of the injury were critical and lived with a lot of uncertainty	-	-
Critical moment	William: The journey to work that was never completed <i>"I was unable to breathe at the scene, air ambulance landed to assist the road paramedics to enable me to breathe; they inserted a tube through my throat. Erm, air ambulance left, they thought I was dead, road ambulance took me to hospital, handed me over to the staff at (hospital name omitted) who then... so I was... I am trying to think... GS3 at the scene which is "clinically dead", then when I was handed over to staff at (hospital name omitted) they found some signs of life and they got me going"</i> .	3
	Mark: It was initially critical <i>"I could not move at all"</i> .	6
Living with uncertainty	Simon: In the haze of SCI <i>"It was not real [...]. I feel like I am in limbo and I do not think I am going to be able to explain why [long pause] this could sound strange, yeah I feel like I am floating; I am somewhere between dead and alive; here and not [...] I just tried to stay positive, but I was just despondent"</i> .	27, 37, 31
	Andy: The initial anxiety and concerns regarding work return following the injury <i>"Well for a start I did not even know whether I was going to move again [...] and if there was any form of work I could get back to"</i> .	21
	Jack: The initial absence of realisation of the injury <i>"Half the time I thought I was dreaming"</i> .	8
	Mathew: The initial psychological trauma caused by the lack of awareness about the permanency of the injury <i>"Well I was a bit scared [...]. And he used to sit there and wiggle his toes and I used to sit there and try and wiggle mine and I could not. And I just thought how can he do it and I cannot"</i> .	5
	Jeff: Living the initial moments of the injury between awareness of the trauma and hope of reduction of the trauma <i>"I knew I was paralysed, but there is always hope that they could fix me up in hospital"</i> .	2

<p><b>1.b. Complex presentation of the experience of receiving medical care and rehabilitation</b></p>	<p>-</p>	<p>-</p>
<p><b>Frustration over poor medical care</b></p>	<p><b>Henry:</b> Medical issues following the first injury due to lack of patient education <i>“I found the whole experience very daunting [...] tackling issues with the fact that because I had not had the specialist spinal input [...]. I think that if I had had the specialist input at the beginning, I think from a patient education perspective, I would have been more aware of some of the problems a spinal cord injury causes”.</i></p> <p><b>Mark:</b> The frustrating medical care <i>“They took me to A&amp;E. A&amp;E are not used to dealing with spinal cord injuries”.</i></p> <p><b>Andy:</b> The preventable severity of the injury is blamed on medical care <i>“Whereas if it had been done months before the outcome may have been a lot different”.</i></p> <p><b>Jack:</b> Experiencing poor medical care <i>“Well they are all individual rooms, and they knew nothing about spinal cord and I basically went from a semi healthy person... [...] I was extremely ill, I lost a stone in weight”.</i></p> <p><b>Mathew:</b> Experiencing low quality medical care following the injury <i>“The treatment I had there was absolutely ridiculous [...]. I could not cope with it and they were just ignoring me”.</i></p>	<p>6</p> <p>5</p> <p>5</p> <p>11, 12</p> <p>2</p>
<p><b>A satisfying quality of rehabilitation</b></p>	<p><b>Henry:</b> Resilience after the first injury with good rehabilitation <i>“By the time I got to rehabilitation my legs started to move so within intensive physiotherapy I ambulated with a walking stick for seven years and I went back to work”.</i></p> <p><b>Mark:</b> Physical improvement highlighted the rehabilitation experience <i>“Five weeks they discharged me, let me go home for the weekend and at Stoke Mandeville my progress just continued to accelerate”.</i></p> <p><b>Mark:</b> The triggers for re-building life were related to a supportive rehabilitation team <i>“When I was discharged they have a bi-annual conference, [...] and they always have a patient story and they asked me to come back and speak”.</i></p> <p><b>Andy:</b> An active rehabilitation period <i>“They took me downstairs to the normal wards, and then they started doing the physio and the hydro and the different pieces on that and the gymnasium work and working on treadmills and things like that and trying to get back, trying to get things working again”.</i></p> <p><b>Andy:</b> Support for community reintegration through rehabilitation <i>“So it was all sort of trying to, you know, get you ready for the outside world again I suppose”.</i></p> <p><b>Jack:</b> The rehabilitation hospital worked as a haven from poor medical care and health deterioration <i>“It was literally from getting into Stoke Mandeville</i></p>	<p>2</p> <p>6</p> <p>13</p> <p>6</p> <p>33</p> <p>14</p>



	<p>[Rehabilitation facility] <i>it was probably a week afterwards that I started to feel human again</i>”.</p> <p><b>Mathew:</b> Gratefulness to be at a specialised rehabilitation programme <i>“The time I had at Stoke Mandeville was good”</i>”.</p>	3
<b>1.C. Living with a physically reduced QoL following the injury</b>	-	-
<b>Medical complications</b>	<p><b>Henry:</b> The relationship between physical complications and QoL <i>“I had to learn different bowl routines which were quite demoralising but it is just the nature of the beast [...] if the bowels are not working properly I have to cancel appointments and things just in case I have an accident [...]. It can have a detrimental effect on daily living”</i>”.</p> <p><b>Henry:</b> Physical complications and work <i>“I was periodically ill with various different complaints because of my spinal cord injury”</i>”.</p> <p><b>Mark:</b> The struggle before hitting the road back to work <i>“I was on sick leave for one year. Because obviously after a spinal cord injury it was completely understandable I was not in a position to go back to work”</i>”.</p> <p><b>Andy:</b> The impact of the injury on activities of daily living <i>“It is quite a life changing thing really because you go from being a full employed, active person to not being able to move”</i>”.</p> <p><b>Mathew:</b> Barriers related to physical health hindered RTW following the injury <i>“Well I want to get back to work yes [...]. Well there is issues with my stomach”</i>”.</p> <p><b>Jeff:</b> Acknowledging the physical difficulties of currently doing the pre-injury job <i>“I was very active before so I know I can never clean windows. I can clean the downstairs windows but, you know, I just see it as a... I cannot climb up the stairs, I cannot climb up the ladder. And now I have got a tube inserted below my stomach straight in through my bladder. I look at it and think hmmm...”</i>”.</p>	3, 27 4 8 3 30 13
<b>Dependency on others</b>	<p><b>Simon:</b> The challenges with relying on others <i>“Those were the two hardest aspects of my life to lose; independence and privacy”</i>”.</p> <p><b>Andy:</b> The new self that is dependent on others <i>“I have got to rely on a lot of other people doing even silly minor tasks that you would do yourself, like making a cup of tea or whatever you know [...]. It takes a lot of self-respect away from yourself, knowing that you cannot provide for people, or yourself even”</i>”.</p> <p><b>Jack:</b> The physical challenges that impeded community re-integration <i>“It was all lots of other problems trying to get carers to come in and help me get on to the bed”</i>”.</p>	30 7, 30 2
<b>2. Reflecting on dynamics of social interaction following SCI</b>	-	-

<b>2.a. Post-injury sociality is a thorn in the flesh</b>	-	-
<b>Social isolation</b>	<p><b>Chris:</b> The dire need for social fulfilment <i>“I am now stuck in my house with nobody and... no social... this is it. I understand that the only part of work that I want now, to be honest, is this social interaction [...]. I would put money now to go back to work to be around people”.</i></p> <p><b>Simon:</b> The battle to reintegrate <i>“I was becoming very bored [...]. I felt totally cut-off, yeah my friends were not around me”.</i></p> <p><b>Jeff:</b> Post-injury social challenges and reactions to them <i>“I basically lived in this downstairs room from March 2015 until August 2016. I lived in this small room with a bed with my family upstairs and I would just stare out the window. [...]. You just go in a really dark place, a really dark place. So it did affect me emotionally”.</i></p>	14, 24 17, 29 15
<b>Restricted social activities</b>	<p><b>William:</b> The loss of a positive social life <i>“Social activity is now much more restricted [...]. I cannot go to football matches [...] I cannot drink now; I end up in lots of pain when I drink alcohol”.</i></p> <p><b>Andy:</b> The negative impact of the injury on social life <i>“Going to theatres, swimming, cinemas car shows and things like that we used to like going to, and now it is a lot more awkward to do those sort of things. Because like you know if you have got to get in somewhere, sometimes especially if you have got to use the wheelchair it is not as easy going round outdoor places, again is not as easy”.</i></p>	16 9
<b>2.b. Accentuating support</b>		-
<b>Thankful for a great support</b>	<p><b>Chris:</b> The gratefulness to a present financial support <i>“She [partner] still has to go to work, we still have to pay the bills”.</i></p> <p><b>Simon:</b> The push that kept the current flow <i>“I was just despondent. But I had Stephany with me and my family are very encouraging”.</i></p> <p><b>Andy:</b> The internal support through partner <i>“I think between us both we [partner and I] do try and keep positive and try and do bits that we can do when we can do them”.</i></p> <p><b>Henry:</b> The narrowed social network as a motivator <i>“A friend of mine who had already done his, a friend and colleague, he said why do not you do your master’s [...]. My best friend is a head teacher of a school in (UK City – name omitted) and we, he sort of, he rings me nearly every day and we sort of bounce ideas off each other”.</i></p> <p><b>Mathew:</b> The positive support after the injury <i>“I have done a couple of bits and pieces with my sister”.</i></p>	23 31 28 21, 36 18

<p>The dreadful lack of support</p>	<p><b>Chris:</b> The sore feelings of being let down <i>“Nobody else is thinking of me [...]. I feel a bit aggrieved with the fact that my work colleagues should have made sure that after hospital though I was okay”.</i></p> <p><b>Mark:</b> Lack of support was a fundamental factor for entering a relapse phase <i>“A lot of animosity from her because she realised that I was not coming back”.</i></p> <p><b>Mathew:</b> Lack of support from wife after the injury <i>“Well my wife told me she did not want anything to do with me when I was in Stoke [Rehabilitation facility]. So that did not go down too well [...]. I think if there was her around I think I would have got to work by now. Because with her assistance things do get on a lot easier do not they when you have got a partner to help you than when you have not”.</i></p>	<p>30, 35</p> <p>7</p> <p>12</p>
<p>3. The bittersweet feelings about work</p>	<p>-</p>	<p>-</p>
<p>3.a. Pre-injury work: looking back with nostalgia</p>	<p>-</p>	<p>-</p>
<p>Pre-injury work was a source of enjoyment</p>	<p><b>Chris:</b> A comprehensively enjoyable life before the injury <i>“That is what I used to enjoy... just going to work, going to the gym, coming home and spending time with my partner [...]. As soon as I had the accident, cannot ride the motor bike, you are not big anymore, you are not scary... everything is gone [...]. I used to think that that mattered before, you know, to look good, to be big, scary or whatever. Now, that I am not in that job, I see that it does not matter. You do not have to be big or scary or whatever”.</i></p> <p><b>Simon:</b> Work was a life that was fully embraced <i>“That is what I always wanted to do in my life”.</i></p> <p><b>William:</b> It was a job full of motivations <i>“Just found it more and more interesting”.</i></p> <p><b>Henry:</b> Emotional attachment to previous work <i>“I think that the job itself was interesting”.</i></p> <p><b>Mark:</b> The positive pre-injury career life <i>“I had a very successful career, I learnt a lot”.</i></p> <p><b>Andy:</b> Perceiving previous work as meaningful <i>“I do not know whether you would say work was a priority, work is a necessity is not it [...]. It is more of a necessity but I think if you have got a job that you enjoy doing then it is not so much of a chore. It is, I suppose like you say, it is a part of your life but you do enjoy it so you are not just doing it to earn money to live sort of thing. But it all sort of goes into the same bracket does not it”.</i></p> <p><b>Mathew:</b> Pre-injury work was valued for its psychological rewards <i>“Well enjoyed work. I do not know if you saw MasterChef last night but you just get enjoyment out of doing it. Cannot really say any more than that, you cannot explain it any more than that”.</i></p>	<p>8, 12, 5</p> <p>28</p> <p>6</p> <p>3</p> <p>20</p> <p>20</p> <p>22</p>

<p>The social value of pre-injury work</p>	<p><b>William:</b> Work was all about its social atmosphere <i>“You have got the camaraderie with your colleagues, erm once that finishes, it is very different and it is quite difficult to deal with”</i>.</p> <p><b>Jack:</b> Sharing knowledge with like-minded individuals and working with a team spirit formed the meaning of previous work <i>“If I wanted help building something or someone wanted help building something it would be ‘oh any chance of give us a hand’ if it was tea time or lunch time. And it was also that sharing of knowledge [...] it is a family. It was not a case of just going down to work, it meant to me because it was a proper family. It was not a case of you just went, did your work, you went home”</i>.</p> <p><b>Mathew:</b> The social meaning of pre-injury work <i>“I miss mucking around with my friends and that and playing on those sort of things [...]. I miss speaking to people. That is about it to be honest”</i>.</p> <p><b>Jeff:</b> The passion of doing pre-injury work <i>“It was an eye opener [...]. I loved it [my job]. I used to hear so many funny stories, I learnt so many things. I would be cleaning away and they would just be chatting, chatting, chatting, and it was quite interesting”</i>.</p>	<p>15</p> <p>54, 55</p> <p>22</p> <p>9, 11</p>
<p><b>3.b. Victimised workers by their own injuries</b></p>	<p>-</p>	<p>-</p>
<p>Helplessness due to the injury resulting in losing work</p>	<p><b>Simon:</b> It is not working <i>“I find it hard to keep up; I was extremely productive”</i>.</p> <p><b>Andy:</b> Feelings of being a victimised worker by the injury <i>“So it was a very much a sort of, a very dark time really because I have always worked, always enjoyed my work, and I’ve always worked hard [...]. We all go through life thinking, making plans for the future or when I am 20, when I am 30, when I am 40 I will do this, I will do that. It takes all that away and it does literally, you know, well it takes your whole life away really in one respect and you have got to start rebuilding it brick by brick really”</i>.</p>	<p>39</p> <p>21, 36</p>
<p>Feeling angry towards the injury for causing job loss</p>	<p><b>Henry:</b> Emotional detachment from previous work <i>“I feel as if I have been robbed of my profession because of my spinal cord injury”</i>.</p> <p><b>Mark:</b> Dealing with the emotional trauma of leaving work <i>“I have always been successful in what I was doing, I felt very resentful because I felt pushed out of my career [...]. I felt deflated, the reason being, as I said I have been in sales for twenty years, well just under twenty years. I have got a bundle of letters of accolade for a fantastic sales career and if I am to be honest I felt very, very angry”</i>.</p>	<p>34</p> <p>18</p>

3.C. In the eyes of others	-	-
	<p><b>William:</b> The different forms of employer’s discrimination against disability <i>“There were several incidences where I questioned what they were doing and was laughed at [...] tasks that my previous company had me doing that I would consider menial secretary tasks were things like checking spreadsheets that had nothing to do with maintenance activities”.</i></p> <p><b>Mark:</b> Discrimination at work was the most significant factor for relapse <i>“I had never missed target before, I missed target in June and I thought okay maybe it is just because I am just coming back but I missed by some distance and I thought ‘that is unusual’ [...]. You do not have to be a rocket scientist to work that out. It was clearly, maybe they saw me as I would be a bit of a burden coming back to work because potentially I was not going to be as fit and as strong and be able to work full time. So, it was maybe easier for them to increase the targets the way they did”.</i></p> <p><b>Jack:</b> Fighting social stigma of a dependent and non-working wheelchair user <i>“People look at me and they go ‘you have done great things for this, you have done great things for that’, but when you talk about work they go ‘oh it is because you are in a wheelchair’. Yeah but that is not the point though. I have still got from basically from my chest upwards it all still works quite happily. So why cannot I do something”.</i></p>	24  16, 17  43
4. Achieving inner-peace and moving forward	-	-
4.a. Striving to maintain a strong self-image following spinal cord injury	-	-
The strong self-image	<p><b>Chris:</b> Striving for social equality after the injury <i>“I am very happy to put the blue badge at parking, you know, close to say that I am disabled, but to be honest to be returning to work I would not want a label; “oh look, oh look, he has got a little cushion and Chris has got another ten-minute break now”, you know, I want to be equal to everybody else, you know”.</i></p> <p><b>Simon:</b> Difficult, but gradually learning to live with it <i>“I sort of finding myself exaggerating what I do voluntarily a little bit [...]. I am just trying to sound busier than I am”.</i></p>	17  36
The strong self-image of a father	<p><b>Mark:</b> The desire to maintain the image of a breadwinner father <i>“I cannot lean on my kids for support. I am their dad. Yeah? They are not my support network. I have to be my own in that respect [...]. I have got a great external face. I do not show everyone my inner core, how I have been feeling at times, so they see me as strong, they see me as coping. So maybe they think I do not need them”.</i></p> <p><b>Jeff:</b> The desire to maintain an image of a strong father and a husband is forcing acceptance of the injury <i>“You cannot be depressed if you have got a wife and two kids, there is no time to be depressed, you got to just suck it in and just carry on doing what you did before but emotionally it still affects. I am deeply affected by it but you have to just get on with it [...]. It is very hard because I have to act a lot because I do not want them seeing me</i></p>	35, 36  15,21

	<i>moping around and you know, I cannot say I am in pain all the time, because I do not want them to see that”.</i>	
<b>4.b. Self-reconciliation</b>	-	-
<b>Self-awareness</b>	<b>William:</b> Awareness of the change that the injury has made to work life <i>“It was my decision. I cannot sit in an office for eight hours a day [...] there are lots of things I cannot do in the aircraft industry. That will immediately put me out of running for any job that I might otherwise be able to apply for [...]. It is going to be very difficult for me to find a job that suites my ability”.</i>	11, 21, 24
<b>Satisfaction</b>	<b>Andy:</b> The manifestation of accepting the new self <i>“I am still pushing myself, but you can only push yourself as far as your body will let it go. With the damage that is there, it is never going to be 100% now I do not think. Still, I still hope to think it would be but I think realistically it is not going to be. So, you have to live on what you have got, I suppose”.</i> <b>Jack:</b> Phased acceptance of the injury <i>“It is what it is at the end of the day. But you have just got to make the best of it, you have just got to try and get over it. There was a lot of points when I thought I do not want to end up in a bloody chair I want to be walking like everybody else, and you just think it is not going to happen, I will be okay, I will deal with it for another, I will deal with it and you deal with it for another month and you look at it and you go ‘yeah I will not walk again’ but you know, I would still like to walk now”.</i>	36  16
<b>Contentment</b>	<b>Chris:</b> The injury was a chance to reconstruct the self <i>“I used to think that that mattered before, you know, to look good, to be big, scary or whatever. Now, that I am not in that job, I see that it does not matter”.</i> <b>Jeff:</b> Acceptance is shaped through finding alternatives to enjoying life after the injury <i>“I always say I cannot play football anymore but I can still throw the ball and she can practice her ball skills [...]. I might not have any legs but it does not matter. It does not matter. I am quite happy”.</i>	5  22
<b>4.c. Turning a new chapter in vocational life</b>	-	-
<b>The motivation to RTW</b>	<b>Simon:</b> The light at the end of the tunnel <i>“I do not know if I can handle the pressure, the practical aspects of things, and I will try, I will keep on trying, because you never know until you try”.</i> <b>Mathew:</b> Manifestation of keenness to RTW <i>“Well I want to get back to work yes [...]. Well I think it just makes you more normal really. Sitting round here during the day is not exactly exciting. It just makes you more normal really [...]; speaking and talking to somebody”.</i>	38  19, 24

<p>The shift in nature of work following the injury</p>	<p><b>Chris:</b> A diversion much needed <i>"I certainly would not be employed by somebody else anymore. Erm, I would... I would want to be my own boss"</i>.</p> <p><b>Mark:</b> Taking up a different job after work that has both materialistic and cultural values <i>"I want to speak to kids in secondary school because I believe we have got a lost generation and if I can inspire and motivate even one or two, that makes my injury worthwhile"</i>.</p> <p><b>Mathew:</b> The injury is an opportunity to start a new job <i>"It [the injury] has changed my career path. Because now I have got to do stuff on the computer where I have always wanted to be hands on [...] well I will be doing... ordering stuff and pricing out menus and that sort of thing [...]. I have done a couple of bits and pieces with my sister. To be practicing because it will be using Word. So yeah so I have done a couple of bits and pieces"</i>.</p>	<p>15</p> <p>14</p> <p>17, 18</p>
<p>The concrete plans to RTW</p>	<p><b>Mark:</b> Starting the new paid-job is only a matter of time <i>"I am excited... I am going to make the most of my life [...]. At the moment I am speaking for free but I do have plans to create a business around it and to establish myself as a speaker. As I said I have already kind of made a start but I am kind of testing the water in terms of I am not charging. I would really love 2017 to be my proper year of launch"</i>.</p> <p><b>Jack:</b> Post-injury motivation to work is following concrete steps <i>"Well I am actually starting work on the 3<sup>rd</sup> of January it is three weeks I am doing for free as a trial period"</i>.</p> <p><b>Jeff:</b> Practical plans to do voluntary work following the injury <i>"A neighbour of mine works with adult special needs and when she gets back off her holiday she is got a list of phone numbers that I can ring"</i>.</p>	<p>21, 14, 28</p> <p>34</p> <p>19</p>
<p>The actual start of a new vocational plan following the injury</p>	<p><b>Henry:</b> The compensation that voluntary work has made to life after retirement <i>"So subsequently I have been, they called me in and I have been volunteering for them for about a year now [...]. It is just a general disability charity [...] so initially when I was asked to come along and volunteer they wanted me to be part of their wellbeing programme [...]. I certainly think that by doing those things it has improved my wellbeing"</i>.</p>	<p>18, 28</p>

### Write up

Having generated a *table of master group themes* which represented a thematic framework of the nine participants' accounts, the next step was to write up the results. In an IPA study, this step includes interweaving a large amount of participant data with the researcher's interpretations. This is to say, the write up of the results was the accumulation of the researcher's initial comments on transcripts, the *group themes* and *master group themes* that emerged during the analysis of the interviews, all of which were supported by extracts from participants' transcripts and analysis of their individual tables of *superordinate themes*.

Writing up the results was a rather analytic process, in which more details and interpretation emerged. In addition, not all participant extracts included in the table of *master group themes* were used in the write up of the results, as the task here was to select evidence that could feed into the captured meaning of the data rather than listing all evidence.

The final draft of the results was written up in a narrative format guided by *master group themes* and *group themes*. The sub-headings appeared in the table of *master group themes* (see Table 8) for clarification for the reader but did not appear in the write up of the results, as the researcher wanted the narratives to flow and not become too descriptive.

The sequence in which the *master group themes* were presented in the findings chapter was 'case within theme' which, according to Smith and colleagues (2009), is the most orderly sequence in IPA. This sequence refers to presenting each *master group theme* while giving evidence from participants' transcripts to support the *group themes* within it (Smith et al., 2009).



### **Data protection**

Before presenting the findings of the first study in the next chapter, it is worth drawing on the plan for data protection in this thesis.

Maintaining complete confidentiality about participants is an ethical consideration when conducting research (Willig, 2013). In this thesis, to maintain anonymity, none of the audio-recorded interviews were saved on the recorders or on the computers under participants' real names, but instead, participants' recordings were identified by numbers (participant 1, participant 2, etc.) Also, during the transcription, analysis and write up of the data, participants and their partners and/or wives were given pseudonyms. Also, all data leading to the identification of any participant during the transcription, analysis or write up of the findings in this thesis were either changed or omitted (e.g., names, occupations, workplaces, locations, hospitals).

For the purpose of maintaining confidentiality of patient information (i.e., names, contact details and age), contact between the recruiters and the researcher was done on the phone or through secured, monitored and official email accounts of Birkbeck, University of London and the recruiters'.

The non-identifiable data generated from the thesis were stored in secured computers and secured file drawers at Birkbeck, University of London. Access to the data was limited to the researcher and the academic supervisor for the sole purpose of working closely and monitoring this thesis. Any transmission of data was done via secured, monitored and official Birkbeck, University of London email accounts.

The audio-recordings related to this thesis are planned to be destroyed after three years of the date they were collected and as soon as the researcher passes her PhD degree (this information was included in both documents of the participant information sheet and informed consent form provided to all participants in this thesis).

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## Chapter 5: Findings

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### An overview of the master group themes

All the *master group themes* that emerged in the first study were included in the write up of the results. While the themes varied in how relevant they were to participants' experience of unemployment following spinal cord injury (SCI), they all had elements that contributed to understanding the experience as a whole.

Figure 9 presents an overview of those *master group themes* and their *group themes*.

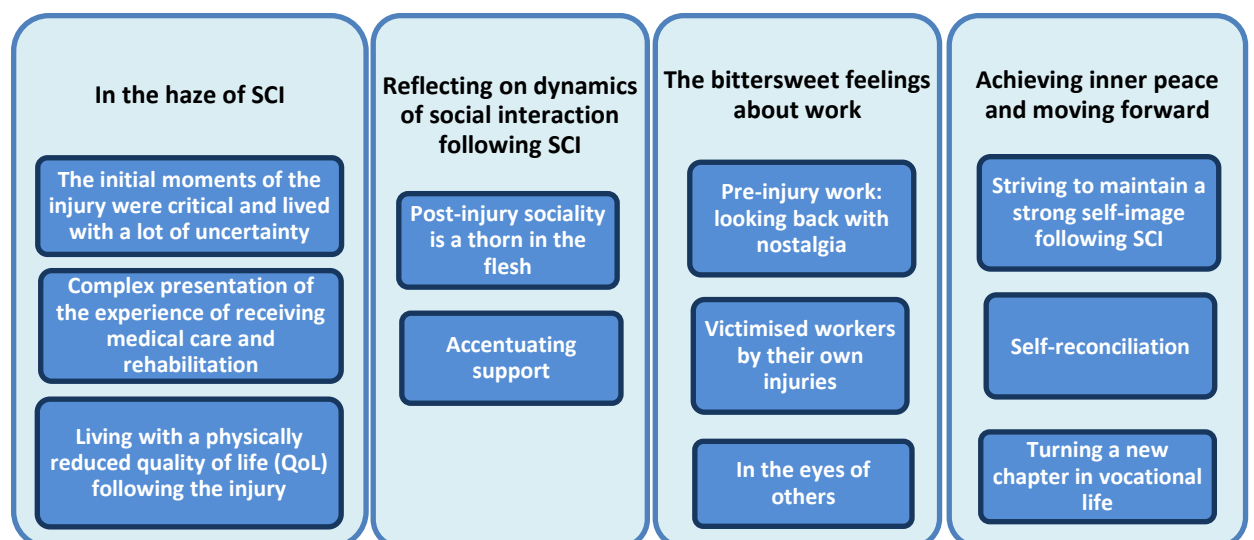


Figure 9. Overview of themes in the first study

The first *master group theme* (*in the haze of SCI*), sets the scene for the rest of the *master group themes*, as it mainly focused on the origin of participants' injuries and the challenges they faced during its acute stage as well as the early period of receiving rehabilitation and returning to the community. With a narrative of the physical challenges of the SCI participants, the first *master group theme* aimed to give the reader a pertinent introduction to the devastation the health condition of SCI brought to the participants' lives, which in most cases affected other aspects of life after SCI. In other

words, the first *master group theme* offered a context for the later challenges around work.

As will be seen shortly, feelings of uncertainty about the injury prognosis, the quality of rehabilitation that reflected the ability to physically improve, medical complications and dependency on others, all affected participants' perceptions of the possibility of return to work (RTW) at an early stage of the injury or even at later stages.

While the second *master group theme* (*Reflecting on dynamics of social interaction following SCI*) presented participants' narratives during a later stage, it was similar to the first *master group theme* in that it helped set the scene for more concrete accounts of work and work return.

The second *master group theme* focused on participants' accounts of social participation as well as the receipt of support from their family, friends and colleagues following SCI. It included fewer issues relating to medical and physical challenges than the first *master group theme*. Although its main focus was on social aspects, this second theme incorporated data that was directly relevant to perceptions relating to work return after the injury (such as a lack of support from spouse resulting in work non-return).

Lastly, the third and fourth *master group themes* (*the bittersweet feelings about work and achieving inner peace and moving forward*) included participants' explicit accounts of pre-injury work, work loss and RTW following SCI. It can be said that these two *master group themes* presented the core of the experience of SCI unemployment for the nine participants in the first study.

Table 9 presents demographic information for the nine participants stemming from the findings of the first study.

Table 9

*Demographic information for the nine participants stemming from the findings of the first study*

<b>Name</b>	<b>Injury occurrence</b>	<b>Relationship status</b>	<b>Father/ family provider ?</b>	<b>Pre-injury job</b>	<b>Experience of RTW following SCI? (if yes, details)</b>	<b>Moving forward with vocational life? (if yes, details)</b>
<b>Chris</b>	Traumatic (RTA)*	Living with partner	No	Security guard	No	Yes, showing motivation
<b>Simon</b>	Traumatic (fall)	Living with partner	No	Humanitarian aid worker	No	Yes, showing motivation
<b>William</b>	Traumatic (RTA)	Married	No	Aircraft maintenance engineer	Yes, but resigned	-
<b>Henry</b>	Traumatic (spinal stroke)	Living with partner	No	School teacher	Yes, but was medically retired	Yes, currently working as a volunteer
<b>Mark</b>	Traumatic (fall)	Living with partner	Yes	Sales specialist	Yes, but resigned	Yes, made concrete plans
<b>Andy</b>	Non-traumatic (progressive)	Married	Yes	Truck driver	No	-
<b>Jack</b>	Traumatic (RTA)	Married	Yes	Warehouse coordinator	No	Yes, made concrete plans
<b>Mathew</b>	Traumatic (RTA)	Separated	Yes	Head chef	No	Yes, showing motivation
<b>Jeff</b>	Traumatic (fall)	Married	Yes	Window cleaning specialist	No	Yes, made concrete plans

(RTA)\*: Road traffic accident

## Findings

### **Master group theme 1: In the haze of SCI**

All participants, except one (Chris), talked about the medical and physical challenges they faced during the incident of their injury, shortly after this time when they were medically treated and rehabilitated, and finally after their rehabilitation discharge and once they were back in the community. Eight participants (Simon, William, Henry, Mark, Andy, Jack, Mathew and Jeff) talked about the early moments of their life-changing event of SCI; they described the initial stages of their injuries when they went through physical health challenges as well as the impact of this on different aspects of their lives, including work.

This first *master group theme (In the haze of SCI)* split into three themes: **(A)** The initial moments of the injury were critical and lived with a lot of uncertainty, **(B)** Complex presentation of the experience of medical care and rehabilitation and **(C)** Living with a physically reduced QoL following the injury.

#### **A) The initial moments of the injury were critical and lived with a lot of uncertainty**

At the beginning of the interviews, the researcher asked for an overview of their SCI; participants started by describing how their injuries occurred and the feelings they had at that time. Eight participants (Chris, Simon, William, Henry, Mark, Jack, Mathew and Jeff) had sudden and traumatic incidents of SCI, whereas one participant (Andy) had a non-traumatic progressive health condition which was later diagnosed as SCI.

William described the very early moments after he was hit by a truck while on his way to work on his motorbike, and how he was instantly treated by paramedics at the scene:

*I was unable to breathe at the scene, air ambulance landed to assist the road paramedics to enable me to breathe; they inserted a tube through my throat. Erm, air ambulance left, they thought I was dead, road ambulance took me to hospital, handed me over to the staff at (hospital name omitted) who then... so I was... I am*

*trying to think... GS3 at the scene which is "clinically dead", then when I was handed over to staff at (hospital name omitted) they found some signs of life and they got me going. (p. 3)*

It is striking to note that although William was unconscious at the scene of the incident, he reported what happened to him as if he was living those critical moments consciously. Although he only knew from others telling him about what happened to him once he regained consciousness, he was able to describe how life-threatening his condition was and the ways in which the medical team saved his life.

Other participants described the early moments of their injuries as being lived in chaos. However, while this was a temporary situation for some, it was more permanent for others.

Andy spoke about his feelings when his progressive health condition reached its peak and he had to be hospitalised:

*Well for a start I did not even know whether I was going to move again, that was the first thing and then obviously how much I would recover and what movement, and if there was any form of work I could get back to. (p. 21)*

Diagnosed with SCI four years ago, Andy recalled how he initially had many questions about the prognosis of his condition. Although he was aware of the general impact of the injury on his health, he had limited knowledge of the potential impact of it on his daily activities. He also doubted that he would be able to RTW; at that time, Andy viewed recovery and work as related to each other, meaning he perceived the level of his recovery as a determinant of the work he was going to be able to do.

Simon had a lot more going on, which he explained in this passage:

*It was not real [...] I feel like I am in limbo and I do not think I am going to be able to explain why [long pause] this could sound strange, yeah I feel like I am floating; I am somewhere between*

*dead and alive; here and not [...] I just tried to stay positive, but I was just despondent. (p. 27, 37 & 31)*

Simon described being in a state of denial when the injury first happened. The situation at that time felt like a dream, or maybe a nightmare, as it was too hard for him to comprehend that the traumatic impact of the injury on his life was real. However, Simon quickly shifted from speaking in the past tense to the present tense in order to reflect that he was still living this dream, or nightmare. He used powerful terms, such as “limbo”, to describe himself as being in a continuous wrestling with acceptance of his new condition. This was also emphasised when he used antonyms such as “dead and alive” and “positive and despondent” to suggest that he still had oscillating reactions towards his injury.

## **B) Complex presentation of the experience of receiving medical care and rehabilitation**

Five participants (Henry, Mark, Andy, Jack and Mathew) presented the complexity of their experience of the immediate medical care they received after being injured and the quality of the rehabilitation programme they attended right after that. All five participants viewed their experience of pre-rehabilitation care at the hospital as poor, whereas their experience of rehabilitation was good.

This theme will focus on two participants (Henry and Jack) as their accounts had the richest examples demonstrating the difference in experience between the two settings.

Henry experienced two incidents of spinal stroke; the first one was minor, while the second was severe and left him as a wheelchair user. He described his initial experience with the first incident as follows:

*I found the whole experience very daunting [...] tackling issues with the fact that because I had not had the specialist spinal input [...]. I think that if I had had the specialist input at the beginning, I think from a patient education perspective, I would have been more aware of some of the problems a spinal cord injury causes. (p. 6)*

As the medical teams at the hospitals where Henry was admitted following his first spinal stroke were not specialised in SCI, he believed that the lack of patient education there contributed to him not being prepared to deal with the subsequent complications of his injury.

Jack spoke about his experience of being initially rescued from the incident scene and taken to the hospital, where he believed medical care was inadequate:

*Well, they are all individual rooms, and they knew nothing about spinal cord and I basically went from a semi healthy person ... [...]. I was extremely ill, I lost a stone in weight. (p. 11 & 12)*

In this passage, we can see that Jack was not receiving a satisfying and specialised level of healthcare at the general hospital, and that in addition, he was experiencing health deterioration due to lack of adequate care. Jack reported his feelings of loneliness at the hospital as he was admitted to a ward where he was not able to interact with other patients.

However, in contrast to their experiences in general hospital settings, both Jack and Henry were mainly satisfied with their experiences in rehabilitation settings.

Henry talked about the fruitful period he spent at the rehabilitation facility after his first injury, which contrasted with his poor experience at the hospital:

*By the time I got to rehabilitation my legs started to move so within intensive physiotherapy I ambulated with a walking stick for seven years and I went back to work. (p. 2)*

Henry was satisfied with the level of care he received during rehabilitation, because it helped him improve his physical abilities and eventually feel able to reintegrate into his community and RTW. Although Henry did not mention the patient education at rehabilitation as being better than at the general hospital, rehabilitation was the key to the initial improvement in his condition after the first injury.



Meanwhile, Jack, who experienced deterioration in his health during his admission to general hospital, found that transferring to rehabilitation felt like a safe haven and a place where he was able to restore his well-being:

*It was literally from getting into Stoke Mandeville [Rehabilitation facility] it was probably a week afterwards that I started to feel human again. (p. 14)*

Here, Jack used the phrase “*feel human again*” to emphasise that the rehabilitation facility provided him with the basic healthcare that he lacked at the hospital where he was first injured. This phrase was very powerful in making us think about how the situation was like at the general hospital. It is possible that Jack thought that he was being treated inhumanely, where his physical needs and maybe his emotional needs, too, were not looked at by the healthcare team at the general hospital.

### **C) Living with a physically reduced QoL following the injury**

The relationship between SCI and QoL is meaningful. QoL refers to the personal perception of physical and mental well-being. Among the main physical challenges to the well-being of people with SCI are health, independence and the physical ability to work (Dijkers, 1997), which this theme will focus on.

Seven participants (Simon, William, Henry, Mark, Andy, Jack and Mathew) shared their personal accounts of struggling with either health issues or a lack of independence that contributed to a reduced QoL after being discharged from rehabilitation to the community.

One of the main challenges to the health of many SCI individuals is lack of bowel and bladder control, for which a catheterisation management routine has to be created.

Henry described his experience with this health challenge:

*I had to learn different bowel routines, which were quite demoralising, but it is just the nature of the beast [...] if the bowels are not working properly I have to cancel appointments*

*and things just in case I have an accident [...]. It can have a detrimental effect on daily living. (p. 3 & 27)*

For Henry, losing control over bowel and bladder was life-changing; he described how his post-injury life became more demanding because of this inescapable change, which he referred to as “*the beast*”. Henry illustrated his feelings towards this “*beast*” with a tone of shame, perhaps because it was affecting his self-image and self-confidence. While Henry described his problems with bowel and bladder management as “*detrimental*” to his daily activities, the context in which he was speaking could also suggest that work was among those daily activities that were negatively affected by the injury. Note the context of the term “*detrimental effect on daily living*”; Henry was referring to going for appointments and meeting people as being affected by his bowel issue, where he could be referring to doing his pre-injury job of teaching.

Like Henry, the injury resulted in Jeff having to catheterise. However, Jeff was more explicit in expressing his frustration with the bladder complications preventing his RTW as a window cleaning specialist:

*I was very active before so I know I can never clean windows. I can clean the downstairs windows but, you know, I just see it as a... I cannot climb up the stairs, I cannot climb up the ladder. And now I have got a tube inserted below my stomach straight in through my bladder. I look at it and think hmmm. (p. 13)*

In this passage, Jeff’s examples of basic tasks in his previous job which he was not able to do anymore illustrated his frustration over his inability to RTW following the injury.

Beside challenges with bowel and bladder management, another important component of experiencing a reduced QoL following SCI was losing independence in managing daily tasks. This was a prominent issue for Simon, Andy and Jack following their hospital discharge, which put a lot of strain not only on them but on their families as well. Those three participants spoke about how their loss of physical independence due to their injuries created chaos in their lives and the lives of their families.

Andy, who used a cane for mobility and had limited hand function following the injury, expressed his frustration with being dependent on his family:

*I have got to rely on a lot of other people doing even silly minor tasks that you would do yourself, like making a cup of tea or whatever you know [...]. It takes a lot of self-respect away from yourself, knowing that you cannot provide for people, or yourself even. (p. 7 & 30)*

For Andy, independence was part of his pre-injury identity; as a truck driver, he used to carry out heavy physical duties by himself. Although he does not directly refer to his previous work in the above passage, it can be read that Andy was making a comparison between his old independent self and new dependent self in relation to work. In other words, in the above passage, Andy was referring to himself as being unable to carry out “even silly minor tasks” anymore, which implied that the impact of the injury was even more immense on more major aspects of his life, such as his pre-injury work.

This interpretation was also supported by Andy’s reference to his post-injury self no longer being a provider. That is to say, Andy was denoting that being previously a truck driver not only meant that he was strong and independent, but also a person on whom others depended both physically and financially. By losing this identity of the family provider after the injury, Andy’s self-perception was negatively impacted.

### **Master group theme 2: Reflecting on dynamics of social interaction following SCI**

Eight participants (Chris, Simon, William, Henry, Mark, Andy, Mathew and Jeff) drew on different social aspects of their post-rehabilitation lives: both the ability to be socially active, and the level of outside support highlighted the post-injury social experience of the participants.

Reflecting on the above, the following two themes emerged: **(A)** Post-injury sociality is a thorn in the flesh and **(B)** Accentuating support.

### **A) Post-injury sociality is a thorn in the flesh**

Many participants talked about their post-rehabilitation experiences of being unable to return to their social routines. They talked about this as being a result of their limited emotional or physical capabilities to cope with their new lives after the injury. While Chris, Simon and Jeff described having limited interest in being around others after the injury and therefore suffering loneliness, William and Andy described their sense of losing the enjoyment associated with going out for social activities due to outdoor physical barriers. At other times, having minimal social interaction was due to the injury.

Jeff talked about his experience of loneliness at home after hospital discharge:

*I basically lived in this downstairs room from March 2015 until August 2016. I lived in this small room with a bed with my family upstairs and I would just stare out the window. But when the kids came home then I would sort of snap out of it and I sort of did not want to see my friends. You just go in a really dark place, a really dark place. So it did affect me emotionally. (p. 15)*

Here, Jeff was recalling the time when he returned from the hospital to his house after the injury and was forcibly isolated from his family due to his inability to go up the stairs to his bedroom. He used contradictory language in this passage; where he first described the room as having a window that he would stare out of, he then described the room as being a metaphorically dark place. Although the reader could understand that the window in the room was bright with sunlight, Jeff emphasised that the room was a “*very dark place*”. This representation of the room as being similar to a cell with no lights illustrated the despair and agony that Jeff was living with at that time due to being socially isolated.

Similar to Jeff, Chris described his social isolation as follows:

*I am now stuck in my house with nobody and... no social... this is it. I understand that the only part of work that I want now, to be*

*honest, is this social interaction [...]. I would put money now to go back to work to be around people. (p. 14 & 24)*

However, while Jeff spoke about his social isolation as an issue that only lasted for some time after his hospital discharge, Chris described it as a current issue. Using the present tense, Chris described himself as being “*stuck*” in his house, where he felt confined. His description sounds as though he was imprisoned, because it was so difficult for him to go out and interact with others after the injury. Chris was indirectly attributing this confinement to his house to the injury, of which he perceived himself to be a victim.

In addition, this social isolation was a direct result of Chris not going back to work after the injury. He used a powerful phrase to demonstrate that going back to work was the only way to escape his social isolation:

*I would put money now to go back to work to be around people.*  
(p. 24)

Although this could tell us something about Chris’s passion for work, it is more about the way he envisaged absence from work as a current struggle, and social isolation as a potential relief from the struggle.

In addition, other participants described physical limitations in the body as being the reasons for their social isolation. William and Andy expressed difficulty with being socially active after their injuries.

The impact of the injury on William’s social life was huge:

*Social activity is now much more restricted [...]. I cannot go to football matches [...] I cannot drink now; I end up in lots of pain when I drink alcohol. (p. 16)*

Here, William was using the language of comparison between his life before and after the injury; he was describing the difficulty with going to social events after the injury, and how pain usually got in the way of doing so. He mentioned two social activities that he thought

the injury had impacted the most; attending football matches and drinking alcohol. As those two activities are usually done together with other people, not being able to do them after the injury has affected the social dynamics that William previously enjoyed.

On the other hand, Andy discussed how physically overwhelming it was to go out and visit leisure places with his partner due to their lack of wheelchair accessibility:

*Going to theatres, swimming, cinemas car shows and things like that we used to like going to, and now it is a lot more awkward to do those sort of things. Because like you know if you have got to get in somewhere, sometimes especially if you have got to use the wheelchair it is not as easy going round outdoor places, again is not as easy. (p. 9)*

Andy used the term “awkward” to demonstrate the struggle he went through every time he wanted to go out for pleasure. Losing the spontaneity to do this highlighted the awkwardness that Andy was describing; he used the language of comparison throughout the passage to explain how spontaneous it used to be to go out for activities and socialising before the injury as opposed to how it was after that.

## **B) Accentuating support**

While the first theme of the ‘post-injury sociality is a thorn in the flesh’ focused on the ability to be social, the second theme of ‘accentuating support’ will focus on participants’ expectations of others in terms of offering support after hospital discharge and how important this was in their SCI experience, including the ability to RTW.

In this theme, six participants (Chris, Simon, Henry, Mark, Andy and Mathew) talked about the importance of receiving physical and emotional support from others. By ‘others’, participants referred to family, friends and work colleagues. Participants either described the important role of their families or friends in helping them cope with the new challenges after returning to their homes, or the negative consequences of lacking support from them when it was most expected.

For instance, Simon, who was a pre-injury overseas humanitarian aid worker, talked about the difficulty of acquiring quadriplegia and losing a successful career after SCI. After he returned home from the rehabilitation hospital, he experienced despair. As he talked about this, he immediately mentioned the emotional support of his partner and his family in helping him get through this despair:

*I was just despondent. But I had Stephany [partner] with me and my family are very encouraging. (p. 31)*

Although Simon used the past tense to describe the period of his despair, suggesting that he has made some psychological improvement, he used the present tense to describe his partner's and family's emotional support, suggesting that it continued.

While Henry's account was similar, he described a more concrete form of support. Several of his friends and colleagues believed in his ability to maintain his productivity following the injury and therefore provided their help:

*A friend of mine who had already done his, a friend and colleague, he said why do not you do your master's [...]. My best friend is a head teacher of a school in (UK City – name omitted) and we, he sort of, he rings me nearly every day and we sort of bounce ideas off each other. (p. 21 & 36)*

In the first part of this extract, Henry attributed his achievement in completing his master's degree in Education after his first SCI incident to the support of a friend and a colleague, to whom he was thankful. In the second part, Henry described the support of another friend, who was a fellow teacher and who motivated him to look for a job other than teaching. Henry spoke about those two friends very positively, making it clear that their support made a tangible difference in his life following SCI.

In contrast, Chris lacked support from his work colleagues after the injury:

*Nobody else is thinking of me [...]. I feel a bit aggrieved with the fact that my work colleagues should have made sure that after hospital though I was okay. (p. 30 & 35)*

The tone of frustration that Chris used here indicated that he was expecting a lot from his work colleagues, who let him down. To him, colleagues were expected to be friends and offer their support outside work. The term “aggrieved” can be seen as a reflection of how he viewed work after the injury. There was a double frustration of not being physically able to RTW after the injury and not being emotionally supported by work colleagues.

However, in Mathew’s case, lack of support had a more direct effect on his ability to RTW after the injury than Chris:

*Well my wife told me she did not want anything to do with me when I was in Stoke [Rehabilitation facility]. So that did not go down too well [...]. I think if there was her around I think I would have got to work by now. Because with her assistance things do get on a lot easier do not they when you have got a partner to help you than when you have not. (p. 12)*

Although in the first part of the passage Mathew suggested that his wife did not want to support him during his rehabilitation period, in the second part of the passage he suggested his wife’s lack of support extended to a longer period after rehabilitation. This is to say that when Mathew was discharged after the rehabilitation period and wanted to RTW, support from his wife was still not there.

Mathew believed that his wife’s emotional and physical support would have been fundamental after the injury. Because he acquired a complete SCI, which meant he became a power-wheelchair user, Mathew was physically dependent on others and needed support in most of his daily activities.

Mathew believed that his wife would have had an important role in helping him regain his active role at work; he attributed his difficulty in going back to work to her lack of support.



For him, his wife being by his side was an essential element in his post-injury life that he was lacking.

### **Master group theme 3: The bittersweet feelings about work**

Focusing on personal accounts about work, all participants discussed their feelings towards their jobs from three different perspectives: nostalgia, agony and bitterness.

This *master group theme* split into three themes: **(A)** Pre-injury work: looking back with nostalgia, **(B)** Victimised workers by their own injuries and **(C)** In the eyes of others.

#### **A) Pre-injury work: looking back with nostalgia**

Participants in this theme expressed their longing to return to the work they used to do before the injury. They also expressed what their work had meant to them; some talked about its personal value, while others talked about its social value.

For seven out of the nine participants (Chris, Simon, William, Henry, Mark, Andy and Mathew), pre-injury work had a personal meaning as it was something they enjoyed doing. Regardless of the type of work participants did before the injury, the longing to return to those enjoyable vocational lives was important.

When the researcher asked Andy about his perceptions of his previous work, he answered:

*I do not know whether you would say work was a priority, work is a necessity, is not it? [...] To earn money so you can live really. So it is, as I say it is not a priority, it is more of a necessity but I think if you have got a job that you enjoy doing then it is not so much of a chore. It is, I suppose like you say, it is a part of your life but you do enjoy it so you are not just doing it to earn money to live sort of thing. But it all sort of goes into the same bracket does not it. (p. 20)*

Andy's nostalgia for his work was clear in the way he looked at the positive side of it. For him, work was a source of spiritual fulfilment as much as it was a source of fulfilling physical or materialistic needs. Although Andy believed work could be demanding, the fact that he enjoyed it made him feel that it was less demanding. Andy believed that work was not only an important element of his life, but it was also essential as it was the main source of income he depended on before the injury. However, what was striking in this passage was Andy's view of work as a source of enjoyment and a source of finance at the same time. The term "chore" usually refers to a task that is necessary, routine and tedious; Andy was suggesting that because work formed a financial necessity, which usually felt like a 'chore', doing it with joy would not make it feel as such anymore.

Similarly, Chris was nostalgic for his previous work as a security guard:

*That is what I used to enjoy... just going to work, going to the gym, coming home and spending time with my partner [...]. As soon as I had the accident, cannot ride the motor bike, you are not big anymore, you are not scary... everything is gone [...]. I used to think that that mattered before, you know, to look good, to be big, scary or whatever. Now, that I am not in that job, I see that it does not matter. You do not have to be big or scary or whatever.*  
(p. 8, 12 & 5)

For Chris, going to work was equally enjoyable to going to the gym and spending time with his partner. Instead of listing work together with activities that were usually less interesting to do, such as cleaning the house, work for Chris was equal to doing social activities that were a choice rather than a chore.

Here, it is worth drawing on the similarity between Chris's work as a security guard and the activities that are usually done in the gym. Since Chris did field work rather than office work, he enjoyed being around people all the time, which might have been similar to going to the gym and working around other people. Also, working as a security guard requires being physically strong and fit for the job, which aligned with the character of someone who goes to the gym to exercise. Those two observations that showed the similarity

between working in the field of security and exercising could tell a lot about why Chris considered his work as enjoyable as going to the gym.

In addition, Chris described his daily routine before the injury as going to work then going to the gym before going home and spending time with his partner, which formed a comprehensively enjoyable life that was lost. Since life before SCI was perceived as being enjoyable, Chris spoke about it with nostalgia.

The personal value of work was also clear in Mathew's account:

*Well enjoyed work. I do not know if you saw 'MasterChef' last night but you just get enjoyment out of doing it. Cannot really say any more than that, you cannot explain it any more than that. (p. 22)*

For Mathew, enjoyment was the ultimate meaning of his previous work and the main factor behind his motivation for doing it, which was clear in his following comment:

*Cannot really say any more than that, you cannot explain it any more than that. (p. 22)*

What was striking about this extract was his reference to the entertainment TV show "MasterChef" which he watched the night before the interview. For him, working as a chef meant more than just going and doing the job every day; it meant being excited, lively and productive.

There was a clear longing in Mathew's talk about his previous job, as he still loved to watch something related to it on TV. For him, giving the example of "MasterChef" was the easiest and most direct way to explain his passion for cooking; although he talked about this TV show as an example of the enjoyable nature of his previous work, his tone suggested that he was compensating for the feeling of missing his work by watching it on TV.

Overall, the above analysis showed that nostalgia and enjoyment were very much related concepts. To elaborate, it was interesting to note that Andy, Chris and Mathew all used the

term 'enjoyment', although in different contexts, to express their feelings of nostalgia for their previous jobs.

In a different vein, four participants expressed, in two different ways, the social meaning of previous work in their lives: nostalgia for previous work as a source of informally socialising with colleagues, and nostalgia for previous work as a source of learning from others.

William and Mathew talked about previous work as a source of building informal relationships, while Jeff and Jack talked about it as a source of knowledge gained through socialising.

William described work in this way:

*You have got the camaraderie with your colleagues, erm once that finishes, it is very different and it is quite difficult to deal with.*

(p. 15)

William was longing to work with like-minded colleagues in a social atmosphere that he always liked. The term "*camaraderie*" was a key to the friendship that William formed at work, which was not necessarily formal.

Since the injury meant that William was not able to RTW, it also meant that it was difficult to maintain a strong relationship with colleagues outside work after the injury. This, in some way, relates to the previously mentioned struggle William had with maintaining the ability to enjoy social activities; William was suffering the double challenge of an inability to socialise with colleagues at work and with friends outside work following the injury.

Moreover, when William talked about how his "*camaraderie*" with his work colleagues "*finished*", he did not refer to the injury as the reason for this. Instead, he chose to focus on how much he enjoyed social life with colleagues and how much he wanted that life back.

Similarly, Mathew found it difficult to interact with his colleagues outside work following the injury:

*I miss mucking around with my friends and that and playing on those sort of things [...]. I miss speaking to people. That is about it to be honest [...]. It just makes you more normal really [...]; speaking and talking to somebody. (p. 22)*

It is clear that Mathew was an active and sociable character at work before the injury, which made it emotionally difficult for him to lose the chance of being around his colleagues after the injury.

By repeating the phrase “*I miss*”, Mathew was articulating his longing to spend good times with his colleagues at work; he was longing to interact with colleagues through “*mucking around*”, “*playing*” and “*speaking*”. This demonstrates how important Mathew’s relationship with his previous colleagues was; for him, the social element of interacting with colleagues in a less demanding environment was what he was nostalgic for after leaving work. This was also emphasised when he used the word “*friends*” instead of “*colleagues*” to refer to individuals he used to interact with at work, which captured how much he regarded his previous work as a place to build informal relationships rather than merely a place to do duties.

In contrast to Mathew, who enjoyed “*speaking*” to his friends at work, Jeff enjoyed listening to his clients telling interesting stories:

*It was an eye opener [...]. I loved it [my job]. I used to hear so many funny stories, I learnt so many things. I would be cleaning away and they would just be chatting, chatting, chatting, and it was quite interesting. (p. 9 & 11)*

Although one might assume that working as a window cleaner meant working alone, with minimal interaction with others, Jeff’s experience was different. Note the repetition of the word “*chatting*”, which gave the sense that Jeff was continuously listening to his clients and enjoying it; he was attributing his passion for window cleaning to the opportunity it gave him to interact with clients. In contrast to Mathew, who was longing to return to the relaxed environment of being around friends, Jeff was missing a more provocative

environment that opened new avenues for him to learn about the world through being around clients.

Like Jeff, Jack described his previous work as being a source of knowledge:

*If I wanted help building something or someone wanted help building something it would be 'oh any chance of give us a hand' if it was tea time or lunch time. And it was also that sharing of knowledge [...] it is a family. It was not a case of just going down to work, it meant to me because it was a proper family. It was not a case of you just went, did your work, you went home. (p. 54 & 55)*

In Jack's passage, the sense of team spirit and harmony at work, which created a positive social atmosphere, was clear. For Jack, working with colleagues who were always willing to offer their time and knowledge was invaluable. He used to work in a warehouse and do a lot of physical work, and therefore describing his work team as a "family" demonstrated how much his colleagues were willing to show their physical support. However, for Jack, previous work had an even deeper social meaning than this; it was a place that felt like home, where providing help and exchanging knowledge between members of the team was not something obligatory but rather something that stemmed from love and respect.

Of course, it was hard for Jack to come to terms with losing this deep social meaning at work. Despite this difficulty, when he spoke about good memories of work, he used language that showed nostalgia and passion for returning to it.

## **B) Victimised workers by their own injuries**

Four participants (Simon, Henry, Mark and Andy) expressed their negative emotions after leaving work because of their injuries. These participants described how SCI took away all the good things they had at work, including their dreams and success, and left them suffering emotionally. In this theme, two main emotions informed participants' reactions to their accounts of being workers victimised by their injuries: helplessness and anger.

Simon and Andy felt they had no control over the consequences of the injury on their ability to RTW. They felt that the injury took away their vocational lives, where they felt defeated.

Andy, who was a truck driver, had to leave his physically challenging job after the injury. This made him feel helpless:

*So it was very much a sort of, a very dark time really because I have always worked, always enjoyed my work, and I have always worked hard [...] we all go through life thinking, making plans for the future or when I am 20, when I am 30, when I am 40 I will do this, I will do that. It takes all that away and it does literally, you know, well it takes your whole life away really in one respect and you've got to start rebuilding it brick by brick really. (p. 21 & 36)*

In the first part of this passage, Andy spoke about the deep emotional struggle he lived with after leaving work; he described it as “*a very dark time*”. Andy attributed his despair to the injury for taking away his achievements. As the analysis of the next *master group theme* will demonstrate, Andy showed good psychological recovery and has come to terms with his injury. However, as this passage suggests, there was still a sense of helplessness around the impact of the injury on his employment. This was also clear when Andy described how he had previously been progressing at work, achieving success and building dreams, which the injury took away from him.

This section of Andy's extract is worth looking at closely:

*Well it takes your whole life away really. (p. 36)*

This can be interpreted in two different ways. The first is that the impact of the injury on Andy felt more meaningful than just making him lose his work; it might be that Andy was referring to the injury as attacking many aspects of his life, including work. The second is that for Andy, work meant a lot and therefore losing it because of the injury meant losing a whole good life.

However, perhaps the most important element of this extract is Andy's use of a passive tone. Although he described how the injury had demolished his life as a worker, he sounded at ease with the idea that he could "*start rebuilding it brick by brick*". In other words, when reacting to his injury's destructive impact on his career, while he was extremely displeased, Andy did not sound resistant, but rather accepting of this difficult fact.

Simon, however, sounded even more passive and had little energy to fight his injury and its impact on his job:

*I find it hard to keep up; I was extremely productive. (p. 39)*

Unlike Andy, Simon talked about how he felt emotionally defeated by the injury for making him lose his job. He found it difficult to accept the idea that it was physically impossible to continue being an overseas humanitarian aid worker after the injury. He explained that the reason that he was feeling helpless was his previous ability to be "*extremely productive*". To elaborate, because Simon was so productive at work, he experienced the shocking injury as attacking him in a way that he was too frail to fight. Here, it was interesting to see two such different emotions described in one short sentence; while Simon felt he was someone who was very energetic at work before the injury, he did not have any energy to deal with the consequences of leaving work after the injury. This comparison clearly captured the devastating shift that the injury caused in Simon's perception of himself in relation to work.

Henry and Mark reacted to the consequences of leaving work in a different way. Instead of being passive, they were moved by their feelings of resentment towards the injury for causing them to lose their jobs:

*I feel as if I have been robbed of my profession because of my spinal cord injury. (p. 34)*

This is a powerful quote from Henry, who spoke with an angry tone about having to medically retire from the teaching profession. Henry suffered two episodes of spinal



strokes. After the first episode, he was successful in fighting his weaknesses and RTW with modified working hours and tasks. However, following the second episode, it was much harder for him to continue to work because of his increased physical limitations, leading to him having to give up his profession. Henry spoke about this with a tone of anger, because he felt that the situation was unjust; he depicted the injury as an enemy he entered a battle with, although this was a battle he could not win. Henry's anger was clear in his use of the term "robbed", demonstrating that he felt the injury was not supposed to end his teaching career.

Henry's use of the term "profession" instead of 'job' or 'work' was also powerful because it represented the feelings of the deep loss he suffered after the injury; he was not going to be able to teach anymore. In other words, Henry was angry at seeing his injury preventing him from doing the job he spent so long training to do. The necessity of his medical retirement meant he had to bid farewell to a whole profession.

Mark, similarly, had to resign from his job in sales after the injury:

*I have always been successful in what I was doing, I felt very resentful because I felt pushed out of my career [...]. I felt deflated, the reason being, as I said I have been in sales for twenty years, well just under twenty years. I have got a bundle of letters of accolade for a fantastic sales career and if I am to be honest I felt very, very angry. (p. 18)*

The phrase "I felt pushed out of my career" captured the essence of Mark's reaction to his resignation, because it showed that although his anger was about how his employer treated him unfairly after the injury, it was more about his injury causing the disruption to his work in the first place. Note the use of the expression "I felt", which suggests that there was not an actual action that was taken against Mark by his employer that made him feel angry, but that this was rather an emotional account that Mark had about how the injury made him unable to do the work with the same level of performance as before.

As well as the expression “*pushed out of my career*”, there is further language in this passage which illustrated Mark’s anger with the injury for making him lose his job; that is, the words *resentful*, *deflated* and *angry*. The sheer amount of negative emotion that Mark was expressing in the passage was notable. While Andy, for example, reacted passively to the injury demolishing all his achievements and success, Mark rebelled against his injury and did not accept being its victim. Mark found it hard to think peacefully about what the injury has done to his vocational life; he thought that it had made him lose his confidence as well as the success he had built throughout the preceding years.

However, despite this, it is important to note that Mark was able to move forward with his life after the injury (just the way Andy did – “*rebuilding it brick by brick*”) and change his career to something he was happier with and felt more able to do. In other words, moving forward with vocational life did not mean that deep emotion of rage towards the injury did not exist.

### **C) In the eyes of others**

Among the feelings of bitterness that participants expressed was how they thought others perceived them with regard to employment following SCI. This included participants’ reports about how they were seen by their employers, colleagues and employment agencies with regard to their ability to work following SCI.

Three participants (Mark, William and Jack) talked about their experiences of either applying for work or actually RTW after their injuries, where they were seen by their employers or employment agencies as unfit for their jobs. While those participants believed that they could still perform well at work on the same level as before the injury, they reported that they faced discrimination from their employers or employment agencies.

As mentioned earlier, Mark perceived his employer as discriminating against him when he went back to work for about a year after the injury:

*I had never missed target before, I missed target in June and I thought okay maybe it is just because I am just coming back but I missed by some distance and I thought 'that is unusual' [...]. You do not have to be a rocket scientist to work that out. It was clearly, maybe they saw me as I would be a bit of a burden coming back to work because potentially I was not going to be as fit and as strong and be able to work full time. So, it was maybe easier for them to increase the targets the way they did. (p. 16 & 17)*

Mark felt that his employer was trying to make him feel unable to be as productive as he was before the injury. According to Mark, his employer tried to intentionally make him miss his sales target after his return from the injury in order to show that he was unfit for the job.

As another example, William perceived himself as being able to significantly recover from his SCI and therefore feeling enthusiastic to RTW. However, he felt that this enthusiasm was met with discrimination from his employer:

*There were several incidences where I questioned what they were doing and was laughed at [...] tasks that my previous company had me doing that I would consider menial secretary tasks were things like checking spreadsheets that had nothing to do with maintenance activities. (p. 24)*

In the above passage, William's report of his employer's discrimination against him can be interpreted as taking three main forms: mockery, belittling and underestimation. William talked about how his employer reacted sarcastically to some of his questions and laughed at him, which was an unexpected and disappointing response. William's report of being given "menial" tasks after the injury contributed to a sense of anger as he felt belittled. Finally, assigning William to tasks that were not related to the previous nature of his work formed a strong sense of underestimation by the employer of what he could offer at work following the injury.

Jack, too, talked about his experience of being stigmatised in terms of his ability to work:

*People look at me and they go 'you have done great things for this, you have done great things for that', but when you talk about work they go 'oh it is because you're in a wheelchair'. Yeah but that's not the point though. I have still got from basically from my chest upwards it all still works quite happily. So why cannot I do something. (p. 43)*

In this passage, as Jack perceived it, being in the wheelchair resulted in others discriminating against him by assuming that he lacked the ability to perform the same physical work that he was able to do before his injury. Jack felt that while people often appreciated the good deeds he had done in different life areas before and after the injury, it was disappointing that those people did not believe he could make important contributions after the injury, especially when it came to work.

Although Jack referred to himself being discriminated against about work by “people”, looking at this within the context of the interview, he was actually referring to employment agencies. Jack gave the example of his negative experience with the local employment support agency which potentially did not believe that he was able to do physical work in the wheelchair. He believed that he was viewed by employment agency workers as a person who was not fit to use his body for work. However, he wanted to be viewed as a person who had remaining abilities in his body by which he could be recognised.

#### **Master group theme 4: Achieving inner peace and moving forward**

The fourth and final *master group theme* captured participants' most recent reactions to their injuries. Here, all participants talked about their current emotions towards the injuries and their future vocational plans. This theme presented participants' positive responses in terms of their acceptance of the injury after the physical, social and emotional struggles they suffered in the past as newly injured individuals. As they all had an injury onset of two or more years at the time of the interview, participants were able to show, in different degrees, good psychological recovery.

Seven participants (Chris, Simon, William, Henry, Mark, Jack and Jeff) demonstrated some complexity between their intentions to retrieve their old strong selves at home and/or at work and their ability to accept limitations and move forward. However, despite this being interpreted as complex, it did not necessarily mean it was contradictory. To elaborate, participants' desire to maintain a strong self-image did not conflict with their desire for being self-reconciled. Finally, participants talked about how they wanted to pursue their vocational lives after SCI.

In light of the above, three themes emerged in this *master group theme* of **Achieving inner peace and moving forward**: **(A)** Striving to maintain a strong self-image following SCI, **(B)** Self-reconciliation and **(C)** Turning a new chapter in vocational life.

#### **A) Striving to maintain a strong self-image following SCI**

One of the main mechanisms for achieving inner peace after the injury was participants' efforts not to accept being labelled as "*disabled*". In other words, four participants (Chris, Simon, Mark and Jeff) wanted to convey the message to others that they were not giving up their strong personalities after the injury by letting able-bodied people perceive them as weak and frail. For those participants, coping with the injury meant looking positively at the self and not allowing others to pity it.

While Chris and Simon wanted to maintain a strong self-image with regard to work, Mark and Jeff wanted to maintain their self-images as fathers.

In striving to be equal to non-SCI workers and not be seen as different, Chris said:

*I am very happy to put the blue badge at parking, you know, close to say that I am disabled, but to be honest to be returning to work I would not want a label; "oh look, oh look, he has got a little cushion and Chris has got another ten-minute break now", you know, I want to be equal to everybody else, you know. (p. 17)*

In this passage, Chris talked hypothetically about the possibility of accepting the label of 'disabled person'. When he was in public places with an identification of his disability (such

as a car badge), Chris would not feel particularly identified by name or job position and therefore would be accepting of this label. However, when he was at work, he imagined he would feel more noticeable and identified as a staff member and therefore would want to be equal to his non-disabled colleagues. Chris thought that even if he were lucky to have a supportive employer who recognised his special needs after the injury, he would not feel comfortable being helped with certain equipment, which would lead to him looking different to his colleagues and perhaps being pitied by them.

Looking at the specific physical requirements of Chris's previous job as a security guard can help us understand why he would not want to be treated as someone with special needs after the injury. He mainly described his desire to maintain the vital strong self-image he always had at work as well as the positive social-image among colleagues after the injury.

Similarly, Simon spoke about how he strived to maintain a strong image as a former humanitarian aid worker:

*I sort of finding myself exaggerating what I do voluntarily a little bit [...] I am just trying to sound busier than I am. (p. 36)*

Here, Simon showed how much he was striving to live up to other's expectations of him as being productive after the injury. Regardless of whether or not he perceived himself as being capable of doing high performance work after the injury, it was important for him to give others the impression that he still was. He talked about being "self-conscious" when others asked him about his work status after the injury; he felt that this was causing him a lot of stress and embarrassment, because as time passed after the injury, people expected him to be ready to progress vocationally.

To take himself out of this situation, Simon wanted to stay positive and maintain, as much as he could, his image of himself as a hard worker through telling others that he was busier than he actually was. This seemed a clever way to avoid disappointments associated with having to explain to others the different physical, emotional and social challenges associated with returning to work following the injury.

Simon's use of the words "exaggerating" and "busier" did not necessarily mean that he was untruthful, but rather that he was being less accurate than he could have been. Although he was already doing some work after the injury, it was not as high profile as his previous job. Giving others less accurate information about work demonstrated a plausible defence mechanism that Simon was using to cope with his new situation of unemployment.

However, for other participants, striving to maintain a strong self-image after the injury took a different form. Jeff and Mark talked about their role as fathers and how this led them to hide their physical and emotional pain from their families after SCI in order to maintain a strong masculine image.

Here was how Jeff described being a father with pain following SCI:

*You cannot be depressed if you have got a wife and two kids, there is no time to be depressed, you got to just suck it in and just carry on doing what you did before but emotionally it still affects. I am deeply affected by it but you have to just get on with it [...]. It is very hard because I have to act a lot because I do not want them seeing me moping around and you know, I cannot say I am in pain all the time, because I do not want them to see that. (p. 15 & 21)*

There is a lot going on in this passage, with Jeff describing himself as having a dual character after the injury. Despite perceiving himself as too weak to fight his pain, he believed that he had to act as if he was strong when he was around his wife and children.

It can be argued that Jeff talked about the need to hide this pain from his wife and children in order to maintain a masculine character. Masculinity can be seen as an important concept in this passage as it helped explain the reason for Jeff's response to his pain in the context of his role as a father. This was supported by this particular part of the quote:

*Just carry on doing what you did before. (p. 15)*

Here, Jeff was directly referring to the need to maintain the same image of a father that he had before the injury, which he interpreted as meaning that he had to acknowledge his wife and children's physical and emotional needs while preventing them from acknowledging his. For Jeff, doing so was an obligation that he put on himself after the injury, while his wife and children's role of supporting him was not. He also used language such as *"I cannot, I do not want, you got to and you have to"* to suggest that being an emotionally and physically strong father was not negotiable.

Since it is conceivable that hiding feelings of physical and emotional pain after a life change such as SCI could cause a lot of pressure, doing so for the sake of retaining a strong father image can be seen as a positive action. Despite being ill and depressed, Jeff wanted to fight this through wearing the mask of being healthy, which could be interpreted as a sign of sacrifice, but acceptance at the same time.

Like Jeff, Mark wore a mask of being healthy, and was striving to remain a strong father and a family provider after the injury:

*I cannot lean on my kids for support. I am their dad. Yeah? They are not my support network. I have to be my own in that respect [...]. I have got a great external face. I do not show everyone my inner core, how I have been feeling at times, so they see me as strong, they see me as coping. So maybe they think I do not need them. (p. 35 & 36)*

Mark showed a stronger refusal to give up his role as a father after the injury than Jeff. He refused to accept his children's financial support after SCI while insisting on remaining their source of support. He wanted to keep his dual role as an independent adult and a responsible father even though he faced physical, emotional and financial strains after the injury.

Furthermore, what helped Mark hide his pain was the fact that he was a stoic person, which was clear in his phrase *"I have got a great external face"*. Since Mark was someone who did not usually show his emotions to others, it was easier for him to pretend that he



was managing his life after the injury. Although this could have affected the level of support he got from his family, Mark was willing to sacrifice this for the sake of maintaining his strong image of not needing to rely on anyone, especially his children.

Mark was not annoyed by the fact that his family did not provide him with a lot of support, but instead found excuses for them for not doing so, suggesting that he had reached inner peace about his injury. He attributed the lack of support from them to himself for choosing to come across as having a reserved personality.

## **B) Self-reconciliation**

In this theme, five participants (Chris, William, Andy, Jack and Jeff) showed reconciliation with their limited physical abilities after SCI. They talked about accepting their current limited abilities to perform their jobs or any other life activities in the same way they used to before the injury. Reaching this level of self-reconciliation helped those participants enjoy inner peace and move forward with their lives. In this theme, self-reconciliation was expressed by participants in three different forms: self-awareness, satisfaction and contentment.

William, who had been an aircraft maintenance engineer, was aware of the unsuitability of the industry for him after SCI:

*It was my decision. I cannot sit in an office for eight hours a day [...] there are lots of things I cannot do in the aircraft industry. That will immediately put me out of running for any job that I might otherwise be able to apply for [...]. It is going to be very difficult for me to find a job that suites my ability. (p. 11, 21 & 27)*

Although William RTW for a short period after being injured and reported being faced with discrimination from his employer, he also accepted that working as an engineer was no longer something he could do. For him, not being physically fit to work in an office for eight hours a day was a realistic barrier to continuing to work in the industry of aircraft maintenance. He was also aware that employers would not be interested in recruiting him

for such a job, as he referred to himself as an uncompetitive engineer after the injury. This self-awareness was clearly illustrated by William's calm tone, which demonstrated his acceptance of the impact that SCI had on his vocational life.

Andy was similarly aware of his limited capabilities for doing the same job of driving a truck after the injury:

*I am still pushing myself, but you can only push yourself as far as your body will let it go. With the damage that is there, it is never going to be 100% now I do not think. Still, I still hope to think it would be but I think realistically it is not going to be. So, you have to live on what you have got, I suppose. (p. 36)*

Although Andy was motivated to push himself to physically improve after the injury, he was aware of the limit to his current abilities to carry out certain activities related to his job. He was also aware that what happened to him after SCI was “*damage*” to his body which he had to deal with. The key idea in this passage was Andy's awareness and thus acceptance of the damage to his body after the injury, and the belief that full recovery was not realistic. Although he sometimes was living in a dilemma between hope and reality, being satisfied with the reality of his condition sounded easier for him and helped him achieve inner peace.

Jack initially had some hopes of achieving a full recovery from SCI, but later reached an acceptance of his SCI condition that helped him deal with these unrealistic hopes:

*It is what it is at the end of the day. But you have just got to make the best of it, you have just got to try and get over it. There was a lot of points when I thought I do not want to end up in a bloody chair I want to be walking like everybody else, and you just think it is not going to happen, I will be okay, I will deal with it for another, I will deal with it and you deal with it for another month and you look at it and you go 'yeah I will not walk again' but you know, I would still like to walk now. (p. 16)*

Jack could reach a maintenance level of acceptance over his situation. However, he talked about a phased satisfaction and described going back and forth with his emotions.

In addition, note this striking extract:

*I will deal with it for another, I will deal with it and you deal with it for another month and you go 'yeah I won't walk again' but you know, I would still like to walk now. (p. 16)*

During this phased satisfaction process, Jack used an interesting coping strategy where he was trying to postpone his feelings of being depressed and just numbing them for some time. This coping strategy of temporarily neglecting depression was helpful for him in the long run.

A third form of self-reconciliation after the injury was contentment; Jeff and Chris reported their feelings of contentment even with the negative impact of their injuries on their bodies, which meant that they were able to accept those changes and find alternatives for enjoying life.

Jeff talked about where he thought his happiness lay after the injury:

*I always say I cannot play football anymore, but I can still throw the ball and she can practice her ball skills [...]. I might not have any legs but it does not matter. It does not matter. I am quite happy. (p. 22)*

Although Jeff became paraplegic after a fall, he did not want this to affect his role as a father and was trying to find alternative ways to keep on doing what he used to do with his children before the injury.

In the above example, Jeff described helping his daughter practise her football skills with him before his injury, and then talked about being able to find happiness in continuing to do that now. Even though this meant that he was going to use his hands instead of his legs,

he was able to feel the joy in doing small activities with his daughter. For Jeff, all it took was to accept the way his body was after SCI.

Chris also experienced some changes to his body after acquiring SCI. He lost a lot of weight and looked slimmer than he did before the injury. Nevertheless, Chris reacted to this bodily change as follows:

*I used to think that that mattered before, you know, to look good, to be big, scary or whatever. Now, that I am not in that job, I see that it does not matter. (p. 5)*

This passage supports other extracts from Chris, which showed the strong link he felt between his pre-injury work as a security guard and the need for his physical appearance to be perceived as big and scary. This supports the previous passage where he reported that he could not accept being labelled as “disabled” in his workplace. However, in this passage Chris presented himself as being relieved that he no longer had to worry about maintaining the identity of being big and scary, as he was not at work anymore. This in itself was an eye opener for Chris, and eventually helped him achieve contentment.

### **C) Turning a new chapter in vocational life**

A high level of achieving inner peace and moving forward with life after SCI was demonstrated in the participants’ plans to, or their actual RTW. When the researcher asked participants about their decision to RTW, seven of them (Chris, Simon, Henry, Mark, Jack, Mathew and Jeff) articulated their intentions, plans or achievements with regard to being productive after the injury. This took four main forms: motivation to RTW, shift in work nature, concrete plans to RTW and the actual start of a new vocational plan.

Simon and Mathew expressed their desire to RTW one day. They were both determined and keen to start a job and retrieve the sense of productivity that they had lost after the injury. Simon said:

*I do not know if I can handle the pressure, the practical aspects of things, and I will try, I will keep on trying, because you never know until you try. (p. 38)*

Simon was determined to try to find a suitable job after the injury. This was a positive sign of coping; despite him expressing his feelings of helplessness over the impact of the injury on his life (as mentioned in an earlier *master group theme*), he was trying to keep positive and look for work that would suit his current physical abilities. Although he felt that it could be difficult to work while in a power-wheelchair due to his limited independence, Simon did not want to give up. These complex feelings are reminiscent of when Simon said he was in “*limbo*”; although he previously expressed his inability to cope with the challenges the injury caused in his life, he showed some ability to cope through being determined to seek a suitable job.

Mathew also wanted to RTW; he expressed positive thoughts about recommencing work instead of staying home all day long:

*Well I want to get back to work yes [...]. Well I think it just makes you more normal really. Sitting round here during the day is not exactly exciting. (p. 19 & 24)*

The main motive behind Mathew’s keenness to RTW after the injury was to retrieve some features of his pre-injury life. This is to say, Mathew viewed work as a main tool to normalise life after the injury; his longing for the social atmosphere of pre-injury work, as mentioned in an earlier *master group theme*, was a fundamental reason for his motivation to RTW.

Although Mathew left his chef job six years ago when he was injured, he still demonstrated an interest in going back to this field, although not necessarily to cooking itself:

*It [the injury] has changed my career path. Because now I have got to do stuff on the computer where I have always wanted to be hands on [...] well I will be doing... ordering stuff and pricing out*

*menus and that sort of thing [...]. I have done a couple of bits and pieces with my sister. To be practicing because it will be using Word. So yeah so I have done a couple of bits and pieces. (p. 17 & 18)*

As a head chef, Mathew used to prepare meals, which required him to be physically active. However, after the injury, he became a power-wheelchair user, and preparing meals became more challenging. Instead, Mathew needed to find a job that was more suited to his post-injury abilities, and with the help of his sister, he started learning to use the computer in order to train himself to do refectory management instead of cooking.

As Mathew had to shift his intention from returning to doing his old job as head chef to taking on a new role in an office, this desire allowed him to be motivated to stay productive after the injury. Although this was only a plan, thinking about it and working to achieve it showed that Mathew was able to move forward with his vocational life post SCI.

Similarly, Mark gave up his previous work as a sales specialist and started a plan to work in motivational speaking, which he considered a shift to a new passion:

*I want to speak to kids in secondary school because I believe we have got a lost generation and if I can inspire and motivate even one or two, that makes my injury worthwhile. (p. 14)*

This plan to transition from sales to humanitarian work was a major career shift for Mark; in the above passage, he described how the humanitarian work of motivational speaking could make a positive change in society and at the same time could be an emotionally rewarding way to become productive following the injury.

Not only did Mark have a passion for commencing motivational speaking, but he also had a concrete plan to start this as a business:

*I am excited... I am going to make the most of my life [...]. At the moment I am speaking for free but I do have plans to create a business around it and to establish myself as a speaker [...]. As I*

*said I have already kind of made a start but I am kind of testing the water in terms of I am not charging. I would really love 2017 to be my proper year of launch. (p. 21, 14 & 28)*

Mark was in a stage of doing a free trial period for his new passion as a motivational speaker, and he perceived that achieving the goal of starting his own business in this field was only a matter of time. He sounded pleased about what he had done so far and excited about what he was moving forward to doing.

Finally, the only participant who was actually back to some sort of work at the time of the interview was Henry:

*So subsequently I have been, they called me in and I have been volunteering for them for about a year now [...]. It is just a general disability charity [...] so initially when I was asked to come along and volunteer they wanted me to be part of their wellbeing programme [...]. I certainly think that by doing those things it has improved my wellbeing. (p. 18 & 28)*

The job that Henry had been doing for around a year at the time of the interview was not paid, but rather voluntary. However, Henry seemed pleased and proud of this work. He talked about this voluntary job in a charity association with a tone of excitement as he believed that he was able to recommence his path to productivity after the injury.

As Henry's voluntary job was in the area of improving the wellbeing of disabled individuals, it might be that he saw this as a compensation for the sense of fruitfulness he used to have in his previous profession in teaching. In more detail, helping disabled individuals to improve their wellbeing was perceived by Henry as a tool for also improving his own wellbeing, which might have been a rewarding feeling that mirrored the feeling he used to have when teaching students and observing their improvements.

This new experience of doing voluntary work instead of paid work was a great sign that Henry was moving forward with his life after the injury, since losing his profession in

teaching did not stop him from remaining productive, even if this meant doing a lower profile job with more emotional than financial remuneration.



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## Chapter 6: Discussion and conclusion

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### Introduction

The first study in this thesis aimed to explore the personal experiences of nine male participants who became unemployed following spinal cord injury (SCI). All participants were based in the UK and had either manual or office jobs before their injuries, which they did not do anymore.

The first section of this chapter will discuss the connections uncovered within the findings of the current study and how they were integrated, while the second section will discuss the findings in relation to the existing literature on employment and social participation following SCI. This discussion will clarify where the findings added to the current picture and where they highlighted differences. The final three sections will present the study's contribution to knowledge, implications, and suggestions for future research before highlighting the researcher's reflections and reflexivity notes.

### General discussion

In the first study, each *master group theme* presented a certain period of time or a stage that participants have gone through. Each *master group theme* reflected participants' feelings, expectations, challenges and general accounts of that particular time or stage, which may or may not have changed as time passed.

Each *master group theme* presented a different stage of adjusting to SCI, which contributed to the presentation of a coherent narrative. The first of these themes started by highlighting participants' journeys in physical treatment at hospital and rehabilitation, while the second highlighted the social aspects associated with their reintegration into their communities after being discharged from rehabilitation. The third *master group theme* encompassed the later stage of participants' emotional realisation that return to work (RTW) was a challenge following SCI. For some, the perception of employers'


discrimination against their disabilities was a barrier for RTW. Finally, the fourth *master group theme* highlighted the inner peace and acceptance that participants expressed towards being unemployed as well as their efforts to recommence a new vocational life.

Thus, the sequence of the presented four *master group themes* helped structure a narrative that could take the reader with the participants on the journey of their acquired SCI, including the transition from employment to unemployment. However, although the four *master group themes* helped formed a unique piece of research, the uniqueness was not in the structure of the narrative so much as the idiographic approach to the lived experience of unemployment for people living with SCI.

Furthermore, the four *master group themes* emerged in a way that meant they were able to present four different life aspects (that is, physical, social, emotional and vocational) respectively. As mentioned earlier, although not all the four *master group themes* directly represented the vocational life of the participants after SCI, participants often naturally linked their narratives to the experience of unemployment. To elaborate, in the first *master group theme*, the issues presented about SCI employment were significant to participants' physical challenges, such as uncertainty about prognosis, the impact of rehabilitation on RTW and medical issues affecting the decision to RTW. The second *master group theme* presented issues around receiving support and being able to socially interact with others, and linked these issues to RTW. The third *master group theme* presented participants' emotional struggle with realising that their injuries had a significant effect on their ability to carry out or return to their pre-injury work. Emotions that arose included nostalgia, anger and the perception of discrimination. The fourth *master group theme* presented the effect of acceptance, resilience and motivation on recommencing work, and therefore this theme was mainly about the vocational aspect of participants' experience of unemployment following SCI.

It was striking that all nine participants touched on the four different aspects of physical, social, emotional and vocational life when they talked about their experiences of leaving work after SCI. This approach to sense making, adopted by all nine participants during their

interviews, told us something about the significant impact of unemployment following SCI on the four aspects of life rather than just the vocational aspect.

Although each life aspect (physical, social, emotional and vocational) was more meaningful within a certain stage (see Figure 10), all aspects overlapped with each other in the different stages. The same applied to each stage presented in the findings of this study; although each *master group theme* was more meaningful for a certain stage in participants' lives after SCI, it could sometimes overlap with other *master group themes* as well. In Figure 10, this sign  indicates this.

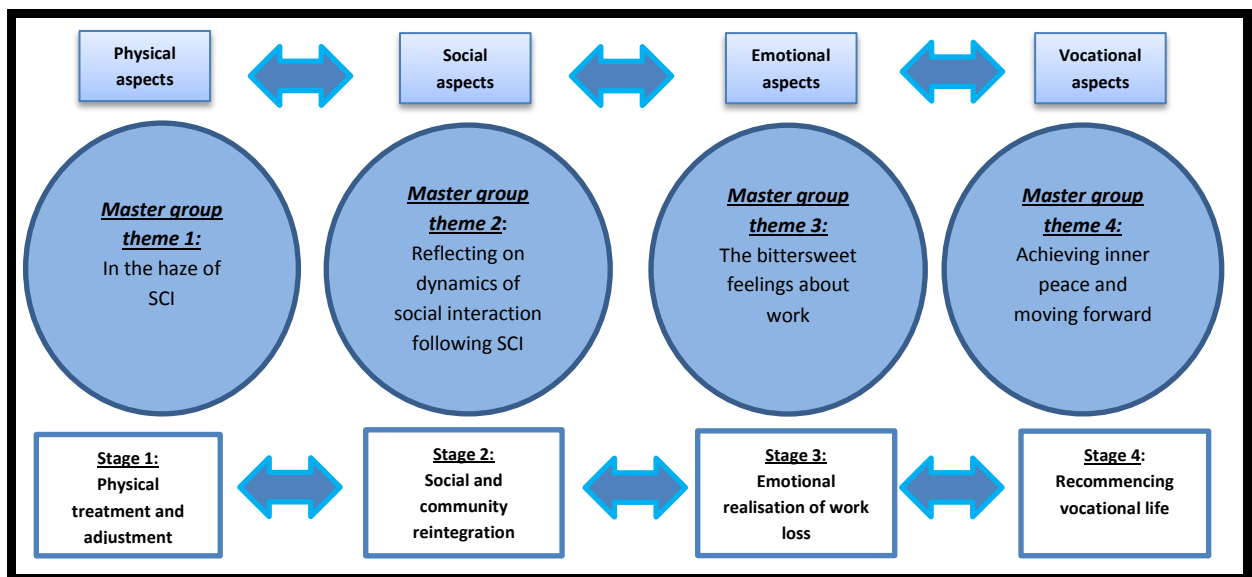


Figure 10. Interconnections between *master group themes* in the first study

It is worth mentioning that although this stage approach of the four *master group themes* might have been influenced by the researcher's own interpretative analysis of the participants' individual accounts, there was no prior intention to do so. There was nothing in the interview schedule for the first study that would seem to suggest these stages; the analysis was also not forced to fit those stages or match the different life aspects mentioned above.

## Discussion of each master group theme

### **Master group theme 1: In the haze of SCI**

The first *master group theme* highlighted the initial trauma of SCI; it mainly encompassed the physical challenges that participants had gone through during the phases of injury occurrence, hospital treatment, rehabilitation and finally transition from rehabilitation to community. This *master group theme* structured a short and miniature narrative of the initial phase of the SCI trauma, which helped understand participants' negative shift from being healthy to being chronically ill or 'disabled'.

A number of existing studies have used quantitative measures to examine the different adjustment stages to SCI. For example, a longitudinal study by Stensman (1994) found that the most difficult stage of the injury was during the first half year. Although this resonates with findings from the current study, the latter particularly drew on the difficulty of the initial stage of SCI from the perspectives of participants by using a qualitative method. As the current study used a phenomenological approach, it gave space to participants to speak freely and therefore was able to draw on the very early moments of the injury occurrence and the complications with being rescued and treated at the hospital, findings which add depth to the quantitative research.

In a different vein, Kennedy and Rogers (2000) suggested that the highest scores for anxiety and depression were noted during the acute stage of SCI. While those authors looked at the wide scope of psychological wellbeing in SCI participants and noted its relation to the acute stage of the injury, the findings of the current study focused on the particular psychological challenge of feeling uncertain about the injury and its future. The current participants expressed their personal accounts of how medical complications during hospitalisation led to the particular feeling of uncertainty about potential abilities after the injury, including the ability to RTW, and the amount of recovery that could be gained.

While previous research has suggested an association between self-efficacy and long-term plans for social participation (Umucu et al., 2016) and employment following SCI (Craig et

al., 2015), the current study described the temporary state of uncertainty following SCI; that is, the lack of self-efficacy was temporary and mainly meaningful to participants during the acute stage of SCI. However, other studies echoed the current study by drawing on the negative psychological state of uncertainty as it is experienced by newly-injured participants. For example, while being new to SCI resulted in difficulties in making decisions about the simplest everyday tasks, such as what to eat, participants in Scheel-Sailer, Post, Michel, Weidmann-Hügler, and Baumann Hölzle's (2017) study were able to overcome the sense of uncertainty in their lives as they progressed with their rehabilitation programmes.

Nevertheless, prolonged feelings of uncertainty were present in the case of one participant – Simon – who talked about being in “*limbo*” even five years after acquiring SCI. This could be explained by Simon's high injury level and the medical complications from which he was continuously suffering. Previous research by Kleiber, Brock, Lee, Dattilo, and Caldwell (1995) showed that the loss of ability to participate in activities in the long term after hospital discharge was associated with feelings of uncertainty.

During the transition from the incident of injury scene to hospital, the traumatic and unpleasant experience of receiving immediate medical care followed by rehabilitation was well highlighted by participants in the current study. Similarly, Maharaj, Hogan, Phan, and Mobbs (2016) have shown that admitting SCI patients to specialised spinal units instead of standardised medical units was crucial for delivering adequate care and avoiding complications.

Much existing research has explored participants' experiences of going to rehabilitation at the beginning of their SCI but does not necessarily distinguish this from their experiences of receiving treatment in acute medical units prior to going into rehabilitation. To elaborate, while previous research highlighted the SCI experience during hospital admission in general (whether in acute or rehabilitation units), the current study was able to reflect on the different experiences of being initially admitted to acute medical units and going to rehabilitation following SCI. For instance, while previous research demonstrated that SCI patient education was among the main factors for overall successful rehabilitation (e.g., Brillhart & Johnson, 1997), the current study found that this aspect was particularly

important during admissions to acute medical units. Also, while previous research emphasised the positive effect of interacting with fellow SCI patients in rehabilitation centres (Carpenter, 1994; Dickson et al., 2011; O'Connor et al., 2004), the current study highlighted the need for these interactions to start before newly-injured people are transferred to rehabilitation units.

Overall, it can be seen that similar findings to those in the current study around the needs of people living with SCI during the initial phase of the injury have been noted elsewhere in the literature. However, the current study was unique in reporting the different needs of these participants at different stages of their treatment following SCI.

Moreover, Henry was able to RTW after the first episode of his spinal stroke due to the quality of his physical rehabilitation, which he perceived to be excellent. Although some previous research found that good preparation in all aspects of life was the most significant facilitator for active social participation and RTW after discharge from SCI rehabilitation (Vissers et al., 2008; Wilbanks & Ivanokva, 2015), findings from this study illuminate this picture by suggesting that this preparation is helpful mainly in improving the level of physical activity.

The first *master group theme* in this study also covered the initial period of returning to the community following discharge from rehabilitation. Although most of the participants had positive rehabilitation outcomes, they articulated health challenges that they faced after being discharged. For the majority of the participants, the transition from rehabilitation units to community settings seemed traumatic, as this was a period during which they realised they had to accept their long-term physical limitations. Understandably, this was the stage when reduced quality of life (QoL) was more recognisable, and the need to adapt to a new life outside the hospital was more warranted. Findings in the work of Dickson and colleagues (2011), O'Connor and colleagues (2004) and Nunnerley and colleagues (2013) supported the concept of reduced QoL after discharge from SCI rehabilitation, which was also influenced by the lack of resources related to physical and psychological care.

Existing literature has used both quantitative (Geyh et al., 2013) and qualitative (Whitehurst et al., 2014) approaches to explore QoL after SCI, but has not necessarily

described the subjective accounts of those SCI individuals who had low QoL scores. The current study was able to fill this gap by highlighting the personal views of people living with SCI on the limitations with bowel and bladder control after leaving the hospital as well as their reflections on the psychological distress they associated with being catheterised.

Limitations in bowel and bladder management were also found to challenge the ability to RTW following SCI. Jeff, who worked as a window cleaner prior to his injury, described how his loss of bowel and bladder continence made him think twice about being able to return to this physical job. Similarly, while exploring barriers to post-SCI employment, Chan and Man (2005) reported that loss of control over bowel and bladder was a factor affecting job consideration and exploration.

Loss of independence was also reported by participants as significantly reducing QoL following SCI. Andy, who used to work as a truck driver, articulated the negative impact on his self-respect of having to rely on others after the injury. A similar experience was noted by O'Connor and colleagues (2004), who found that losing a sense of independence was an attack on the sense of self, and that coming to terms with the new self who was dependent on others was a significant challenge following SCI. Andy's financial strain after leaving work was an additional problem for him. Similarly, financial stressors have been found to be among the psychosocial problems associated with unemployment following SCI (Khazaeipour et al., 2014), and one of the barriers to coping with life after SCI (Babamohamadi et al., 2011).

When compared to existing research on SCI independence, the current study uniquely reflects on loss of independence as being an attack on self-respect and financial status, and can therefore highlight its comprehensive effect on QoL.

### **Master group theme 2: Reflecting on dynamics of social interaction following SCI**

This *master group theme* on social dynamics was important, because it covered social aspects that were related to how likely it was that participants could engage in social activities as well as their perceptions of the efforts of others to provide support following SCI. Findings highlighted the struggle with socialisation after SCI hospital discharge as well

as the period of time when SCI individuals realised that their injuries would prevent them from going back to their social routine, including work. Previous thematic analysis (TA) findings by Smith and Caddick (2015) showed that SCI participants who had been living in a care home for an average of 2.3 years experienced loneliness, and that this loneliness was related to feelings of self-alienation rather than boredom. While this study supported those findings, it also reported loneliness and loss of interest in socialisation as strong feelings among those SCI individuals who were living in the community and were surrounded by their families.

Previous research explored the temporality of social isolation after SCI; echoing the current study, one longitudinal study (Craig et al., 2015) found that 55% of a sample of people living with SCI struggled with social participation when they were assessed for their adjustment to their conditions six months after hospital discharge. Dickson and colleagues (2011) also reported that isolation and loneliness were highly prevalent in those SCI patients who were recently discharged from rehabilitation.

However, while Newman and Krause (2016) reported that those who had been living with SCI for longer periods of time were observed to have lower levels of social isolation, the current study emphasised that feelings of social isolation can stay with SCI individuals for long periods after their injuries (e.g., Chris reported feeling socially isolated even two years after his injury).

Regardless of financial considerations, Chris wished he could go back to work and interact with colleagues the same way as he had before his injury. Similarly, Marti, Einhardt, Graf, Escorpizo, and Post (2012) found that SCI RTW was not related to finance, but rather to social fulfilment and avoidance of boredom. The current study, which used an idiographic approach, could give a voice to SCI participants as they expressed their sense of being socially isolated.

A review from Amsters and colleagues (2016) resonated with the current study in reporting pain as a leading factor to limited social life after SCI. However, the current study, with its phenomenological and idiographic approach, was able to describe in more detail how physical pain could be a barrier to social activities; as an example, William talked about the



pain he used to experience every time he tried to go out to socialise, especially when going out for a drink, where alcohol consumption was always a physical pain stimulator.

While the above instance is in line with the medical model of disability (by identifying physical pain as the main barrier to socialisation after SCI), other participants in this study offered accounts which were more consistent with the social model of disability by reporting the frustration of not being able to attend social activities in the ways that they could before the injury, due to lack of accessibility in certain public places. Although previous studies have reported that environmental factors in general (Amsters et al., 2016; Barclay, McDonald, Lentin, & Bourke-Taylor, 2016; Tsai et al., 2017) and lack of accessibility in public places in particular (Babamohamadi et al., 2011; Fougeyrollas & Noreau, 2000; Levins, Redenbach, & Dyck, 2004; Löfvenmark et al., 2016) can impede social participation after SCI, the current study was able to explore this in the context of unemployment – that is, the long-term impact of social isolation on RTW following SCI.

Moreover, by highlighting important aspects of the social model of disability, participants in this study talked about how being provided with support was important, and that this reflected social dynamics following SCI. In more detail, as the social model of disability emphasises the role of society in either enabling or disabling those with an impairment, participants in the current study demonstrated how support from their partners, family members, friends or colleagues either facilitated or hindered social participation following SCI, and particularly employment.

A series of studies (such as Amsters et al., 2016; Barclay et al., 2016; Geyh et al., 2012; Levins et al., 2004) reported that a fundamental facilitator for interpersonal interaction following SCI was partner support. This finding was echoed in the current study, which was able to add more detail to the impact of support from certain individuals on vocational life after SCI.

The current study demonstrated the important role played by the spouses of people living with SCI in their RTW. Mathew spoke about the experience of being abandoned by his wife after the injury, and the impact of this on his ability to RTW. Findings from the literature agreed that social support was an important factor in obtaining employment for veterans

following SCI (Cotner, Keleher, O'Connor, Trainor, & Ottomanelli, 2014). Burns, Boyd, Hill, and Hough (2010) also identified social support from significant others as being among predictors of employment in an SCI correlational study. However, the current study was able to describe the struggle that resulted from a lack of support from a spouse following SCI, as well as ways in which this support might have helped the RTW process. The current study was also able to give details, through participants' personal accounts, of how both physical and emotional support from spouses were important to enhance RTW for people living with SCI.

Finally, a study that evaluated SCI quality of relationships and perceived social support found that support from partners and family members was more important than support from friends (Tramonti, Gerini, & Stampacchia, 2015). This contradicted the current findings; Henry emphasised that his friends' support and encouragement after his first spinal stroke led him to take up a master's degree course, which was relevant to his career in education. Other studies lend support to Henry's experience, where financial rather than emotional support from friends helped improve social participation for people living with SCI (Barclay et al., 2016).

### **Master group theme 3: The bittersweet feelings about work**

The third *master group theme* was one of the most important in the study, as it illustrated the core of the experience of leaving work following SCI. Themes that emerged here presented the participants' feelings, both positive and negative, when they spoke about their previous work.

Participants in this *master group theme* expressed a great passion for their previous work at the same time as agony over losing it, while sometimes perceiving that they were being discriminated against by previous employers following SCI. Despite this passion for work and the fact that participants had been unemployed for a number of years after their injuries, none were able to return to full-time employment (except for Henry, who disclosed during the interview that he had started working as a volunteer in a charity association). This contradicted findings in the literature, which suggested that having pre-injury work experience (Krause et al., 2010; Yasuda et al., 2002), being employed at the

time of the injury (Pflaum, McCollister, Strauss, Shavelle, & DeVivo, 2006) and valuing work (Crewe, 2000) predicted post-SCI employment.

In addition, some findings have suggested that pre-injury intensity of work can influence RTW after SCI (Yasuda et al., 2002), where returning to less physically demanding jobs predicted post-SCI employment (Tomassen, Post, & Van Asbeck, 2000). However, in the context of the current study, intensity of work either before or after the injury was not something that participants related to in terms of how they perceived RTW, because they were focused on their longing for their previous work and their anger over losing their jobs, regardless of the type of work they used to do prior to SCI or were able to do following it.

In the current study, nostalgia and longing were powerful concepts that participants in the current study drew on, suggesting that they had previously found work satisfying. Similar findings (Brines, Salazar, Graham, & Pergola, 1999) have indicated high scores of pre-injury work satisfaction among injured workers as well as a negative relationship between the injury and the dislike of the pre-injury job.

In contrast, while a review of the literature on the life satisfaction of people living with SCI found deep feelings of nostalgia for pre-SCI life in general (Post & Van Leeuwen, 2012), the current study found that these feelings were linked to pre-SCI work in particular, which was an important finding that emerged from the exploration of the experience of unemployment following SCI.

Further, Lohne and Severinsson (2005) suggested that longing was an important theme in SCI participants' concept of hope during their first year of the injury, with participants in the current study continuing to long for their pre-injury work even a number of years post SCI. This finding suggested that the concepts of longing and nostalgia can stay with SCI individuals as long as they do not RTW after being injured. Although the current study related the nostalgia that participants had for their pre-injury work to its personal and social value, this did not mean that participants were able to RTW following their injuries.

Nostalgia and enjoyment of pre-injury work were also linked in this study. Other authors have uncovered similar findings; for example, Clifton (2014b) suggested the link between

the concept of happiness and employment following SCI. However, the current study was able to shed more light on this relationship by giving direct voice to its participants, whose accounts of being nostalgic about pre-injury work were richer than their accounts of generally enjoying work.

In the current study, pre-injury work had a personal meaning rather than a materialistic one. While some studies in the literature found that pre-injury work was an important source of finance, since having an income (Bergmark et al., 2011; Chapin & Kewman, 2001) and being financially independent (Chan & Man, 2005; Chapin & Kewman, 2001) were important benefits of employment, most participants in the current study did not refer to finance as either a challenge after the injury or a motivator to RTW. While two participants did speak briefly about their reduced QoL due to lack of a regular income after the injury, there was not sufficient data from participants to form an experiential theme about finance.

While most existing studies in this area, including those of Bergmark and colleagues (2011), Chan and Man (2005), and Chapin and Kewman, (2001), focused on the value of work from the perspective of RTW following SCI, the current study uniquely focused on the value of work from the perspective of unemployment after SCI.

Nostalgia was linked to the social value of pre-injury work for participants in the current study. William described a great feeling of camaraderie at work, which he had lost. Other studies reported the negative impact of SCI on relationships in general (e.g., Garrett, 2012), and on relationships at work in particular (e.g. Chan & Man, 2005; Chapin & Kewman, 2001; Hay-Smith et al., 2013; Schedin Leiufrud et al., 2014). While the current study supported those findings, it added to them by highlighting the negative impact of SCI on feelings towards pre-injury work in particular.

Furthermore, nostalgia about previous work was linked to the opportunity to learn from others. For example, while Jack talked about how he always sought help from his colleagues in learning something new every day, Jeff used to listen to his clients when cleaning windows and learn new things as they chatted. This is a unique finding. Existing literature has tended to draw on the social value of work as being an opportunity to do

something for others. SCI participants in studies by Chan and Man (2005), Hay-Smith and colleagues (2013), Schedin Leiufrud and colleagues (2014), and Wilbanks and Ivankova (2015) described how contributing to their societies formed the personal meaning that work had for them, while Hammell (2007a) reported that contributing something to others was important in emphasising the sense of self-worth after SCI. However, participants in the current study viewed pre-injury work as a source of knowledge, where others contributed to teaching them something new every day.

The positive feelings of nostalgia and satisfaction about previous work in this study were mixed with negative feelings due to job loss after SCI. Participants' negative feelings about losing pre-injury work were similar to those noted in a study examining the satisfaction level for social participation after SCI, where employment received low scores (Schönherr, Groothoff, Mulder, & Eisma, 2005a). However, this study illuminated deeper negative feelings than just dissatisfaction; it described participants' painful emotional struggle and feelings of victimisation over having to leave their jobs because of SCI.

The qualitative approach utilised by this study allowed a thorough description of the phenomenon of victimisation and its relation to the concept of loss after SCI. Manifested in many SCI studies, the concept of loss was linked to grief (Tulsky et al., 2011), which could be prolonged rather than temporary (Dickson, Allan, & O'Carroll, 2008; Duggan & Dijkers, 1999). Similarly, the current study showed how sad feelings related to work loss stayed with participants for many years after the occurrence of their injuries.

Feelings of loss and victimisation were illustrated in the participants' feelings of anger and helplessness. Lohne (2001) conducted a literature review on SCI hope and found that such feelings were frequent emotional responses to SCI. Duggan and Dijkers (1999) also found that hope was affected by the sense of loss following SCI, and that feelings of helplessness were experienced after gradually coming to terms with the permanency of the disability instead of during the initial stage of the injury. These findings resonated with the experiences of participants in the current study, who still presented feelings of despair towards their chances of regaining employment.

Andy discussed his sense that his injury had ended all his future plans and dreams. While Andy was referring specifically to his future hopes for work, this finding is similar to one noted in a meta-analysis by Hammell (2007b), where participants talked about their narratives of shattered dreams after SCI.

While not many studies in the SCI literature referred to helplessness as being associated with loss of work, the closest work was that of Fadyl and McPherson (2010), who found that the availability of emotional resources (that is, the ability to help oneself) was important in helping SCI individuals adjust to the trauma of leaving work.

Related to feelings of victimisation are those of anger, which is a common emotion among individuals with SCI. In developing a contemporary patient-reported outcomes measure for SCI, Tulskey and colleagues (2011) reported that anger was frequently noted in participants' accounts. Moreover, according to Craig, Tran, and Middleton (2017), SCI usually follows adjustment theory, which is influenced by grief and loss stage theory. Adjustment theory has five main stages: denial, anger, bargaining, depression and despair, and finally acceptance of reality. However, Clifton (2014a) suggested that SCI individuals do not necessarily follow certain adjustment stages at certain times, but instead experience a mixture of emotions that can be negative, such as anger, or positive, such as determination. While the current study supports adjustment theory, its findings are closer to Clifton's (2014a), since participants did not strictly move from the stage of anger to the stage of acceptance, but rather fluctuated between both at the time they were interviewed.

Nevertheless, anger in the current study particularly referred to the loss of work, which in many studies, it did not. Although all of the above studies (i.e., Clifton, 2014a; Craig et al., 2017; Tulskey et al., 2011) were relevant to the experience of SCI, none were related to the particular feeling towards pre-injury work. The current study, using the idiographic approach of IPA, was able to shed light on anger as a manifestation of the phenomenon of victimisation in the particular experience of losing work after SCI.

So far, it could seem as though the participants were blaming the injury itself for causing their job loss, which is an observation that reflects the medical model of disability.

However, most participants in this study also referred to themselves as victims of employment agencies, their employers or colleagues for discriminating against them, which is an observation that reflects both the social and the human rights models of disability. Mirroring the social model of disability, Henry talked about how his workplace was not environmentally adapted to meet his physical needs after SCI, which meant he was forced to medically retire from his job in teaching. In the context of the human rights model of disability, William, Mark and Jack spoke about their traumatic experiences of facing stigma and discrimination following SCI either when RTW for some time or during the period of job exploration. Jack talked about his struggle with being stigmatised as a wheelchair user, which initially made it difficult for him to find a job after SCI; he suffered when employment agencies focused on his disability rather than the powerful abilities he maintained after his injury. These negative attitudes from the community towards people with SCI as well as a focus on disabilities rather than abilities were also noted in other studies, where social stigma led to poor psychological adjustment (Babamohamadi et al., 2011) and reduced emotional health (Tulsky et al., 2011).

More studies have reported the positive association between work discrimination and SCI current employment (Conroy & McKenna, 1999), as well as the negative impact of employers' stereotypes about the low performance of SCI people at work (Jongbloed, Backman, Forwell, & Carpenter, 2007). In the current study, William described such discrimination. His employer refused to implement modifications to the workplace after his SCI. The implantation of required modifications in the workplace was found to be crucial in the decision to RTW after SCI (Fadyl & McPherson, 2010), while a lack of modifications can be a barrier (Lidal et al., 2009). These findings chime with William's experience, where the discrimination of his employer and their refusal to implement the necessary modifications for him in the workplace resulted in him leaving his job after SCI.

#### **Master group theme 4: Achieving inner peace and moving forward**

The fourth and final *master group theme* of this study illustrated the point where participants reached resilience and acceptance of their SCI after going through different stages of physical, social and emotional challenges. Supporting results by Lohne (2001)

showed the connection between SCI, hope and time, where the longer the person lived with SCI, the more he or she was able to accept the permanency of the condition. Other results indicated that turning points in SCI individuals' lives usually followed a gradual process, where time was important to redefine the sense of self (Duggan & Dijkers, 1999).

The previously mentioned theory of adjustment (Trieschmann, as cited in Craig et al., 2017) is relevant here, with the final stage of the theory (that is, acceptance) matching the current participants' acceptance of their injuries after going through anger and despair. However, findings in this *master group theme* demonstrated that some participants still had residual anger and despair, while at the same time accepting their limited functional and vocational abilities as a result of the injury. This complexity in reacting to the trauma of SCI is similar to Clifton's (2014a) description of swinging between emotions.

The desire to sustain a self-image that is not belittled by others was clear in several participants' accounts. Similar to the findings of Holmlund and colleagues (2018), acceptance of SCI was facilitated by participants' attempts to be perceived as equal to able-bodied people, and not be labelled as 'disabled' either at work or at home.

In many studies (e.g., North, 1999), changes in body-image impacted the psychological well-being of people living with SCI, where the loss of the old body-image was usually grieved. While this emotion was reported to have a negative impact on the decision to RTW after SCI (Fadyl & McPherson, 2010), due to a perceived failure to meet social expectations (Sheldon, Renwick, & Yoshida, 2011), the current study reported the motivation to maintain the old self-image as a sign of self-confidence manifested in the desire to be perceived as equal to non-SCI workers.

This study drew on the difficulty of presenting the post-SCI unemployed self to others, with particular attention to positive coping strategies for this. Simon illustrated the difficulty he had when he talked to others about himself after SCI, and although he described himself as initially being 'self-cautious', he was able to use the coping strategy of exaggerating how busy he was in order to avoid being belittled. Although the current study emphasised the findings of others (e.g., Kalsi, Turkistani, Sykes, Lucas, & Zarnegar, 2016) around the negative impact of being underestimated as a person living with a disability on having the



ability to RTW, Simon was able to deal with this challenge and so perceive the decision to RTW as one that would be possible for the future.

The desire to maintain a strong and positive self-image was also related to current participants' roles as fathers and family providers. Appearing to be healthy and responsible as well as strong fathers and family providers was a requirement for these participants following SCI. This was influenced by the concept of masculinity, which is supported by other studies; for example, one systematic review revealed that a loss of masculinity had a direct impact on how SCI men represented themselves and how they successfully managed their relationships (Nolan, 2013).

Jeff's experiences illustrated the initial hardship of maintaining the role of husband and father following SCI. As Jeff felt he was responsible for fulfilling the needs of his wife and children after the injury, regardless of his personal needs as a disabled person, he had to disguise his pain and pretend he was strong enough to take care of his family. Jeff had to show that he could maintain the same strength and ability to provide for the family as before SCI. Chan, Lee, and Lieh-Mak (2000) found that people who were married prior to SCI were more depressed and less satisfied with their social role than those who were married post SCI. Although those findings were similar to Jeff's experience, he was able to overcome this challenge by hiding his despair and pain from his family as a sign of resilience to SCI.

With a focus on unemployment, Mark described refusing financial support from his children after losing his pre-injury work. This finding complemented findings noted in Kalsi and colleagues' (2016) work, where being a male family provider was perceived as a central role in life and an important component of self-identity in the context of RTW following a disability.

However, unlike findings noted in Hay-Smith and colleagues' (2013) study, where employed versus the unemployed SCI individuals were motivated to work in order to support their families and continue to take the role of breadwinner, Mark, in the current study, wanted to maintain his image as a providing and responsible father regardless of his inability to work after being injured.

In a different vein, reconciliation with one's self after SCI was a manifestation of the current participants' acceptance. In the current study, self-reconciliation took three different forms: self-awareness, satisfaction and contentment.

Self-awareness referred to the current participants' realisation and acceptance of their limited physical abilities and job options after sustaining SCI. William was aware that doing his pre-injury work would now be physically difficult for him, and so applying for a similar job would be unrealistic. This demonstrated a link between self-awareness and self-reconciliation, a finding which is similar to that reported in previous research. For example, while Lustig (2005) reported an association between perceived sense of coherence post-SCI and adjustment level, Peter, Müller, Cieza, and Geyh (2012) reported the correlation of self-efficacy with the positive adjustment to life after SCI.

Achieving self-reconciliation also emerged in the current study in the form of being satisfied with life after SCI and while also being hopeful of better physical recovery. Andy and Jack reported that they reconciled with their disability, but still had hopes for functional improvement. In a study by Lohne (2009), hope for further physical improvements was always in the background of SCI participants' thinking, while focusing on the future was always in the foreground.

Moreover, it emerged in the current study that feelings of satisfaction following SCI occurred sometime before participants were back at work, indicating that being satisfied with life after SCI did not necessarily mean that RTW was essential. Although some of the participants who showed a good level of satisfaction with post-SCI life had plans to return to some form of paid or voluntary work soon after their interviews, they did not necessarily link their feelings of life satisfaction with their plans for recommencing employment. While some studies supported this observation (e.g., Schönherr et al., 2005b), others did not (e.g., Putzke, Richards, Hicken, & DeVivo, 2002).

For participants in the current study, the experience of contentment was also a manifestation of self-reconciliation; that is, participants learned how to live with SCI and find alternatives to enjoying life following their injuries. Here, contentment was about finding the positives in a seemingly negative situation; for example, Jeff used to play

football with his daughter before the injury and was still able to enjoy this from his wheelchair after SCI. Similarly, Tulsy and colleagues (2011) found that SCI resilience reflected the ability to live with the injury and overcome limitations.

To reach contentment, participants had to reconcile with themselves after a long period of despair. This was similarly noted in a longitudinal study exploring the notion of hope in SCI individuals three to four years after the injury, which showed that adaptation to new traumatic life contexts usually followed a cycle, where it took individuals time before they could enjoy life in the same way as before the injury (Lohne, 2009).

Overall, the current study was able to show that self-awareness, satisfaction and contentment uniquely illustrated self-reconciliation following SCI. The particular focus on the experience of job loss for people living with SCI means this study differs from existing ones.

A more concrete step towards achieving acceptance and inner peace was participants' plans to move forward with their vocational lives following SCI. The feelings they had gone through since the time of their injury, including nostalgia for previous work, anger over losing that work, and in some cases attempts to RTW which were thwarted by employers' discrimination, all resulted in participants wanting to make a new vocational start. Contradictory findings were noted in Dickson and colleagues' (2008) work; these authors used an IPA approach to explore the lived experience of SCI and found that participants were unable to return to activities they used to enjoy before the injury and also did not engage in new activities that were fulfilling. Although the time passed since participants' injuries in Dickson and colleagues' (2008) work was long (ranging between two and 14 years), the sense of loss of identity and self-control was still strong for those participants. While the current study looked at a similar injury onset time (ranging between two and nine years) and noted similar residual feelings of loss and frustration, the current participants were able to challenge those feelings and start thinking about ways to recommence their productivity.

In the current study, being able to choose the type of work to return to following SCI was a sign of achieving inner peace and moving forward. Without input from others, Mark decided to stop working in sales, which was his area of expertise prior to the injury, and start working as a motivational speaker. Mark's case was similar to those noted by Ville (2005), where the ability to take ownership of the proposition of employment was gradually gained without referring to SCI rehabilitation professionals for help.

Changing career was a clear manifestation of the impact of the injury on the current participants, where in most cases, pre-injury work was no longer physically feasible. While Duggan and Dijkers (1999) reported that career change was considered a major turning point in the lives of SCI individuals, the current study emphasised that it could be a positive sign of adjustment to SCI. To elaborate, Henry also started doing voluntary work at a charity association after he had to retire from teaching following the injury. Although this was not an ideal alternative for Mark, he felt that it contributed to a sense of achievement. Supporting findings from Hess, Meade, Forchheimer, and Tate (2004) stated that depressive symptoms were higher among unemployed people with SCI compared to both full-time and part-time workers with SCI. The current study builds on this by emphasising that doing any mode of work, and not necessarily the preferred or best option, could contribute to better adjustment and inner peace after SCI.

### **Contribution to knowledge**

The first study offered an understanding of what it is like to become unemployed as a result of acquiring SCI. Some of the findings in this study, such as those related to notions of independence, social support, anger and self-reconciliation, echoed previous research on SCI, whether qualitative or quantitative. However, this study contributed to the literature by highlighting these experiences as being particularly relevant to the experience of SCI unemployment. In other words, this study was able to uniquely relate the above notions to the experience of job loss and described the personal accounts of SCI men from this perspective. Indeed, adopting the approach of interpretative phenomenological analysis (IPA) contributed to the idiographic presentation of those notions in the experience of SCI unemployment.

Furthermore, most existing research focused on descriptively reporting factors that could contribute to or hinder RTW for people living with SCI, such as level of medical care. However, these studies lacked an interpretation of the meaning of these factors and the connection between them that allows the production of a narrative that reflects the subjective experience of people living with SCI. In contrast, this study referred to such factors arising from the experience of unemployment for people living with SCI and interpretatively linked them to each other to form a coherent and a meaningful narrative.

The four *master group themes* in this study presented this coherent and meaningful narrative by reflecting on the subjective experience of SCI unemployment from the perspective of four aspects: physical, social, emotional and vocational. Those four *master group themes* have followed a theoretical stage approach, where each presented a certain stage of participants' post-SCI lives, although there was some overlap.

### **Implications and future research**

By thinking back to the first moments after sustaining their SCI, participants in the first study highlighted the chaos they experienced in their lives. They described the time when they were first admitted to the hospital and were in an acute condition. They also described the uncertainties they lived with at that time, when they were unsure about their prognosis and the challenges they might face after the injury, including the ability to RTW. There seemed to be a severe lack of reassurance and support during participants' initial hospitalisation period, as the focus of the healthcare team was on medical care rather than a balance of medical and psychological care. This could be related to the fact that participants were initially admitted to non-specialised medical units, where healthcare staff had limited knowledge of SCI. All this led to participants receiving limited education about their condition and therefore living with a lot of uncertainties. In the light of those findings, admitting SCI participants to spinal units where they can receive specialised treatment, sufficient patient education and early vocational interventions is necessary during the initial period of the injury, in order to help reduce the long-term negative impact of their conditions on their QoL.

Most participants in this study viewed the start of their rehabilitation programmes as a positive milestone in their lives after SCI. They talked about the acceptable level of physical improvement they achieved due to the great help from their rehabilitation therapists. However, although they enjoyed good levels of recovery and support while rehabilitated, this did not positively influence their accounts of post-rehabilitation ability to RTW. To elaborate, when participants were back in their communities, they faced physical challenges (such as a lack of physical independence and a lack of bowel and bladder management) as well as difficulties in socially reintegrating, which either influenced or were influenced by their experience of work absence.

In addition, while participants admired their rehabilitation therapists for helping them improve physically, participants did not reflect on being engaged in RTW support programmes, although one participant mentioned the positive influence of physical improvements on his ability to RTW. Exploring the experience of unemployment using an IPA approach demonstrated the importance of providing vocational rehabilitation (VR) services in rehabilitation settings, which was not reflected on in participants' accounts. Influenced by the social model of disability, a major implication of this study is the need to provide structured programmes to help SCI patients in rehabilitation centres to obtain employment by focusing on social and environmental facilitators and overcoming barriers to their participation instead of only working on improving their physical health. It would also be worth conducting future research with SCI individuals who are aware of or have received VR services during their rehabilitation period, but remained unemployed afterwards, in order to compare their experiences to those of the current participants.

As mentioned above, following discharge from rehabilitation and return to the community, a major challenge highlighted by participants was that of being socially active. As participants tried to settle in their homes and learn how to adapt to their disability, life was different to how it had been before the injury. Participants were not able to go out of their homes easily because of physical restrictions, and so they found themselves confined to their houses with minimal interaction with others. Understandably, this affected their emotional and social states as well as their ability to RTW. In the context of the social model of disability, the first study offered an insight into the stage of returning to the

community, which importantly includes the challenges associated with the structure of the environment. Overcoming these challenges would help SCI individuals be socially active and, eventually, vocationally productive.

In this regard, the role of community organisations and support groups can be crucial; it is important for those establishments to acknowledge the early social needs of people living with SCI after their hospital discharge, as this is usually the time they need the maximum support to adapt to their new lives after the injury. Based on the findings of this study, and in the context of the social model of disability, the current researcher would encourage community organisations and support groups to embrace SCI individuals and arrange with rehabilitation services to take over their role of support after those individuals are discharged from hospital into the community, mainly by eliminating social and environmental barriers. Embracing SCI individuals socially during their initial period after hospital discharge could have a beneficial effect on community reintegration and therefore on the ability to RTW. It would also be worth conducting future research to explore the extent of this effect, in the long term, which could indeed include the ability to RTW.

Also, on a smaller scale, the first study helped give an insight into the role of family members, friends and work colleagues in supporting SCI individuals during their difficult times after the injury. Those who were offered support by individuals close to them acknowledged and appreciated this; they spoke about this support as having a positive effect on their ability to adjust to their injury and feel more productive. For example, feeling able to RTW for a short while or embarking upon an academic degree were influenced by the positive support of individuals close to participants.

In contrast, lack of support from such individuals resulted in some SCI participants finding it harder to adjust to their injuries and therefore not being able to RTW. It is thus important for rehabilitation programmes, in early interventions, as well as community organisations and support groups, at a later stage, to involve those who are close to SCI individuals in setting and implementing vocational goals. Future research focusing on family members, friends and work colleagues of unemployed SCI individuals would be beneficial in order to explore their views on the support they provide and what facilitates or hinders it.

As time passed after sustaining SCI, the desire to return to a 'normal' life increased; core to the experience of unemployment was how participants talked about previous work, their feelings after leaving it and for several, attempts to stay at work after the injury, which failed due to employers' discrimination. Almost all participants had a severe longing to return to their pre-injury work. Regardless of whether they were able to do the same work after SCI or not, pre-injury work had both a personal and a social value for them. Due to this highlighted deep value, and considering the human rights model of disability, a suggestion arising from the first study is for policy makers to put pressure on employers to keep their existing employees at work even after they acquire SCI wherever possible. It is also recommended that policy makers ensure that returning to the same job after SCI happens as often as possible, and that medical retirement or work termination due to SCI happens as rarely as possible. This would ensure that people living with SCI are being treated equally to able-bodied and are not being marginalised because of their disability.

Moreover, the first study shed light on the experience of a few participants who RTW with their pre-injury employers, but then faced discrimination. There were different forms of discrimination practised against those participants, including being underestimated, belittled and stigmatised. As this was reported from the perspective of SCI employees, it would be beneficial for future research to explore how employers perceive their employees after acquiring SCI, and so uncover what could lead them to behave in a discriminatory fashion.

The feeling of being victimised by SCI for having taken away a whole vocational life formed the core of the experience under investigation in the current study and was a unique phenomenon that added to the literature of SCI. Generally, the deep sense of work loss was experienced by participants as either helplessness or anger; the first study highlighted those negative emotions as psychological challenges that participants went through, or continued to struggle with, as a result of leaving work after SCI. An implication of this would be for psychological services in both rehabilitation facilities and community organisations to focus on how people living with SCI perceive job loss and the impact it may have on their lives. In other words, psychologists should pay attention to vocational aspects



when providing psychological services to both newly injured and long-term injured SCI individuals.

Since this study highlighted the emotional experience of leaving work for participants with an SCI onset of two to nine years, it is worth conducting longitudinal research to help psychologists understand the development of negative emotions following job loss in SCI individuals.

Despite their psychological struggles with job loss, participants were striving to stay positive; this study provided an insight into the acceptable level of resilience that most participants achieved in relation to work. Striving to keep the image of masculinity and family breadwinner was a positive sign of adjusting to SCI; participants did not want to be pitied by others for being less able to work or take care of their families. This suggests important implications of the current study in the domain of SCI rehabilitation; psychologists, occupational therapists and VR officers should consider the importance of maintaining the old strong self-image for the person with SCI, especially when discussing issues related to employment after the injury. It would be interesting to investigate through future research how SCI rehabilitation professionals implement the concepts of masculinity, fatherhood and breadwinning in their VR interventions, and the effect of this on employment outcomes.

Moving forward with vocational life was influenced by participants' sense of reconciliation with their conditions, where they showed an awareness of their job limitations, a satisfaction with the different work options they could do after SCI and an ability to find alternative activities to enjoy after their injuries. As this demonstrated participants' high level of knowledge and ability to manage vocational life post SCI, it is crucial for VR officers and members of support groups who work on programmes for SCI RTW to treat people living with SCI as decision makers, as long as the latter show the desire to do so.

### **Considerations and reflections**

The following section will highlight a number of considerations and reflections in relation to the first study. The aim of this study was to understand detailed accounts of the experience of unemployment for people living with SCI, and therefore a small sample size (nine participants) was used to maintain the focus on the quality, rather than quantity, of the emergent data. One cannot generalise from this qualitative study, meaning it was not the case that the same findings were expected to be sought from similar groups in similar settings. Instead, the study aimed to offer a perspective about the experience of SCI unemployment from a small group of participants and give the reader the opportunity to consider how the findings may relate in a wider context.

Furthermore, all participants received their rehabilitation at the same facility, which could make their retrospective accounts unique to that facility. However, while participants were recruited from the same rehabilitation facility to maintain homogeneity of the sample, the study's commitment to idiography allowed the data to capture individual views and experiences of rehabilitation, thereby contributing to the validity of the study.

Participants were initially approached by a member of the centre at which they had their rehabilitation, who spoke to them about recruitment and provided them with the necessary information about the study. It could be argued that this may have pressured participants to participate in the study, either because they thought that by taking part they were showing gratitude to the spinal centre or because some of them still had follow-up visits at the centre and therefore might have been concerned that refusing to take part in the study would have had an impact on their future treatment. However, the documents that were handed to those participants to read (the participant information sheet) and sign (the informed consent form) ensured it was clear that participation was entirely voluntary, and that their participation or not would not affect any further treatments at their spinal centre. In addition, both the researcher and the member of the spinal centre who approached participants gave verbal reassurance to participants about this before the interviews were conducted. Finally, as several SCI individuals who were contacted by the

spinal centre for possible recruitment did not give their consent to take part in the first study, this gave assurance to the researcher that it was less likely that participants who agreed to take part in this study felt under pressure to do so.

Finally, the homogeneity of the sample in terms of gender, which was influenced by the commitment of the current IPA study to idiography, can be seen as a strength; the sample consisted of nine men, resulting in some interesting gender specific data about masculinity, fatherhood and family breadwinning.

### **Reflexivity notes**

The following section will outline aspects of the researcher's thoughts around reflexivity in relation to the first study. The researcher was initially touched by some of the participants' accounts in this study, such as Henry and Mark's accounts of losing their jobs following SCI. She therefore initially interpreted their accounts of helplessness and anger as demonstrating hatred of their situation. However, when the academic supervisor audited the analysis of those participants' accounts, he advised that there was no evidence in their data that suggested hatred, and that it was an over-interpretation to make such a claim. Following this, the researcher grounded herself in the accounts of the participants rather than her own feelings, and found that anger and helplessness were the only bitter feelings presented by these participants following their injuries.

In contrast, some participants' accounts were viewed by the researcher with a more accurate lens; her previous work experience with SCI individuals led her to recognise the credibility of some accounts. For example, Andy, as a truck driver, believed that it was going to be difficult for him to find an alternative job following his SCI, as his knowledge lay in manual and physical work that he was not able to do after his injury. Having worked with many people in a similar position to Andy's in the past, the researcher interpreted Andy's lack of vocational plan after SCI as logical and justified rather than blaming it on demotivation. Another example is of William, whose account was mainly perceived by the researcher as his attempt to depersonalise his story and feelings. The researcher found that she expected this approach from William to her interview

questions, as in her experience, SCI individuals like William, who still have a court case and are awaiting a verdict after their injury accidents (see pen portraits in chapter 4), usually choose to disclose limited information to professionals and researchers in order to not affect their cases.

The researcher did not view this acknowledgment of the credibility of her participants' accounts as a problem in the analysis, but rather a strength. The researcher believed that it was an analytical privilege to be aware that some participants' accounts were reinforced by restrictions imposed on them by society. In the cases of Andy and William, the researcher believed that, as the social model of disability suggests, society was hindering social participation and RTW. This was either by limiting job opportunities for disabled people (in Andy's case) or by indirectly forcing disabled people not to disclose their plans to RTW publicly in order to receive fair verdicts after their accidents (in William's case).

Moreover, some participants' accounts resonated with the researcher on a personal level. For instance, during Jeff's interview, his metaphor of being confined to his bedroom after his injury, on the ground floor away from the rest of his family, was a feeling to which the researcher could relate. The researcher was also living by herself and away from her family at that time. Further, Simon's account of his affected self-image after leaving a high-profile job due to the injury resonated with the researcher's personal experience of having her postgraduate programme interrupted for a period of time due to family issues. Simon's account of wanting to sound busier than he actually was when others asked him about his work status after the injury resembled the researcher's experience during the interruption of her studies.

While those feelings of resonance were sometimes inevitable, there was an initial concern that they could affect the validity of the analysis; perhaps they had the potential to take the analysis to a different level, in which the researcher might over-interpret Jeff and Simon's accounts in the light of her related personal account. However, again, the academic supervisor's close and constant audit of the analysis during its different stages helped alleviate this issue.

In a different vein, due to cultural and gender differences between the researcher and her participants, some deep meanings of participants' accounts could have been unintentionally missed. For example, when Jack talked about his struggle to find a new job after his injury and the stigma he faced during that time, he began to cry. The difficulty for the researcher in handling this situation mainly lay in the fact that Jack was a male and she a female. It felt overwhelming for the researcher to have a man crying in front of her and she was not sure, culturally, what the best reaction should be. This might have led her to change the way she asked some questions after Jack was able to talk again to make them sound less personal, which may have affected the depth of his account in the interview.

Relatedly, the researcher believed that working in the field of rehabilitation of people with long-term injuries tends to leave support providers either very sympathetic to their clients or very resistant to such sympathy. While always sympathetic, the researcher was not familiar with the ways in which most support providers in the UK approach their clients and whether visible sympathy was culturally acceptable in the UK. The researcher, for example, was touched by Mathew's account of his wife leaving him after the injury. The researcher experienced anger on Mathew's behalf that she was not sure she should show him, which might have unintentionally hindered her to request further elaborations.

As mentioned earlier in this thesis, before conducting the interviews for the first study, the researcher sought advice from her fellow PhD student, who was a British male suffering a SCI, on the potential risks related to participants' emotional accounts and the suggested ways to handle them. However, it could be that it was difficult during the actual interviews for the researcher to promptly decide on the proper level of sympathy to show to Jack and Mathew. The researcher, therefore, decided that it was safer not to engage them in more potentially difficult conversations. This could unintentionally affect the depth of the collected data.

## **PART B**

### **Study 2**

#### **Understanding the lived experience of those who provide spinal cord injury (SCI) vocational support in the community**

*“If I can educate other people and help other people, with a spinal cord injury, then my job is done”.*

Current participant Vicky (p. 29)

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## Chapter 7: Literature review

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### Introduction to this chapter

Pre-spinal cord injury (SCI) work had a special value for participants in the first study, which they expressed through being nostalgic for this fruitful and socially fulfilling period of their lives. Therefore, losing work after SCI was associated with agony and feelings of victimisation. While some of those participants initially struggled with uncertainties about their ability to be productive again and/or receive unspecialised SCI care, others suffered from social isolation and/or discrimination in their attempts to return to their pre-SCI jobs.

After coming to terms with their new SCI conditions, the majority of the participants showed their motivation to return to work (RTW) that suited their current capabilities and conditions; where some verbalised their desire to do so, others had concrete plans.

Beside this, participants' accounts made no reference to seeking and/or receiving professional support in relation to work after SCI, neither during rehabilitation or after going back into their communities.

Looking at these factors, it is clear that SCI participants' distress over job loss and discrimination was followed by periods of re-initiating productivity, with no reference to engaging in vocational support at either time. Therefore, it would be interesting to talk to those who provide this type of support to SCI individuals in order to understand how they perceive their role in tackling issues relevant to unemployment and RTW. Conducting research in which those providers are given the opportunity to express their accounts is warranted, as their experience of vocationally supporting SCI individuals is meaningful.

While this will be fulfilled in the second study of this thesis, this chapter will present the relevant literature for the topic by starting with a brief introduction to vocational rehabilitation (VR) in terms of its scope and its service providers' competencies, followed

by a review of previous research carried out in the area of VR service providing. In the final section of this chapter, the rationale for conducting the second study will be discussed.

### **A brief introduction to vocational rehabilitation (VR)**

#### **Definition of VR**

VR can be defined as the activities that aim to help people living with an injury who have a work history to return to the labour market through restoring their work capacities (Selander, 1999). The Department for Work and Pensions (2004) in the UK defines VR as the process in which barriers to RTW after an injury, illness or impairment are overcome through assessing needs and required adjustments as well as providing staged RTW and education before finally rebuilding capacity for work.

In light of the above definitions, the current study will refer to VR as a comprehensive set of employment services that can include both support related to RTW and first-time preparation for work. According to Gard and Söderberg (2004), both of those services have been suggested as highly effective for many individuals living with disabilities.

The following section will provide an introduction to VR as a job discipline, including its scope of service and competencies of providers.

#### **Scope of service in VR**

There are many types of VR services that can help people living with SCI to RTW. Amongst these is 'supported-employment'. As a commonly used intervention in high-income countries (World Health Organisation and International Spinal Cord Society, 2013), supported-employment emphasises skills related to job readiness, counselling, job placement, post-placement support, in-job training and follow-up services (Ottomanelli & Lind, 2009). Job placement services, for example, such as networking, matching job descriptions to individual's functions, assessing job search abilities and interview preparation as well as identifying necessary accommodations and assistive technology, were found to predict employment in people living with SCI (Marini, Lee, Chan, Chapin, & Romero, 2008).



## **Service providers in VR**

Providing VR services is the responsibility of a multidisciplinary team who should aim to facilitate RTW or prevent job loss following an injury that leads to disability (Gobelet, Luthi, Al-Khodairy, & Chamberlain, 2007). In practical terms, this means that individuals who have health-related limitations for functioning at work are usually approached by professionals from different disciplines to help them optimise their work participation (Escorpizo et al., 2011). The multidisciplinary VR team would normally include professionals such as occupational therapists, physiotherapists, psychologists, vocational counsellors, job trainers, case-managers and agencies for job placement (Gobelet et al., 2007).

The World Health Organisation and International Spinal Cord Society (2013) recommend that different agencies and sectors collaborate and work in multidisciplinary teams in order to maximise their success in providing VR services. They make specific recommendations to governments, organisations employing health and social care professionals, non-governmental organisations and organisations for disabled people about providing the necessary services for SCI individuals, including those relevant to social participation and employment.

Among those recommendations is that governments improve SCI rehabilitation and support services in order to prepare people living with SCI for work and ensure that anti-discrimination legislations and accessibility standards are applied when those individuals want to RTW. On the other hand, it is recommended that non-governmental organisations develop rehabilitation programmes based in the community, empower people living with SCI through employment and promote peer-support services and networking. Finally, it is recommended that health and social care professionals empower SCI people and their families to be more independent, take part in more research and get more training in raising awareness about SCI (World Health Organisation and International Spinal Cord Society, 2013).

## **Competencies of service providers in VR**

It is important for rehabilitation providers working in healthcare settings to address both the biomedical and psycho-emotional needs of SCI individuals and that they receive effective training to fulfil those needs in the therapeutic process (Lusilla-Palacios et al., 2015). Promoting client-centred practice by professionals working in SCI rehabilitation programmes is important as it helps engage people living with SCI in the therapeutic process as active contributors (Hammell, 1995). According to a survey relating to rehabilitation counselling, commitment to clients, professional behaviour and competence were among the most important qualities that clients looked for in their rehabilitation counsellors (McCarthy & Leierer, 2001).

A study by Leahy, Chan, and Saunders (2003) stated that the major job skills in counsellors working in rehabilitation included vocational counselling, community-based rehabilitation services and case-management. This study also showed that the major knowledge domains in this profession included career counselling, counselling theories, rehabilitation resources and disability systems.

Furthermore, the highest-rated competency among VR practitioners was knowledge about agencies and changes in systems (Defur & Taymans, 1995). Supporting results from Shaw, Hong, Pransky, and Loisel (2008) showed that among the identified main competency domains reported by coordinators for RTW for people living with disabilities were knowledge about labour policy and medical conditions.

As can be seen, providing VR services for people with injuries, including those with SCI, is the responsibility of a multidisciplinary team in rehabilitation as well as different community sectors and agencies. VR service providers play an important role in helping people with injuries, including SCI, with their RTW process, meaning they must be highly skilled and trained. However, little is known about the personal experience of this group in providing this type of service.

This chapter will now review the literature on aspects related to those providing vocational support to people living with disabilities, including SCI, in rehabilitation settings and in the community to identify gaps that warrant the exploration of their personal job experience.

**Literature review on VR providers**  
**Selection criteria of reviewed papers**

For the purpose of reviewing the literature related to the second study in this thesis, two separate searches on *PSYCH INFO* database and *GOOGLE SCHOLAR* were conducted during the month of July 2017 and were checked for updates in January 2018. The selected papers for this literature review had the following criteria:

- Both qualitative and quantitative papers
- Papers published between the years of 1970 and 2017 (it was difficult to narrow the period of publications more than this due to limited research results)
- Papers published in peer-reviewed academic journals
- Papers published in English
- Papers using reports mainly from healthcare and disability rehabilitation providers (interviews, surveys or retrospective data)

The papers that were excluded either did not meet the above inclusion criteria or discussed specific roles of therapists, such as sexual education or wheelchair skills for SCI, which were not relevant to the topic of the second study.

The following keywords were used on *PSYCH INFO*: (*vocational, employ\*, unemploy\*, work, return to work, support, service\*, spinal cord injury, work\* with, perspectives, experience, provide\**). From a large number of hits, the top 80 relevant papers were reviewed, and a total of 24 papers were selected and included in the literature review of the second study.

To expand the search, the same keywords were used on *GOOGLE SCHOLAR*. Out of a large number of hits, the top 20 relevant papers from each search were reviewed, and a total of nine papers were selected and included in the literature review (duplicated results from the previous search on *PSYCH INFO* were excluded).

**Literature review of VR providers**  
**Emergent themes from reviewed papers**

The following three main themes emerged from the reviewed papers about VR providers:

**(1)** Perceptions of different rehabilitation aspects addressed by rehabilitation service providers, **(2)** Rehabilitation service providers' relationships and communication skills with their team members as well as with their patients and **(3)** The experiential accounts of rehabilitation service providers.

**1) Perceptions of different rehabilitation aspects addressed by rehabilitation service providers**

The first main theme that emerged from the literature review presented perceptions of rehabilitation service providers about different rehabilitation aspects:

**A) Service providers' perceptions of physical aspects of rehabilitation**

With the aim of using healthcare professionals' views to identify complications with SCI and relate them to the *International Classification of Functioning, Disability and Health (ICF) model*, Scheuringer and colleagues (2010) used a worldwide internet survey to ask psychologists, physiotherapists, occupational therapists, social workers, nurses and physicians questions related to their professional backgrounds followed by open-ended questions related to the functional, environmental and personal problems faced by SCI individuals. Scheuringer and colleagues (2010) reported that healthcare professionals cited complications related to body function and self-care as the most common problems following SCI.

*A.1. Perceptions on physical barriers*

Riegel and Eglseder (2009) conducted an internal quality improvement survey with eight occupational therapists working in SCI rehabilitation settings, with the aim of evaluating the occupational therapy services of an inpatient specialised ward in the United States. Among the results were physical barriers, which included a lack of access to transportation. Occupational therapists felt that they had a responsibility to address these barriers but

believed that they did not have the sufficient knowledge and training to help their SCI patients learn how to drive. However, occupational therapists in this study reported that another physical barrier in SCI was the difficulty of physically accessing public places, which they felt they were able to help with by providing training during community outings for their SCI patients.

A study across three countries (United States, Italy and Canada) assessed, through direct observations, cultural differences in the beliefs of healthcare professionals about the importance of the functional goals of people living with SCI during the period of rehabilitation (Ditunno et al., 2006). This study included physical therapists, occupational therapists, recreational therapists, psychologists, social workers, nurses, physiatrists and rehabilitation administrative assistants. Results showed that there was a discrepancy between the professionals from the United States and those from Canada and Italy relating to the domain of mobility, since in the United States rehabilitation professionals tend to discharge SCI patients as soon as they achieve the minimum level of mobility independence, while rehabilitation professionals in Italy and Canada tend to keep SCI patients in the rehabilitation hospital until they achieve their maximum ability for independence and mobility. However, professionals in all three countries agreed that bowel and bladder management was important for independence as well as for achieving high physical and psychological quality of life (QoL) after SCI. Therefore, this study was able to shed light on how the diversity in values and attitudes towards people with SCI, which stemmed from cultural differences, could have an influence on therapeutic goals and functional outcomes (Ditunno et al., 2006).

#### *A.2. Perceptions of self-care*

Kroll (2008) conducted semi-structured interviews with a number of rehabilitation professionals, including VR counsellors, to explore rehabilitation needs of SCI patients. According to those rehabilitation professionals, one of the components used to measure the necessary length of stay at the rehabilitation hospital was SCI patients' willingness to go back to their homes. However, many SCI patients stayed for a short while at the hospital

and went home without being provided with sufficient training or the appropriate level of preparation to care for themselves (Kroll, 2008).

Guidetti and Tham (2002) interviewed occupational therapists to explore their therapeutic strategies for providing self-care training to their disabled patients. Among those strategies was that of helping patients find motivation for attending self-care training by explaining its purpose and displaying video clips of other patients who were able to benefit from this training to achieve their goals. Another strategy was to help patients achieve their training goals through making explicit expectations, supporting them to know their limitations as well as their level of independence, maximising their competencies, enabling them to practise the self-care tasks themselves and finding new solutions to their challenges. Finally, occupational therapists in this study reported that they had to provide self-care training that was adjusted to their patients' needs, especially by considering their pre-injury experiences and balancing the challenges of activities in the self-care training with the actual ability of patients to perform those activities (Guidetti & Tham, 2002).

## **B) Service providers' perceptions of psychological and emotional aspects of rehabilitation**

### *B.1. Perceptions of psychological issues*

According to rehabilitation professionals in Kroll's study (2008), SCI patients' inability to learn skills for self-care was not only due to the short period of rehabilitation programmes, as mentioned before, but also the impact of some psychological factors, such as denial, anger and depression, which were associated with their injury.

However, results from a study by Cushman and Dijkers (1990) showed that rehabilitation professionals could sometimes overrate their SCI patients' level of depression. Cushman and Dijkers's (1990) results also showed that the increase of accuracy in rehabilitation professionals' ratings of their SCI patients' depression did not correlate with the increase in the working years of their profession.

## *B.2. Perceptions of principles for providing psychological care*

In terms of principles to be followed when providing psychological care to SCI patients, Brackett, Condon, and Kindelan (1984) reported that rehabilitation professionals described the need to always show their patients that they are important, valued and dignified. Rehabilitation professionals also described the need to inform their patients, in detail, about why certain medical procedures had been undertaken and the role of rehabilitation professionals in providing those procedures (Brackett et al., 1984).

Kroll (2008) reported that rehabilitation professionals emphasised the need to explain to their SCI patients the role they could play as patients through providing sufficient information about their medical conditions to their therapists.

## **C) Service providers' perceptions of social aspects of rehabilitation**

### *C.1. Perceptions of rehabilitation support*

Occupational therapists in Riegel and Eglseder's (2009) study believed that self-advocacy was an important outcome of rehabilitation. While occupational therapists in Isaksson and Hellman's (2012) study emphasised this, they also tried to balance the amount of support they gave to their patients so that the latter could maintain their motivation to be independent. However, in both of these studies, the importance of providing support from all members of the rehabilitation team and the positive influence of this on rehabilitation outcomes were strongly emphasised. This was because establishing therapeutic relationships helped acknowledge barriers in the community and prepare patients to face and overcome them (Riegel & Eglseder, 2009).

### *C.2. Perceptions of peer support*

The role of peer support was also acknowledged by professionals as influencing the rehabilitation programme. Through observing the reactions of SCI patients when interacting with their peers, occupational therapists in Riegel and Eglseder's (2009) study reported that peers were able to identify many social concerns of their patients.

In addition, the observations of occupational therapists in Isaksson and Hellman's (2012) study emphasised the importance of their SCI patients interacting with peer supporters, especially those participating in non-profit organisations, for learning what it would be like to live with SCI in the community.

In the same vein, Haas, Price, and Freeman (2013) interviewed five SCI rehabilitation therapists to explore their views on community peer support services for their patients and found that those therapists appreciated the role of peer supporters and considered them valuable members of the rehabilitation multidisciplinary team. Rehabilitation therapists in this study also emphasised the role of peer supporters in enhancing the psychological status of others living with SCI, helping them come to terms with the injury and linking them with different healthcare facilities.

### *C.3. Perceptions of support following discharge from rehabilitation*

Continuing to provide care and support to SCI patients after their discharge from the rehabilitation programme was viewed by occupational therapists in Isaksson and Hellman's (2012) study as crucial in ensuring that the goals set during rehabilitation were achieved in the community. Those therapists believed that by providing such care and support, they were able to show how much they understood the social needs of their SCI patients in the community. However, while some studies (e.g., Scheuringer et al., 2010) supported this, others (e.g., Kroll, 2008) reported that rehabilitation professionals complained that they lacked information about their patients' environmental situations outside the hospital and the available resources to help them improve their social participation.

Finally, according to rehabilitation professionals, factors associated with lack of support would usually have a negative impact on SCI patients' ability to gain self-management skills. In other words, confidence and independence may be lost when adequate social support in the community is not provided (Kroll, 2008).



## **D) Service providers' perceptions of vocational aspects of rehabilitation**

### *D.1. Perceptions of RTW services*

VR professionals who participated in Hay-Smith and colleagues' (2013) study suggested that RTW was not usually a priority for SCI patients at the beginning of the rehabilitation programme and therefore their role was utilised at the time of discharge, when patients started to think about going back to their familiar lives after SCI. According to those VR professionals, it was always easier to help someone with SCI return to their pre-injury job than to work on any other plan.

Supporting results showed that, according to VR professionals, returning to the same job as before the injury was the top choice of their SCI patients (Dekkers-Sánchez, Wind, Sluiter, & Frings-Dresen, 2011). Providing tailored VR interventions and monitoring patients during the rehabilitation process were important aspects of working with patients to achieve their goals. After being discharged from rehabilitation, having a supportive social environment, in the forms of good social networks and good role models, was important for RTW following SCI (Dekkers-Sánchez et al., 2011).

### *D.2. Perceptions of scope of services*

In providing employment services through social networks, Cotner and colleagues (2014) interviewed social support network members who worked in an SCI supported-employment programme in the United States. Those members suggested that they conducted one-to-one sessions with SCI individuals not only to help them with job searches, contacts with employers and job development activities, but also to help them with job-site assessment and follow-along VR support.

Earlier studies, such as Targett, Wehman, and Young's (2004), had similar findings, where the role of social support network members was usually seen as going beyond job placement for SCI individuals, as it included developing training skills, implementing workplace accommodations and following up job performance in order to identify any further support needed.

## **2) Rehabilitation service providers' relationships and communication skills with their team members as well as with their patients**

The second major theme in the literature review consisted of work on the principles and challenges of interprofessional relationships and communication skills in rehabilitation settings, as well as principles and challenges of the relationships between rehabilitation professionals and their patients.

### **A) Interprofessional relationships and communication skills**

'Holistic care' in rehabilitation usually refers to working in a team that consists of members from different disciplines who provide care for patients. Rehabilitation professionals in Shroff and Sahota's (2013) study believed that they always needed to increase their knowledge of interprofessional rehabilitation for the ultimate benefits of their SCI patients. Similarly, in Dekkers-Sánchez and colleagues' (2011) study, while doctors and rehabilitation professionals felt initially concerned over the different educational backgrounds, skills and experiences of each other, they went on to emphasise the importance of being trained in interprofessional skills and how to critically reflect on the management of issues related to professional boundaries.

Following Pellatt's (2005) finding that some professionals complained that other members within their rehabilitation teams did not understand their roles, it was recommended that they improve their communication with each other to reinforce understanding of each other's roles. Meanwhile, Haas and colleagues (2013) reported that rehabilitation professionals viewed peer supporters as valuable members of the interdisciplinary team and believed that they were helpful in showing empathy and giving practical advice to SCI patients.

### **B) Relationships and communication skills with patients**

The relationship between rehabilitation providers and their patients has been highlighted in the literature relating to people living with SCI.

### *B.1. Rapport and empathy*

Guidetti and Tham (2002) found that fundamental to the ability to provide good training in self-care was occupational therapists' establishment of positive contacts with their SCI patients. Those occupational therapists suggested that this was an important therapeutic strategy where they were able to establish trust through conversations held during treatments or informal meetings in the rehabilitation department. They emphasised the importance of understanding patients' needs through drawing on their own knowledge and experience of working with previous patients (Guidetti & Tham, 2002).

Similarly, SCI VR professionals in Dekkers-Sánchez and colleagues' (2011) study emphasised the importance of showing empathy to their patients and the need to demonstrate an understanding of the medical condition, provide realistic recovery expectations and set realistic VR goals for work.

### *B.2. Agreement between rehabilitation professionals and people living with SCI*

Pellatt (2007) conducted semi-structured interviews with doctors, physiotherapists, occupational therapists and SCI patients at an SCI rehabilitation centre in the UK for the purpose of understanding whether rehabilitation professionals agreed with their SCI patients about the professionals' roles in the treatment programme. Qualitative findings indicated that there was a meaningful level of agreement between the two groups with regard to the key role of physiotherapists in improving mobility, that of occupational therapists in improving activities of daily living and self-care and that of doctors in leading the rehabilitation team.

Siösteen, Kreuter, Lampic, and Persson (2005) conducted a study with occupational therapists, physiotherapists, social workers and nurse assistants in a spinal unit in Sweden. This questionnaire set out to explore perceptions of problems related to SCI coping and physical and mental well-being before comparing these perceptions to SCI patients' self-reports. For the more visible symptoms, such as physical and functional limitations, rehabilitation professionals were mostly accurate in their assessments of their patients,

while for the less visible symptoms, such as depression and anxiety, rehabilitation professionals tended to overestimate their patients' reports.

Pellatt (2004) focused on how rehabilitation professionals perceived their relationships with their SCI patients compared to how the latter perceived those relationships. This paper identified different levels of paternalism in the relationships between professionals and their patients, which included the former having the power and control to take decisions and steer the latter towards choices.

### **3) The experiential accounts of rehabilitation service providers**

The third and final major theme in this literature review illustrated rehabilitation service providers' experiences of work, which they reported from their own perspectives. This theme included previous qualitative and quantitative research into rehabilitation service providers' positive and negative accounts of their work, how they viewed that work and how they believed it impacted their lives.

#### **A) The seemingly negative experiential accounts of rehabilitation service providers**

Reports from rehabilitation service providers working with injured people of the negative impact of their jobs on their lives took different forms. For example, a large study by Boschen, Gargaro, and Tonack (2005) compared 100 support providers, 100 individuals with SCI and 102 individuals from the general population in terms of community integration and QoL. Results showed that although support providers scored higher than SCI patients in the examined areas, they had a lower score than the general population, which could suggest the negative impact of the support providers' role on their lives.

Similarly, Boschen, Tonack, and Gargaro (2005) used the mixed methods of questionnaires and focus groups to explore the impact of being the support provider of a person living with SCI in the community on the self, and found that the higher the level of support, the lower the productivity, community integration and QoL for the person providing that support. Participants felt that they were emotionally unprepared for their role in the

community and that they had unmet needs with regard to family, relationships and work that negatively impacted their QoL.

Moreover, a grounded theory (GT) study aimed at exploring the general perceptions of 16 SCI rehabilitation staff of their jobs and found that there was an experience of lack of tolerance towards patients' non-compliance with the goals set in the rehabilitation programme, but this depended on both the racial and professional backgrounds of those rehabilitation staff (Devlieger & Balcazar, 2010).

Friedemann-Sanchez, Sayer, and Pickett (2008) used the qualitative methodology of rapid assessment process to examine the perceptions of rehabilitation service providers about the impact of work on them. A total of 56 participants were interviewed, and results showed that educating other staff as well as the general population about disability were the main sources of stress for the rehabilitation providers.

More significantly, burnout was noted among some staff working in the rehabilitation of injured people. Gomez and Michaelis (1995) measured burnout among human service providers, including VR staff, and found that all their 47 participants were within the low to moderate range. Templeton and Satcher (2007) measured burnout in public rehabilitation counsellors and found that providing administrative support predicted emotional exhaustion and depersonalisation of clients.

However, lower levels of occupational burnout in a paper by Elliott, Shewchuk, Hagglund, Rybarczyk, and Harkins (1996) was associated with the perceived ability and confidence to handle problems that arose from working as rehabilitation nurses. Similarly, Clanton, Rude, and Taylor (1992) found that rehabilitation providers who were highly resourceful were less likely to experience occupational burnout.

Salyers, Brennan, and Kean (2013) conducted a quantitative study, where a number of community mental healthcare providers' positive recovery expectations for their patients were positively associated with lower levels of job burnout.

## **B) The seemingly positive experiential accounts of rehabilitation service providers**

Job satisfaction, learning new skills and developing a positive sense of self have been documented in the literature as illustrating the positive consequences of working as rehabilitation service providers for people living with disabilities.

Wittig, Tilton-Weaver, Patry, and Mateer (2003) used mixed methods to explore job satisfaction among 133 rehabilitation care providers for patients with brain injury. Job satisfaction mainly depended on variables related to being appreciated by employers as well as being supported and provided with training in the workplace.

Job satisfaction among rehabilitation professionals in Friedemann-Sanchez and colleagues' (2008) study took the form of perceiving their work with injured veterans as being deeply rewarding. Those professionals expressed their pride in serving people who they believed were "heroes" and perceived their jobs as being important.

In a similar vein, a number of studies suggested that through providing care in rehabilitation settings, professionals learned new skills and improved their knowledge (Boschen, Gargaro, & Tonack, 2005; Friedemann-Sanchez et al., 2008). Gaining a positive sense of self was one of the positive experiences reported in the literature about rehabilitation service providers. For instance, peer supporters working in the rehabilitation of people with multiple sclerosis have reported gaining a great sense of self-acceptance, self-confidence, inner peace, openness and tolerance through their work with their patients (Schwartz & Sendor, 1999). Another study reported that peer supporters gained a sense of self-awareness through working in the rehabilitation of people with SCI (Boschen, Gargaro, & Tonack, 2005). Finally, while rehabilitation providers for people with multiple injuries in Friedemann-Sanchez and colleagues' (2008) study reported that their job helped them gain a great sense of cohesion with their colleagues, support providers in Boschen, Gargaro, and Tonack's (2005) study reported a great sense of closeness to the SCI patients they used to work with.

### **Summary of the literature review**

The above review of the literature drew on different aspects related to working in rehabilitation and community services for people living with injuries, which included how professionals perceived those services, their relationship with their colleagues and their patients as well as their experiential accounts of their job, especially with regard to satisfaction and burnout.

### **Rationale for the second study based on the above review of the literature**

As seen above, many studies included reports from rehabilitation professionals about their views on the physical, emotional, social and vocational aspects of the people with injuries they treat; meaning the focus of those reports was on patients rather than the rehabilitation and support professionals themselves. However, it is equally important to understand the experience of support providers in order to help them meet their psychological and physical needs. Giving a voice to this group can help them verbalise and overcome their challenges, which not only can help improve their work performance but can also contribute to improving vocational services for people with SCI. Indeed, research in this area could eventually help increase the ability to RTW following SCI.

Moreover, while the literature review above touched on the experience of rehabilitation professionals in their work, it mainly focused on the particular aspects of social relationships, burnout and satisfaction in this experience. More comprehensive views from those professionals are warranted to help understand the wider picture of their challenges, needs and even types of incentives they require to perform well at work. More on this will be covered in the next chapter.

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## Chapter 8: Methodology and method

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This chapter will outline how the substantive work of the second study was completed. It will briefly discuss the second study's methodology, provide information about the research question and objectives and finally explain the method used.

### **Methodology - Interpretative phenomenological analysis (IPA)**

As in the first study, the second study in this thesis was conducted using the qualitative, phenomenological and interpretative approach of IPA. The second study used IPA to explore the experiences of five spinal cord injury (SCI) vocational support providers. Individual case analyses were conducted, followed by a cross-case analysis. Data collection, analysis and presentation of the findings in the second study followed the theoretical framework of IPA; that is, phenomenology, hermeneutics and idiography.

### **Rationale for using IPA in the second study**

Chapter seven's literature review justifies the use of IPA for this study, particularly in the context of the final theme, where rehabilitation and support providers' accounts were discussed.

As can be seen in Table 10 below, the literature in that theme included quantitative studies that mainly focused on the aspects of occupational burnout, job satisfaction and quality of life (QoL). In contrast, using an IPA approach in the second study would enable a more inductive data related to the experiential accounts of doing the job of SCI vocational support providing to emerge. The in-depth, detailed exploration of the personal accounts of vocational support providers that will arise from an IPA reading would allow more space for aspects other than occupational burnout and job satisfaction to emerge from the collected data.



Table 10 also includes qualitative and mixed methods studies that had a main focus on perceptions of the impact of working in rehabilitation on the self and wellbeing. Although it can be argued that the methodologies used in this existing body of literature focused on gaining personal views of the experience of working in rehabilitation and support through the exploration of the impact of the job on the self and wellbeing, using an IPA approach would strongly allow more idiographic views to be gained through studying a small sample of participants. By doing so, the current IPA researcher would be able to get as close to the experience of the participant as possible and would therefore be able to pay attention to the small details and their meaning to participants. In other words, using an IPA approach would allow more understanding of the meaning of the emergent aspects from the data through giving participants the opportunity to make sense of their experiences, and the current researcher to interpret this sense-making as well.

**Table 10**  
*Overview of qualitative, quantitative and mixed methods literature exploring the accounts of rehabilitation and support providers on their jobs*

<b>Qualitative research</b>	<b>Quantitative research</b>	<b>Mixed methods</b>
<i>Grounded theory (GT) and Rapid assessment process</i>	<i>Surveys, questionnaires and scales</i>	<i>Questionnaires + interviews/ focus groups</i>
Rehabilitation providers' perceptions of their job/Perceived impact of doing rehabilitation on self	Assessment of job burnout, community reintegration, QoL and learned resourcefulness in rehabilitation providers	Impact of being a support provider on the self/Job satisfaction/Impact of rehabilitation providing on physical and psychological wellbeing
<ul style="list-style-type: none"> <li>- Devlieger &amp; Balcazar (2010)</li> <li>- Friedemann-Sanchez, Sayer, &amp; Pickett (2008)</li> </ul>	<ul style="list-style-type: none"> <li>- Salyers, Brennan, &amp; Kean (2013)</li> <li>- Templeton &amp; Satcher (2007)</li> <li>- Boschen, Gargaro, &amp; Tonack (2005)</li> <li>- Elliott, Shewchuk, Hagglund, Rybarczyk, &amp; Harkins (1996)</li> <li>- Gomez &amp; Michaelis (1995)</li> <li>- Clanton, Rude, &amp; Taylor (1992)</li> </ul>	<ul style="list-style-type: none"> <li>- Boschen, Tonack, &amp; Gargaro (2005)</li> <li>- Wittig, Tilton-Weaver, Patry, &amp; Mateer (2003)</li> <li>- Schwartz &amp; Sendor, (1999)</li> </ul>

In a slightly different vein, a growing number of researchers have started to use the approach of IPA to understand experiences of employees (Gill, 2014). This came as a result of the shift that psychologists, and more specifically organisational psychologists, made towards using qualitative measures, such as interviews and focus groups, to answer research questions related to why employees behave in certain ways at work (Ehigie & Ehigie, 2005), as well as to increase scientific and practical knowledge about the meaning of human behaviours in work situations for the purpose of solving problems and improving job satisfaction among employees (Muchinsky, 2006). This work in the field of organisational psychology matched the research question of the second study and its commitment to the theoretical underpinnings of IPA.

### **Main research question**

The second study in this thesis asked: **what is it like to work in a community organisation and provide vocational support to individuals with SCI?**

Similar to the first study, this research question was committed to the approach of IPA in that it was open, experiential, exploratory and focused on meaning.

The theoretical and methodological justifications for the second study as well as the value of understanding the experiences of vocational support providers for people living with SCI in relation to the first study in this thesis were mentioned in both previous chapter and earlier in this chapter. Alongside those justifications, researching this topic was derived from the researcher's personal experience of working as a vocational rehabilitation (VR) service provider for SCI patients in rehabilitation settings. Working within a multidisciplinary team in SCI rehabilitation, the researcher felt that VR was not perceived to be as important as other disciplines in rehabilitation and was usually given less attention by physicians, nurses, occupational therapists and physical therapists, which had the potential to subsequently affect how SCI patients themselves perceived VR services. However, since VR services are crucial for people living with SCI, these experiences left the researcher determined to give voice to VR providers through research and to make their experiences, including their successful stories and challenges, heard.

It was important for the researcher to emphasise that the aim of the second study in this thesis was to focus on the personal experiences of VR service providers rather than their perspectives of people's experiences of unemployment and RTW following SCI. This was because of the significance of this personal experience and its importance in developing the field.

### **Objectives**

The main objectives of the second study were to answer the following:

1. How does working as an officer at an SCI community organisation and providing vocational support to individuals with SCI affect daily living?
2. What are the benefits and the challenges related to providing SCI vocational support in the community?

### **Ethics**

The researcher was informed that it would be difficult to recruit VR support providers working in rehabilitation in the UK, as she would need to go through a similar lengthy National Health Service (NHS) ethics process to the first study in order to interview such a group. Therefore, with her academic supervisor, she decided to take the route of SCI community organisations. This route was more accessible, especially as the researcher had already started volunteering for some of those organisations and had established connections that would aid the recruitment of participants in this second study.

In going with this plan, after gaining approval from two SCI community organisations in the UK, the second study received ethical approval from the Department of Psychological Sciences at Birkbeck, University of London. This process started by discussing the design of the study with the academic supervisor and completing the ethics form under his supervision.

The particular ethics form used was for research involving adults; it contained details of the study's rationale, recruitment, method, sample, settings, informed consent, procedure,

interview schedule, ethical considerations, lone worker policy, distress management plan for participants and data protection plan.

The ethics form was completed by the researcher then audited by the academic supervisor before being submitted to the ethics committee at the Department of Psychological Sciences at Birkbeck, University of London in June 2017. The ethical approval was a straightforward process with no requested clarifications or amendments; it was received in July 2017 (Appendix 6).

### **Eligibility criteria of the sample**

#### **1) Inclusion criteria**

The second study had the following inclusion criteria:

- Workers who have a current role or a recent experience in providing SCI individuals with vocational support
- Workers who provide or previously provided SCI individuals with vocational support as paid workers or volunteers at a UK community organisation supporting people with SCI
- Based in the UK
- Aged 18 and above
- Male or female
- English native speakers
- Able to provide consent to take part in the study

#### **2) Exclusion criteria**

Those who did not meet the inclusion criteria were excluded from participating in this study.

### **Justification of eligibility criteria**

In the previous literature review, it could be seen that the focus of most existing studies in this area was not necessarily on SCI support providers themselves. The health condition of SCI is a devastating and a life-changing one, and therefore often requires specialised care; SCI support providers usually work in specialised units and community organisations, where they can provide exclusive care related to SCI. The second study aimed to explore

the personal accounts of this unique and specialised group of providers who worked with SCI individuals.

Even though a small number of studies included SCI rehabilitation professionals and support providers in their samples, the focus was primarily on their accounts of providing medical care or services related to community reintegration. Despite the value that those studies might have in improving services, there seemed to be a lack of research about the experience of providing vocational support in particular. Supporting SCI patients to RTW and preparing them for this unique experience, through different vocational services, could be equally valuable to medical and community services.

As the second study focused on vocational support providers, it aimed to understand the experience of those who worked at community organisations for people with SCI. This was because most of the samples used in the existing literature included healthcare professionals working in rehabilitation settings, while the experience of those who provide vocational support in the community received less attention. Although, as mentioned earlier, both rehabilitation facilities and community organisations are expected to maximise their efforts in providing SCI vocational support (World Health Organisation and International Spinal Cord Society, 2013), they must also carry out different tasks and have different responsibilities, depending on the nature of the settings in which they work. This is due to differences in qualifications and focus of support. Again, since the latter group receives less attention from researchers, their experiences were worth exploring in this second study.

In addition, participants in the second study had to be native English speakers because, similar to the first study, using IPA meant that the language used by participants and the researcher's interpretation of that language were important factors in the analysis.

Since the literature did not seem to suggest any impact of the variables of age or gender on the experience of officers working in support services for people with SCI, the second study was not age- or gender-specific; it included both male and female participants, who were aged 18 and above.

### **Sample homogeneity and size**

A total of five participants were recruited in the second study. In keeping with IPA, the sample used in this study was small, purposive and homogenous.

### **Recruitment**

Recruitment of participants in the second study was done using the technique of 'snowballing', where one person usually sows the seeds by being the initial source of potential participants, and then those participants themselves suggest others and so on (Sadler, Lee, Lim, & Fullerton, 2010). 'Snowballing', or what could be called 'referral by research participants', is identified as one of the most frequently used techniques of sampling in IPA (Smith et al., 2009). In this study, the five participants were identified and accessed through their work colleagues. At the time of the interviews, all five participants were working or volunteering for two different SCI community organisations based in the UK.

The researcher, under the supervision of Professor Jonathan A. Smith, was able to ensure that participants met the inclusion and exclusion criteria. In the period between July and August 2017, the researcher made initial contacts with the five participants and sent them invitation letters (Appendix 7), participant information sheets (Appendix 8) and informed consent forms (Appendix 9) via email. There was not a specific time limit to when participants had to give their agreement for participation, but those who did were quickly scheduled for face-to-face interviews with the researcher at a date, time and location convenient to them. The consent forms were signed both by participants and the researcher prior to the start of the interviews.

### **Consent**

The researcher took responsibility for sending off the informed consent forms to the five participants via email and gaining their written signatures on them before the start of the interviews. The researcher retained all original copies of signed consent forms in a secured file at Birkbeck, University of London. Each participant was sent a photocopy of his/her signed form via email following the interview.

Participants in this study were not remunerated for taking part.

### Participants

Four of the participants in this study were male and one was female. All were native English speakers. All participants provided vocational support to people with SCI as part of their role at a community organisation; three participants were peer support officers and two were RTW programme managers (mean years of experience in all participants = 4.6). Although it was not in the inclusion criteria of this study, it turned out that all participants were themselves living with SCI.

Detailed information about the demographics of the five participants who took part in this second study is in Table 11.

Table 11  
*Demographics of participants in the second study*

<u>Name</u> <i>(pseudonym)</i>	<u>Gender</u>	<u>Job title</u>	<u>Job contract</u>	<u>Spinal cord injured?</u>	<u>Years of experience</u>
<b>Liam</b>	M	Peer Support Officer	Voluntary	Yes	9
<b>James</b>	M	RTW Programme Manager	Paid	Yes	3
<b>Derek</b>	M	RTW Programme Manager	Paid	Yes	4
<b>Vicky</b>	F	Peer Support Officer	Paid	Yes	2
<b>Adam</b>	M	Peer Support Officer	Paid	Yes	5

Table 12 summarises the demographics of participants in the second study.

Table 12  
*Summary of participants' demographics in the second study*

<u>Gender</u>	<u>Job title</u>	<u>Job contract</u>	<u>Spinal cord injured?</u>	<u>Years of experience</u>
Male = 4 out of 5	Peer support officers = 3 out of 5	Paid = 4 out of 5	SCI / Wheelchair user = 5 out of 5	Average = 4.6
Female=1 out of 5	RTW Programme Managers = 2 out of 5	Voluntary = 1 out of 5	-	-

### **Data collection**

The following section will explain how the data in the second study were collected, including details about the interview schedule, the settings for the interviews and pen portraits of participants.

It is important to note that the process of data collection in this study was similar to the first study. However, the following sections will highlight where some differences took place:

#### **1) Interview schedule**

The second study used semi-structured interviews with five participants to understand their experiences of providing vocational support to clients with SCI in community settings. This type of data collection method fitted with the aim of the study and the theoretical underpinnings of its chosen methodological approach of IPA.

The interview schedule was developed based on the reviewed literature, and in particular the studies mentioned in Table 10 above, as these helped identify areas for potential questions. It consisted of 11 main questions; although this number was slightly larger than suggested for IPA studies (Smith et al., 2009), the nature of the topic required asking a number of questions before reaching the core of the experience of its participants. Each question had a probe intended to help the researcher make elaborations during the



interviews. Although those probes were warranted as part of the structure of the interview schedule (in order to be prepared before the interviews), it was good to note that the researcher did not feel that she struggled to elicit rich data from her participants, and therefore hardly used any of them.

The full interview schedule of the second study, with probes, is in Figure 11 below.

- 1. Can you please tell me about your role in the charity organisation?**  
*(Probes: what type of work do you do? what type of tasks and responsibilities do you have at work?)*
- 2. How do you find doing this type of work?**  
*(Probes: do you like doing this job? do you or do you not enjoy doing this job?)*
- 3. Would you say you find this job satisfying?**  
*(Probes: is it a job that you are proud of?)*
- 4. Would you say that your work has an impact on your daily life?**  
*(Probes: does work impact your mood and relationships outside work?)*
- 5. How would you describe your relationship with SCI individuals who you work with and support?**  
*(Probes: is it easy to establish a rapport with people who you help at the charity organization? do you find that you get close to people who you help at work?)*
- 6. What are the challenges of doing this job?**  
*(Probes: what is difficult about doing this kind of job?)*
- 7. What are the challenges that your clients face when intending to RTW?**  
*(Probes: what barriers do they face? are they realistic barriers?)*
- 8. How do your clients overcome those challenges?**  
*(Probes: do you help them overcome those challenges, and how?)*
- 9. What are the benefits of doing this job?**  
*(Probes: what is good about doing this kind of job?)*
- 10. Can you tell me about a case that you worked with, where you were successful in helping a client with work return?**  
*(Probes: can you recall a particular client who you helped achieve the goal of going back to work? can you tell me how you felt?)*
- 11. How do you see the future in relationship to this job?**  
*(Probes: do you look forward to developing your career path through this job?)*

Figure 11. The interview schedule of the second study

As Figure 11 demonstrates, the first question in the interview schedule aimed to understand the background of the work that participants did as vocational support providers. The next two questions asked about how participants perceived their work, while the question that followed was about the impact of work on their QoL. Following this, a question on perceptions of relationships at work was asked. The next set of questions was related to how participants critically evaluated their job, in terms of benefits, challenges and coping mechanisms. The final question was relevant to how participants viewed the future of their job. Table 13 summarises the areas of exploration in the interview schedule of the second study.

Table 13  
*Interview schedule of the second study - areas of exploration*

Area of exploration	Question number
Work background	1
Perceptions of work	2, 3
Work and QoL	4
Relational aspects of work	5
Critical evaluation of work	6,7, 8 9,10
The foreseen future of current work	11

It was intended to start the interviews with questions that would make the participants comfortable and give them the space to talk freely about their roles as vocational support providers. The more specific questions came afterwards to make participants feel more confident in talking about their daily lives and their relationships with their SCI clients. The more complex questions, however, came towards the end of the interviews, where the focus was on the critical aspects of doing vocational support. The final set of questions aimed to make participants relaxed and comfortable again, as they were encouraged to talk about their ambitions and future plans.

As with the first study, the researcher did not strictly follow the interview schedule, but rather used it as a guide. Participants spoke easily and there were hardly any extended moments of silence.

## **2) Interview settings**

In the second study, four participants were interviewed by the researcher at their workplace, while one participant was interviewed at a designated meeting room at the campus of Birkbeck, University of London. All participants chose the venue, date and time of their interviews. All interviews were audio-recorded. The researcher conducted all five interviews during the period between July and September 2017. Each interview was arranged and conducted at the time that the researcher received the signed informed consent of the participant.

## **3) Pen portraits of participants**

Below are brief pen portraits of the five participants in the second study:

**Liam-** was a very friendly man who was generous with his talking. Although he did not work full-time as an SCI mentor, he was very passionate about his role and was motivated by the idea that people living with SCI should not be marginalised in their societies.

It was interesting for the researcher to hear Liam talking about his role as a mentor as it inspired good memories of her own work experience at rehabilitation, where she had a colleague who had a very similar role to Liam's and with whom she used to do collaborative work.

**James-** was very enthusiastic about participating in the study, because he had a passion for helping improve vocational services for people living with SCI. He was articulate and wanted to help the researcher learn more about his work experience. He was also keen to put the researcher in contact with his colleagues so that they could also take part in the study.

**Derek-** like James, Derek was interested in the topic of the study and wanted to contribute to improving SCI vocational services. He seemed passionate about running the RTW programme at his workplace, which he talked about with a lot of pride.

The researcher met Derek in his office; he was welcoming and introduced her to many of his colleagues.

Throughout the interview, Derek spoke more on behalf of his organisation and less from his own personal perspective. On many occasions, he referred to himself as “we”, suggesting that the work he did represented his workplace more than himself as an SCI vocational support provider.

**Vicky-** as Vicky was the only female participant in the study, the researcher paid close attention to any differences in her experiences compared to the male participants.

Vicky gave the impression that she dealt very professionally with her SCI clients, and did not want to sound as though she was doing them any favour by supporting them. However, she was very passionate about her job, referring to it as her dream job.

**Adam-** was a young man who spoke about his passion for the manual job he used to do before his injury as well as his diverse work experience after acquiring SCI.

During the interview, Adam sounded hopeful and ambitious, but he could see a lot of challenges around helping people who are living with SCI. He was sympathetic towards people with SCI and motivated to do more and more work with them. He thought that the topic of this research was unique and was enthusiastic to hear about its outcomes.

### **Support and debrief**

Before conducting the interviews in the second study, the researcher and her academic supervisor checked that psychological support was available for participants through their workplaces in case they needed it following their interviews. All participants confirmed that psychological support was offered to them, on demand, by their employers.

Although unlikely, the researcher had a plan on how to manage situations where participants became distressed during the interviews as well as a lone worker policy to ensure her own safety at interview sites. All interviews in this study went smoothly, with no issues during or following the researcher's meetings with the participants.

At the end of each interview, in light of Willig's (2013) suggestion, the researcher debriefed the participants by reminding them about the purpose of the study and ensuring them that they could have access to the results of the study when they become available.

### **Data analysis**

This section will explain the process of the analysis of the data collected for the second study.

#### **1) Individual-case analysis**

The IPA analysis for individual cases in this study followed the same steps outlined in the method section for the first study.

An example of a completed table of *superordinate themes* from the individual case analysis of participant Adam is illustrated in Table 14 below.

Table 14

An example of a table of superordinate themes for an individual case (Adam) – Study 2

<u>Themes</u>	<u>Keywords</u>	<u>Page number</u>
<p><b>1. From sowing the seeds to harvesting: the pleasant journey with SCI clients towards Employment</b></p> <p><b>a. The ability to engage with SCI clients since an early stage of their rehabilitation</b></p> <ul style="list-style-type: none"> <li>▪ <b>The ability to quickly screen for those who might benefit from the vocational support</b></li> <li>▪ <b>Implementing an early intervention through peer support for SCI clients</b></li> <li>▪ <b>The pride associated with the opportunity to sow the seeds for RTW with SCI clients</b></li> <li>▪ <b>The pride associated with being able to contribute to raising SCI clients' education about RTW in the time when they mostly need it</b></li> </ul> <p><b>b. The opportunity to give advice and signpost SCI clients to valuable work resources as part of doing vocational support</b></p> <ul style="list-style-type: none"> <li>▪ <b>Peer support is viewed as a mixture of theoretical guidance and practical examples</b></li> <li>▪ <b>Guidance is part of the vocational support services provided to SCI clients</b></li> <li>▪ <b>A structured vocational support programme in terms of frequency, duration and capacity</b></li> </ul> <p><b>c. The confidence associated with the ability to establish rapport with SCI clients</b></p> <ul style="list-style-type: none"> <li>▪ <b>Perceiving self as affable when it comes to dealing with SCI clients</b></li> </ul>	<p><i>When I initially meet people, if they are waiting in a district general hospital, if it seems to be an appropriate topic to talk about, I will talk about it</i></p> <p><i>So I go and support them whilst they are waiting</i></p> <p><i>Just having the opportunity so sow seeds there is fantastic</i></p> <p><i>Part of my role as well is to deliver a vocation and rehabilitation talk at the spinal units</i></p> <p><i>A lot of what we do is guidance, advice and sharing our personal experiences</i></p> <p><i>We guide them towards the Access to Work Scheme</i></p> <p><i>It [RTW course] runs on a bi-monthly basis at (UK hospital name omitted), and we get about five or six people during a day. They spend around 45 minutes with us, so they are sources in that manner</i></p> <p><i>I like to think that I can get on with pretty much anybody</i></p>	<p>4</p> <p>2</p> <p>17</p> <p>27</p> <p>3</p> <p>14</p> <p>4</p> <p>25</p>

<p><b>d. The beauty of working collaboratively with colleagues</b></p> <ul style="list-style-type: none"> <li>▪ <b><i>Cherishing the collaborative work with other disciplines in the vocational support programme</i></b></li> </ul> <p><b>e. The sense of success when harvesting efforts of vocational support</b></p> <ul style="list-style-type: none"> <li>▪ <b><i>The sense of self-fulfilment stemming from making a difference in a client's life after SCI</i></b></li> </ul>	<p><i>It is a really broad picture that we are able to paint for those people</i></p> <p><i>So him coming along to the vocation clinic and writing himself off completely from doing any work in the future has now led to him actually being on board with (charity organisation name omitted) [...]. That was really rewarding</i></p>	<p>5</p> <p>26</p>
<p><b>2. The meaning of peer support is viewed as a constant reference to the personal experience</b></p> <p><b>a. Believing in the need for mutuality between self and SCI clients when providing support</b></p> <ul style="list-style-type: none"> <li>▪ <b><i>Believing in the importance of mutuality</i></b></li> </ul> <p><b>b. Vocational support is empowered by personal experience</b></p> <ul style="list-style-type: none"> <li>▪ <b><i>Believing in the value of peer support for SCI clients stems from personally benefiting from it</i></b></li> <li>▪ <b><i>Generously guiding SCI clients to employment resources that were personally tried</i></b></li> </ul> <p><b>c. Perceiving previous work experience as empowering current work of peer support</b></p> <ul style="list-style-type: none"> <li>▪ <b><i>The previous background of volunteering work with the disabled people reinforced the peer support role</i></b></li> <li>▪ <b><i>Many of the skills gained through previous jobs were transferrable to the job of peer support</i></b></li> </ul> <p><b>d. Perceiving peer support as a job with a double-edge sword in reference to the self</b></p>	<p><i>Obviously personal experiences do not fit for everybody</i></p> <p><i>To be able to talk to spinal cord injured people, that had been injured for a quite a length of time, that had returned back to work, was so important for me [...]. It did show me that it was possible</i></p> <p><i>So I know how beneficial that is</i></p> <p><i>From my years of sports, I did a lot of volunteering in those years [...] and when this role became available, it kind of fitted in to that, because I had already been doing that type of work</i></p> <p><i>I thought well I could put a lot of the skills that I have already got into practice in this role</i></p>	<p>3</p> <p>6</p> <p>14</p> <p>7</p> <p>9</p>

<ul style="list-style-type: none"> <li>▪ <i>Perceiving peer support as a job with a double-edge sword</i></li> </ul>	<p><i>It is very satisfying in some aspects, but it can be challenging in other ways</i></p>	<p>10</p>
<p><b>3. Looking at each SCI client through his/her own lenses</b></p> <p><b>a. Customising peer support to each SCI client's case</b></p> <ul style="list-style-type: none"> <li>▪ <i>Vocational support is individualised</i></li> <li>▪ <i>Empathy with SCI clients' cases where unemployment effects not only the SCI client but his or her significant ones as well</i></li> <li>▪ <i>Considering a holistic approach to the SCI clients' lives when providing peer support</i></li> </ul> <p><b>c. Advocating on behalf of SCI clients as a way of seeing work through their eyes</b></p> <ul style="list-style-type: none"> <li>▪ <i>Believing in the importance of vocational peer support to advocate on behalf of SCI clients to RTW</i></li> </ul> <p><b>d. Understanding the deep need of SCI clients for vocational support</b></p> <ul style="list-style-type: none"> <li>▪ <i>Deep sense of empathy with clients with regards to deciding on a career path after SCI</i></li> </ul> <p><b>e. Acknowledging SCI clients' role in the vocational support programme</b></p> <ul style="list-style-type: none"> <li>▪ <i>Believing that the sense of agency in clients will eventually shape the vocational options after SCI</i></li> <li>▪ <i>Educating SCI clients about their shared role in the vocational programme right from the beginning to avoid frustrations</i></li> </ul>	<p><i>One to one basis</i></p> <p><i>If it is a family, if it is the main earner of the house, the breadwinner, so to speak, they can be quite difficult to work ... well, not difficult to work with, but emotional to work with</i></p> <p><i>My aim is to support spinal cord injured people, their friends, families and healthcare professionals that work for them</i></p> <p><i>It would be great if we were able to go in and speak to employers of newly disabled people, of newly spinal cord injured people, and let them know about what is possible and what is impossible</i></p> <p><i>And I know that from personal experience, because when I finally realised that I could not go back to the job that I had, I really struggled to think which way am I going to go now? It is going to come down to that person at the end of the day, for them to decide what it is that they want to do</i></p> <p><i>We will give them the guidance, the pointers and the action plans, but it is down to that person to then follow through</i></p> <p><i>That is going to be down to them to do the research</i></p>	<p>3</p> <p>18</p> <p>2</p> <p>30</p> <p>13</p> <p>13</p> <p>16</p>



<p><b>f. Believing in the importance of being sympathetic with SCI clients</b></p> <ul style="list-style-type: none"> <li>▪ <b>Sometimes sympathy is inevitable</b></li> </ul>	<p><i>There is certain things about this job that, as much as you try to put on a brave face, it is in the back of your mind that this person is going through that right now</i></p>	<p>19</p>
<p><b>4. Blaming government and community services for not providing proper vocational support to SCI people</b></p> <p><b>a. Viewing the lack of government and community resources as social challenges to SCI RTW</b></p> <ul style="list-style-type: none"> <li>▪ <b>Caseload and geographical demands limit the ability to follow up with each case individually</b></li> <li>▪ <b>The difficulty to access government resources can hinder RTW after SCI</b></li> </ul> <p><b>b. Viewing the government and community systems as hindering motivation of SCI people to RTW</b></p> <ul style="list-style-type: none"> <li>▪ <b>Blaming the government system for putting people off work due to easy access to social benefits</b></li> </ul> <p><b>c. Government and community support systems as struggling to raise awareness about equality in SCI RTW</b></p> <ul style="list-style-type: none"> <li>▪ <b>Blaming the government for not practically implementing the system that supports disabled people to disclose their disability to their employers</b></li> <li>▪ <b>Advocating on behalf of SCI clients to clear misconceptions of their employers cannot be an individualised service due to caseload</b></li> </ul>	<p><i>The area that I cover is huge [...]. So it is the time really</i></p> <p><i>It can be a difficult process to go through to get certain parts of equipment to help</i></p> <p><i>It always seems to revert back to being a relatively easy life to be on benefits</i></p> <p><i>The Access to Work Scheme apparently has a service where somebody can go to either an existing employer or a new employer and speak about disability [...], but I have never seen it being put into action, I have never witnessed it</i></p> <p><i>For us to physically be able to do that for each person, in a role that they wanted to get into, would be impossible for us to do</i></p>	<p>15</p> <p>12</p> <p>29</p> <p>31</p> <p>30</p>

<p><b>5. Demonstrating the ability to manage emotional challenges at work</b></p> <p><i>a. Providing peer support with moderate sympathy</i></p> <ul style="list-style-type: none"> <li>▪ <i>Work experience has helped manage a moderate sympathy</i></li> </ul> <p><i>b. Resilience is about emotional stability when working with difficult cases</i></p> <ul style="list-style-type: none"> <li>▪ <i>Resilience is perceived as a factor that helps avoid SCI clients' cases to trigger personal memories as a peer</i></li> </ul> <p><i>c. Self-reconciliation about the limited ability to provide certain services to SCI clients</i></p> <ul style="list-style-type: none"> <li>▪ <i>Accepting and recognising the limited capacity as a peer supporter in helping SCI clients achieve their goals</i></li> </ul> <p><i>d. The self-awareness to seek psychological support when needed</i></p> <ul style="list-style-type: none"> <li>▪ <i>Using routes other than the one offered by the workplace to get psychological support when needed</i></li> </ul>	<p><i>In the past unfortunately. I have had several cases that have been very, very difficult and hard to switch off from. But again, because I have been doing it for so long, I think I have learnt methods in being able to deal with it</i></p> <p><i>It brings back the memories that I have and the thoughts and feelings that I had. But because I have been doing this so long, I can kind of switch that side of it off, my personal side of it</i></p> <p><i>We are limited in what we can offer. We are not magicians, we cannot make things right again</i></p> <p><i>But I do have an ongoing service that is similar, that I have sought myself, to help in some ways</i></p>	<p>20</p> <p>18</p> <p>10</p> <p>21</p>
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## 2) Cross-case analysis

The next step, that of conducting the IPA cross-case analysis for this study, also followed the same steps outlined in the method section for the first study. However, it is important to note that recurrence of *master group themes* was calculated differently in this study due to the difference in the total number of participants. Thus, in this study, for a *master group theme* to be included, it had to be relevant for at least four out of the total five participants.

The final version of the table of *master group themes* was developed to capture the core of the five participants' experiences in providing vocational support to individuals living with SCI. As will be seen in Table 15 below, four *master group themes* were identified within the data, namely **(1)** Dynamic and reciprocal relationships at work; **(2)** The essence: what vocational support services, where, how and why they are delivered; **(3)** Looking through the lens of SCI clients when providing them with vocational support; the approach of individuality; and **(4)** Looking after oneself as a determinant of perceiving and approaching difficult cases at work.

Table 15

Table of *master group themes* – Study 2

Themes	Participant, individual superordinate theme, <i>corresponding extracts</i>	Page
1. Dynamic and reciprocal relationships with clients at work	-	-
1.a. <i>Mutuality between vocational supporters and SCI clients</i>	<p><b>Liam:</b> Mutuality between mentors and clients structures the support programme <i>“What they try and do is match people with similar injuries to each other, so that the person with the injury can meet someone in very similar circumstances in terms of movement”</i>.</p> <p><b>Adam:</b> The meaning of peer support is viewed as a constant reference to the personal experience <i>“When it comes to sharing personal experiences, everybody's different [...] and with the vast range of levels of injuries and abilities, and ages, obviously personal experiences do not fit for everybody”</i>.</p> <p><b>Derek:</b> The value of mutuality between clients and vocational support providers <i>“People who are on the receiving end are seeing someone who has a similar level of injury, has a similar background and similar story, it is tremendously powerful”</i>.</p> <p><b>Vicky:</b> Peer support does not mean the mutuality between peer supporter and SCI clients <i>“There is no barrier to anybody that can access the service. Different levels of injury, males, females, young, old, it does not really matter”</i>.</p>	<p>2</p> <p>3</p> <p>33</p> <p>11</p>
1.b. <i>Rapport with SCI clients</i>	<p><b>Adam:</b> The confidence associated with the ability to establish rapport with SCI clients <i>“I like to think that I can get on with pretty much anybody, no matter what background they are from, no matter what age. I like to think that I can get on with anybody, which is really vital in this type of work”</i>.</p> <p><b>Derek:</b> The perceived power of peer support in establishing rapport with SCI clients <i>“Definitely a lot of people that we have mentored have come on the course [RTW course] after being mentored”</i>.</p> <p><b>Vicky:</b> The challenges to closely working with individual cases <i>“It is pressures on time more than anything else that restricts the building of relationships”</i>.</p>	<p>25</p> <p>30</p> <p>12</p>

<p><b>1.c. The value of reciprocation</b></p>	<p>-</p>	<p>-</p>
<p><b>Reciprocating support to the workplace</b></p>	<p><b>Liam:</b> Working as a mentor has a personal meaning of reciprocation <i>“It was more like a kind of 'did something and wanted to give something back”.</i></p> <p><b>James:</b> The personal meaning of providing work as a peer supporter is viewed in light of it being reciprocation <i>“I like the fact that I am giving something back”.</i></p>	<p>4</p> <p>17</p>
<p><b>Receiving reciprocation from SCI clients</b></p>	<p><b>Liam:</b> Being a mentor as a sign of self-satisfaction <i>“Getting a card from him, to say 'your visit helped me and encouraged me to go back to doing things', that really was payment enough for me”.</i></p> <p><b>Adam:</b> The sense of success when harvesting efforts of vocational support <i>“So him coming along to the vocation clinic and writing himself off completely from doing any work in the future has now led to him actually being on board with (charity organisation name omitted) [...]. That was really rewarding”.</i></p> <p><b>Derek:</b> The concept of giving and taking back <i>“He is really blossomed in terms of his confidence [...]. That is really core to everything that (workplace name omitted) does”.</i></p> <p><b>Derek:</b> Feedback of work as a missing link in the well-rounded support provided <i>“It is not something we have a great picture of at the moment, because we do not have enough time to call everyone”.</i></p> <p><b>James:</b> The psychological reward <i>“I also found it tremendously rewarding. You know, when you feel like you are helping somebody with not just dealing with their spinal cord injury, but also thinking about what their future can look like, showing them there is a future, that is exceedingly satisfying”.</i></p>	<p>12</p> <p>26</p> <p>34</p> <p>9</p> <p>6</p>
<p><b>1.d. Continuity of vocational support to SCI clients</b></p>	<p><b>James:</b> The strive to continue doing vocational support <i>“The way my role has changed is I am not going out and meeting people for the first time and visiting spinal centres and so on. But I have been doing the job for three years, supported a lot of people through that time and they all have my email and phone number and so it is inevitable that people will continue to come back to me [...]. So I am expecting that I will still be doing bits of vocational support”.</i></p> <p><b>Liam:</b> Supporting the organisation is a sign of supporting the cause of continuity of providing services to SCI clients <i>“I would like to make sure the project is still there, being run and funded. And I could do that possibly from a higher level if I get the chance”.</i></p> <p><b>Derek:</b> The motivated spirit to continue providing vocational support to SCI clients <i>“I think it is definitely part of (workplace name omitted)’s long term strategy [...]. The feedback at the moment is that the course is still useful, in terms of how we manage to build up those placements for people to do work experience and things like that. It's a huge growth area there”.</i></p>	<p>19, 20</p> <p>26</p> <p>28</p>

2. The essence: what vocational support services, where, how and why they are delivered	-	-
2.a. What? The scope of vocational support services	-	-
Guidance and advice	<p><b>Adam:</b> The opportunity to give advice and signpost SCI clients to valuable work resources as part of doing vocational support <i>“A lot of what we do is guidance, advice and sharing our personal experiences”</i>.</p> <p><b>Liam:</b> It is more about advice and guidance rather than practical support <i>“What you can do is obviously give advice about what equipment and things like that might be more beneficial to someone, but I think the government organisations are usually more used in those cases”</i>.</p> <p><b>James:</b> Peer support is about providing advice <i>“We want people to come to us, both in a positive sense of when they want help and support and advice, but also at times of crisis, when they want help and support and advice”</i>.</p> <p><b>Derek:</b> Helping SCI clients become promotable for work <i>“We are also doing things on CV writing, cover letter writing, interview technique, marketing yourself, and generally trying to help people identify a way forward to returning to the workplace”</i>.</p>	3 14 21 3
Signposting	<p><b>Liam:</b> Mentors play the partial role of signposting <i>“A lot of what we do anyway as mentors is signposting, so we signpost people into the right areas that could be useful for them”</i>.</p> <p><b>Vicky:</b> Vocational support is perceived as boosting SCI employment <i>“So it is looking into that and saying, right there is something called ‘Access to Work’, that they could look into, that can help and support them to do that job”</i>.</p> <p><b>Derek:</b> Promoting job placement services to SCI clients through signposting <i>“There is also, as I mentioned before, helping people to find work experience placements”</i>.</p>	15 14 14
Education	<p><b>Derek:</b> Promoting for a better image of the SCI population <i>“It does feel like it is tough work [...]. We are having to change quite a lot of perceptions out there”</i>.</p> <p><b>Vicky:</b> Vocational support is perceived as promoting a good social stance for SCI <i>“If I can educate other people and help other people, with a spinal cord injury, then my job is done [...] the more people that do go back to work, in whatever capacity, then obviously, it is a better sign for the community as a whole”</i>.</p> <p><b>Vicky:</b> Part of the role of being a peer supporter is to carry out interventions for raising awareness about SCI <i>“I also do some training with staff, again in a community setting, general hospitals and spinal units,</i></p>	26 29,18 2

	<p><b>talking about the charity, talking about spinal cord injury and just spreading awareness”.</b></p> <p><b>Liam:</b> Future plans of going up the ladder from being a mentor to being an advocate for the cause of SCI equality and empowerment <b>“I am hoping to get more involved as I get older [...] more pushing towards that side of making sure that the voice of disabled people in society is not marginalised”.</b></p> <p><b>Adam:</b> Blaming government and community services for not providing proper vocational support to SCI people <b>“The Access to Work Scheme, I know we have talked about this a few times now, but the ‘Access to Work Scheme’ apparently has a service where somebody can go to either an existing employer or a new employer and speak about disability, with the employer and the colleagues. And I think that is brilliant, but I have never seen it being put into action, I have never witnessed it, I do not know what they talk about. Something like that would be very, very valuable, because a lot of people just perceive a disabled person as having mental deficiencies as well. And that is often very not the case with a spinal cord injured person, and it is getting that across to people. But how we do that, to the general workforce, I don’t know. It is a challenge is that”.</b></p>	<p>17</p> <p>31</p>
Advocacy	<p><b>Liam:</b> Advocacy on behalf of SCI clients is still the responsibility of the vocational supporter <b>“You can talk to employees and employers, and talk to ... let them know more about what it is and what someone might need”.</b></p> <p><b>Vicky:</b> Advocating on behalf of SCI clients as individual cases <b>“There was this one particular lady, who works [...], but she could not get the train or tubes to get to work, so we looked at that, we talked to her bosses about how she could get back to work [...] and yes she is now back at work, five days a week”.</b></p> <p><b>Adam:</b> Advocating on behalf of SCI clients as a way of seeing work through their eyes <b>“It would be great if we were able to go in and speak to employers of newly disabled people, of newly spinal cord injured people, and let them know about what is possible and what is impossible”.</b></p>	<p>13</p> <p>24</p> <p>30</p>
<b>2.b. Where? The settings of vocational support services</b>	-	-
Clients attending training courses	<p><b>Derek:</b> Courses to promote RTW <b>“(Workplace name omitted) currently runs three courses a year [...]. So they are basically two-day course”.</b></p> <p><b>Adam:</b> Guidance is part of the vocational support services provided to SCI clients <b>“It [RTW course] runs on a bi-monthly basis at (UK hospital name omitted), and we get about five or six people during a day. They spend around 45 minutes with us, so they are sources in that manner”.</b></p>	<p>2</p> <p>4</p>

<p>Vocational supporters carrying out outreach visits</p>	<p><b>James:</b> Outreach and workload as physical challenges to doing vocational support <i>“I was doing lots of travelling and so I was driving quite long distances, to go and see people”.</i></p> <p><b>Vicky:</b> Doing outreach peer support is physically demanding <i>“I would tell you physically, this job is harder than my previous job, because I am travelling a lot, I am in the car a lot, so I am doing a lot more transfers than I perhaps normally would do”.</i></p>	<p>12</p> <p>4</p>
<p>2.c. How? The mechanisms of delivering vocational support services</p>	<p>-</p>	<p>-</p>
<p>Early intervention</p>	<p><b>Adam:</b> The ability to quickly screen for those who might benefit from the vocational support <i>“When I initially meet people, if they are waiting in a district general hospital, if it seems to be an appropriate topic to talk about, I will talk about it there [...] if [...] I can tell from the things that they are saying that they might benefit from coming in, I might promote it to them then”.</i></p> <p><b>James:</b> Putting the personal meaning of peer support into action by proving an early intervention <i>“The idea was to go in and to spend time with somebody who was newly injured, but had expressed an interest in having a meeting, usually through the occupational therapy department or through their own OT”.</i></p> <p><b>Derek:</b> Promoting the early vocational intervention <i>“We know if people are not thinking about work within 6 weeks after their injury, then their chances of returning to work basically get lower all the time as time continues. So that is something that (workplace name omitted) is very passionate about changing as well [...]. If the seed is not planted early on, then it gets harder and harder to change that perception”.</i></p> <p><b>Adam:</b> The pride associated with the opportunity to sow the seeds for RTW with SCI clients <i>“Just having the opportunity to sow seeds there is fantastic as well. So that again is a really positive side of the work that we do”.</i></p>	<p>4</p> <p>3</p> <p>10, 11</p> <p>17</p>
<p>Role modelling</p>	<p><b>Vicky:</b> Perceiving self as a role model <i>“I have been injured for 11 years, and it is talking about life experiences and getting people to see that life will get back on track for them, and just finding out what is out there for them to enable them to do that”.</i></p> <p><b>James:</b> Putting the personal meaning of peer support into action means being a role model <i>“When I go to a spinal centre, I am representing [...] a positive image of somebody who has had a spinal cord injury and got their life back on track again [...]. Because [...] I am independent [...] that does mean I can change people’s perceptions of what they can do and that is very powerful”.</i></p> <p><b>Liam:</b> Being a role model helps SCI clients achieve resilience <i>“Someone else has done it, and you can just talk them through it and how you managed it”.</i></p>	<p>2</p> <p>17, 18</p> <p>7</p>



	<p><b>Derek:</b> The perceived reflection of own experience on providing vocational support to SCI clients <i>“When I was first injured myself, I had to move out of the flat that I was living in and I had to give up the job that I was doing, [...] and my way out, of moving out of my parents' house, was to get a job and get myself somewhere to live, so that was one of the drivers for me, and I feel really passionate that it is a positive thing for people to be doing”.</i></p> <p><b>Adam:</b> Vocational support is empowered by personal experience <i>“What you do on that is bring your education background, your skills, your interests, hobbies, and then it generates work ideas for you. And that is something again that I used myself [...], So I know how beneficial that is”.</i></p>	10 14
<b>2.d. Why? The ultimate goal of providing vocational support services</b>	-	-
<b>Re-building confidence</b>	<p><b>Vicky:</b> Vocational support as a psychological booster <i>“As part of this charity I do, I can certainly make people individually feel more worthwhile than they do [...] so it is boosting their confidence”.</i></p> <p><b>Derek:</b> Part of vocational services is to help SCI clients retrieve their abilities <i>“That includes helping people build up their general confidence through courses, mentoring, wheelchair skills and outreach support services”.</i></p>	19 2
<b>Re-normalising life</b>	<p><b>Liam:</b> Mentoring as a valuable source of motivation to SCI clients <i>“You offer them a certain amount of sessions to talk to them, and within that session you try and help them rebuild their lives following their injuries”.</i></p> <p><b>Vicky:</b> Vocational support is perceived as a way of re-normalising life after SCI <i>“You are talking about helping people, giving them opportunities to go back and get on with their live”.</i></p> <p><b>Adam:</b> Considering the SCI client individually and his/her significant ones <i>“My aim is to support spinal cord injured people, their friends, families and healthcare professionals that work for them”.</i></p>	3 6 2
<b>3. Looking through the lens of SCI clients when providing them with vocational support; the approach of individuality</b>	-	-
<b>3.a. Providing bespoke vocational support to SCI clients</b>	<p><b>Vicky:</b> Customising the support provided as a sign of believing in individuality <i>“It is people specific, and how we manage it, depends on their scenario, their injury, and yes, their situation [...]. I would not have a ‘one cap fits all’ approach to everybody that I see; it really is an individual basis, on whatever we are going to talk about”.</i></p> <p><b>Liam:</b> Mutuality helps provide customised support to SCI clients <i>“It is peer to peer”.</i></p>	16, 23 2

	<p><b>Adam:</b> Customising peer support to each SCI client's case <i>"A big part of my time as well goes into vocational services as well [...] where people come along on a one to one basis and talk about what they want to do for the future"</i>.</p> <p><b>Derek:</b> Demonstrating awareness about the uniqueness of each client's characters and needs <i>"A big chunk who return to jobs that they were doing before, [...]. There is also a group who were maybe unemployed beforehand [...] then there is the people on the fence I guess, who are less sure about what they are going to do"</i>.</p>	<p>3</p> <p>7</p>
<p><b>3.b. Engaging SCI clients in the vocational programme by acknowledging their role in achieving their own goals of RTW</b></p>	<p><b>Adam:</b> Acknowledging SCI clients' role in the vocational support programme <i>"That it is going to be down to them to do the research. We will give them the guidance, the pointers and the action plans, but it is down to that person to then follow through"</i>.</p> <p><b>Vicky:</b> Promoting clients' acceptance of their role in the vocational programme <i>"Getting them to come to their own conclusions, rather than you suggesting [...]. I think that is really important for them to think, that they have got to do that bit themselves, just with a little bit of guidance"</i>.</p> <p><b>Derek:</b> Achieving RTW is a mutual responsibility between vocational supporters and SCI clients <i>"We are not giving people jobs [...], we are just working with them to help them achieve what they want to achieve"</i>.</p> <p><b>Liam:</b> Responsibility of clients to take advantage of mentoring services <i>"You offer them a certain amount of sessions [...] in a way that is led by them really. So they take the lead"</i>.</p> <p><b>James:</b> Delegating some responsibility to clients where they are given the key to explore employment resources further <i>"Giving people direction, but not necessarily giving them all the answers"</i>.</p>	<p>16</p> <p>17</p> <p>27</p> <p>3</p> <p>7</p>
<p><b>3.c. Empathy as a clear sign of implementing individuality at work</b></p>	<p><b>James:</b> The ability to understand clients' feelings and needs as a sign of self-efficacy <i>"And his mum was with him when I saw him and I think it was probably the reaction of his mum, you know, as a parent, and I am a parent as well, where you could see that she was just about holding it all together, for her son, but I should imagine that every time she left the ward, she was in bits"</i>.</p> <p><b>Adam:</b> Understanding the deep need of SCI clients' for vocational support <i>"And I know that from personal experience, because when I finally realised that I could not go back to the job that I had, I really struggled to think which way am I going to go now? [...]. So then I was lost in the system myself. And I can see that going on in people's minds when I am talking about which ways to go. So that is quite difficult"</i>.</p> <p><b>James:</b> Being empathetic as a peer supporter is a plus <i>"People get a spinal cord injury in such simple, silly, ridiculous ways. And I think it is good to be mindful of that"</i>.</p> <p><b>Adam:</b> Looking at each SCI client through his/her own lenses <i>"If it is a family, if it is the main earner of the house, the breadwinner, so to speak, they can be quite difficult to work ... well, not difficult to work with, but"</i></p>	<p>8</p> <p>13</p> <p>9</p> <p>18</p>

	<p><i>emotional to work with, because if you are thinking about their circumstances as a whole, if they are earning money to feed a family, pay the rent and things like that, then that is obviously quite a challenge as well”.</i></p> <p><b>Derek:</b> Demonstrating empathy towards SCI clients’ challenges <i>“People are scared of that change, or of their lives being ... having to make a big change in their life or ... it is scary for people”.</i></p>	17
<p><b>3.d. Looking through the eyes of SCI clients is to feel for their emotional pain</b></p>	<p><b>Derek:</b> Demonstrating sympathy towards SCI clients’ inability to RTW <i>“I hear of different reasons why that happens [...] that is particularly frustrating I think, and I guess that is where I get a bit emotional”.</i></p> <p><b>Adam:</b> Believing in the importance of being sympathetic with SCI clients <i>“There is certain things about this job that, as much as you try to put on a brave face, it is in the back of your mind that this person is going through that right now [...]. I do feel that having that type of quality is important to this role as well. If you were able to completely switch off from all feelings for people, then I do not think you would be the right sort of person for the role”.</i></p> <p><b>Vicky:</b> Working with individual cases has an emotional meaning <i>“If someone has had their injury through, silly is the wrong word, but, something that really could have been avoided [...]. There is a general frustration about people getting the right care [...] because at the end of the day, these people are humans”.</i></p>	24  19, 20  7, 12

<p><b>4. Looking after oneself as a determinant of perceiving and approaching difficult cases at work</b></p>	-	-
<p><b>4.a. Demonstrating the ability to show balanced sympathy to SCI clients</b></p>	<p><b>Vicky:</b> The ability to accept sympathy with clients but balance it with reality <i>“So it is being sensitive about people’s expectations, but also being realistic [...] it makes me sound really callous does not it?, but I have to not, let it bother me”.</i></p> <p><b>Adam:</b> Providing peer support with moderate sympathy <i>“In the past unfortunately. I have had several cases that have been very, very difficult and hard to switch off from. But again, because I have been doing it for so long, I think I have learnt methods in being able to deal with it”.</i></p> <p><b>Liam:</b> Perceived self-resilience as a mentor <i>“I think if you are a caring and empathetic person anyway, which I sort of am, it is hard to separate the two anyway [...] But you have to be able to switch off as well at times [...]. I think I have developed quite good coping mechanisms for being able to get away from”.</i></p>	15, 8  20  24

<p><b>4.b. Demonstrating the ability to manage negative emotions stemming from working with difficult cases at work</b></p>	<p><b>Adam:</b> Resilience is about emotional stability when working with difficult cases <i>“It brings back the memories that I have and the thoughts and feelings that I had. But because I have been doing this so long, I can kind of switch that side of it off, my personal side of it”</i>.</p> <p><b>James:</b> The ability to overcome emotional challenges stemming from work as a sign of self-efficacy <i>“I used to think about my car as my little decompression chamber [...]. I do not feel like I bottle things up, because I am always happy to talk about them”</i>.</p> <p><b>Vicky:</b> The ability to accept work issues and move on <i>“I have been injured for 11 years, so I am over my story, if that makes sense, so no, I cannot think of anything that would be comparable [...]. Once I am not at work, it does not mean to say I do not think about it, but I cannot let it overtake the world”</i>.</p>	<p>18</p> <p>6</p> <p>10</p>
<p><b>4.c. Demonstrating the ability to reconcile with self for being limited in what to offer as a vocational supporter</b></p>	<p><b>James:</b> The ability to understand responsibilities as a vocational and peer supporter as a sign of self-efficacy <i>“I think the difficulty would have been if I thought that my job was about fixing them or doing it all for them”</i>.</p> <p><b>Adam:</b> Self-reconciliation about the limited ability to provide certain services to SCI clients <i>“We are limited in what we can offer. We are not magicians, we cannot make things right again”</i>.</p> <p><b>Vicky:</b> Accepting barriers to achieving supportive goals with clients <i>“Well, but that is a frustration and I am not going to change the world unfortunately, it is all about who is got the money and who is going to pay for it. So that is a frustration, but it is one that is a reality unfortunately”</i>.</p> <p><b>Liam:</b> Self-satisfaction as a sign of resilience <i>“We are limited to what we can do for people [...] ethically you cannot really do that, but you know that is what ... in your heart you want to do stuff for people and help people more [...]. You need to, yeah, I think it is important [to maintain a professional relationship with clients]”</i>.</p>	<p>10</p> <p>10</p> <p>13</p> <p>23</p>

## **Write up**

The write up of the results in this study followed the same style as the first study. It included further interpretations of the participants' accounts of the four *master group themes*, which were accumulated from the different stages of the analysis. This study also presented the final draft of the results in a narrative format guided by *master group themes* and *group themes*; as in the first study, the sub-headings were not added to the write up. Finally, the sequence of the *master group themes* was presented in a 'case within theme' style.

## Chapter 9: Findings

### An overview of the master group themes

The researcher decided to include all four *master group themes* that emerged from the cross-case analysis of the five cases in the second study. Figure 12 highlights those *master group themes* and their *group themes*.

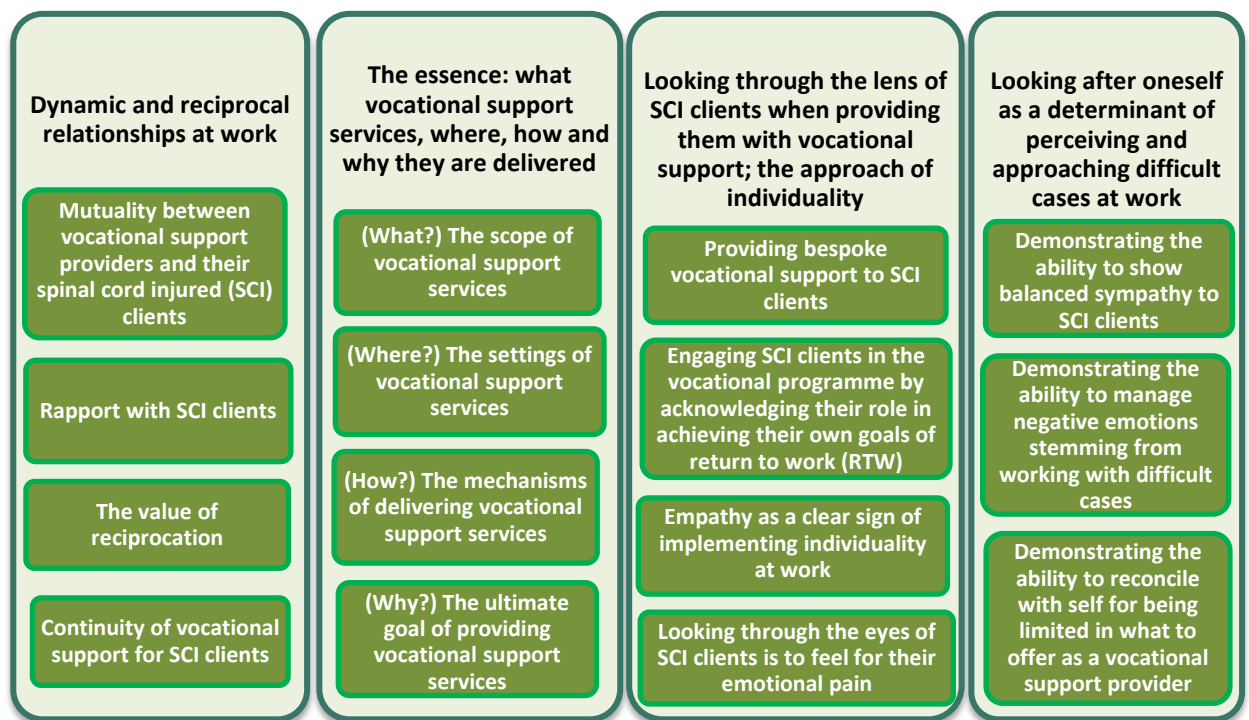


Figure 12. Overview of themes in the second study

### Findings

#### **Master group theme 1: Dynamic and reciprocal relationships at work**

All participants in this study (Liam, James, Derek, Vicky and Adam) talked about different relational aspects at work. The experience of being vocational support providers as well as

providing different types of support to SCI clients influenced the relationships with those clients. In this *master group theme*, those relationships were mainly positive, with participants describing them as dynamic and sometimes reciprocal.

This *master group theme* (**Dynamic and reciprocal relationships at work**) split into four themes: **(A)** Mutuality between vocational support providers and their SCI clients, **(B)** Rapport with SCI clients, **(C)** The value of reciprocation and **(D)** Continuity of vocational support for SCI clients.

### **A) Mutuality between vocational support providers and their SCI clients**

All participants in this study worked within charity organisations that provide support exclusively to clients with SCI. As all participants were living with SCI themselves, their primary role was to provide peer support, with vocational support incorporated into their roles. This concept of mutuality between participants and their clients always came to the surface during the interviews.

Liam talked about how mutuality worked as an essential element at the beginning of the support service:

*What they try and do is match people with similar injuries to each other, so that the person with the injury can meet someone in very similar circumstances in terms of movement. (p. 2)*

For Liam, the first thing to look at when being matched with SCI clients was that they had a similar level of injury to him. This extract suggested that having similar capabilities and limitations to his clients after their injury was a requirement in the support programme.

Derek emphasised the same point, added other elements and described the value of this in boosting services delivered to SCI clients:

*People who are on the receiving end are seeing someone who has a similar level of injury, has a similar background and similar story, it is tremendously powerful. (p. 33)*

Here, Derek believed that not only was similarity in level of injury important when being matched with SCI clients, but also similarity in stories; that is, the wider picture of the injury and its impact on different aspects of life.

Furthermore, the concept of mutuality was important in providing meaningful support and shaping relationships between supporters and SCI clients, where the personal experience of the supporters fed into it:

*When it comes to sharing personal experiences, everybody's different [...] and with the vast range of levels of injuries and abilities and ages, obviously personal experiences do not fit for everybody. (p. 3)*

In the above passage, Adam perceived that it would have been difficult to develop a good relationship with his SCI clients if they were not similar to him in terms of level of injury.

Other participants, like Vicky, perceived mutuality and her relationships with her clients differently:

*There is no barrier to anybody that can access the service. Different levels of injury, males, females, young, old, it does not really matter. (p. 11)*

Vicky thought she could share her personal experience of SCI with any SCI client no matter what level of injury they had, what age or what gender they were.

## **B) Rapport with SCI clients**

Providing support based on the concept of injury mutuality required vocational support providers to establish a sense of rapport with their clients. As the work of vocational support revolved around staying close to SCI clients most of the time and providing activities and talks rather than office or paper work, it was important for participants to be able to form positive relationships with their clients.



Adam said this about his relationship with his clients:

*I like to think that I can get on with pretty much anybody, no matter what background they are from, no matter what age. I like to think that I can get on with anybody, which is really vital in this type of work. (p. 25)*

Here, not only did Adam theoretically believe that rapport was an essential element of providing vocational support, he also referred to himself as being actually able to establish positive relationships with his clients. Note the phrase “*I like to think*”, where Adam felt pleased and satisfied for perceiving himself as affable when it came to dealing with clients.

On the other hand, Derek gave an example of how his positive relationships with SCI clients could result in them being motivated to think about work after their injuries:

*Definitely a lot of people that we have mentored have come on the course [RTW course] after being mentored. (p. 30)*

Here, Derek was referring to a group of SCI clients who received peer support and were motivated to attend vocational training courses afterwards, as can be read from the passage, due to feelings of comfort, trust and enthusiasm.

Hence, we can see from the above that Derek and Adam believed that establishing a good connection with clients was due to internal factors – that is, being approachable and friendly themselves.

In contrast, Vicky believed she was not always able to establish rapport with her SCI clients, and that this was due to external factors:

*It is pressures on time more than anything else that restricts the building of relationships. (p. 12)*

It could be said that Vicky was on the same page with Derek and Adam. She thought that establishing rapport with her SCI clients was valuable and that both herself and her clients were not creating any barriers to this. However, Vicky felt that achieving rapport was

impeded by the time constraints that resulted from the large number of clients with whom she needed to work.

### **C) The value of reciprocation**

Almost all participants described what providing vocational support meant to them by associating it with the notion of reciprocation; vocational support was seen as a dynamic process of giving and receiving. Two-way reciprocation was demonstrated in participants' description of giving something back to the workplace as a sign of appreciation, while also receiving positive feedback from SCI clients about the support provided to them.

Three participants (Liam, James and Derek) had received their own support from the SCI charity organisations before working for them. This meant that when those participants were first injured, the organisations had them as clients and provided them with support. Following this, participants decided to take advantage of job vacancies at those organisations to provide peer support; their decisions were enhanced by the desire to return the favour.

At the time of his interview, Liam had been working as a volunteer peer supporter for nine years at the SCI organisation that once helped him as a client:

*It was more like a kind of 'did something and wanted to give something back'. (p. 4)*

Similarly, James was once an SCI client at a community organisation, and when the researcher interviewed him, he had been employed for three years as a RTW programme manager at that same organisation:

*I like the fact that I am giving something back. (p. 17)*

James's phrase "I like the fact" demonstrated that reciprocation to the workplace did not feel like an obligation or an action that had to be taken to alleviate guilt. Instead, James felt that reciprocating the support and help his workplace had offered him was a source of satisfaction.

At the same time, James was also pleased and satisfied to be appreciated. The way James's SCI clients showed their appreciation for his efforts were perceived by him as follows:

*I also found it tremendously rewarding. You know, when you feel like you are helping somebody with not just dealing with their spinal cord injury, but also thinking about what their future can look like, showing them there is a future, that is exceedingly satisfying. (p. 6)*

For James, providing support for clients meant not only helping them to understand their injuries, but also helping them, in a broader sense, to rebuild their future. The outcome of this effort with clients (whether it was going back to work or being productive in any form) felt reciprocal for James.

Adam emphasised this feeling and gave an example of a client he worked with, where a significant positive change took place:

*So him coming along to the vocation clinic and writing himself off completely from doing any work in the future has now led to him actually being on board with (charity organisation name omitted) [...]. That was really rewarding. (p. 26)*

Adam was proud that he was able to help a client who had been very reserved in his vocational support session to become more engaged. However, because this client eventually went on to help in the SCI charity organisation, Adam was more than proud of his effort as he felt emotionally reciprocated.

#### **D) Continuity of vocational support for SCI clients**

Some vocational support providers (i.e., Liam, James and Derek) expressed their desire to continue doing this job. They showed a commitment to continue serving people with SCI through their organisations.

Liam, for example, talked about his future job plan in this way:

*I would like to make sure the project is still there, being run and funded. And I could do that possibly from a higher level if I get the chance. (p. 26)*

Liam was not only thinking of staying in his current job, but also had ambitions to get promoted to a higher position, where he could have a more effective role in supporting members of the SCI population. His aim to have more power and authority at his work made it clear that he wished to continue to support people living with SCI.

On the other hand, James, who was a vocational support manager at his workplace, had already been promoted to a different position shortly before the researcher interviewed him. However, although his new role still involved serving clients with SCI, he was committed to continue to provide vocational support to his existing clients:

*The way my role has changed is I am not going out and meeting people for the first time and visiting spinal centres and so on. But I have been doing the job for three years, supported a lot of people through that time and they all have my email and phone number and so it is inevitable that people will continue to come back to me [...]. So I am expecting that I will still be doing bits of vocational support. (p. 19 & 20)*

James's passion for providing vocational support was clear in this account, where he chose not to completely withdraw from this previous role. The use of the term "inevitable" suggested that he wanted to leave the door open for going back to the vocational support role anytime by continuing to help his clients in this area when they asked for help.

Finally, whereas James's plan seemed personal and enhanced by his passion for this role, Derek's plan was more collaborative:

*I think it is definitely part of (workplace name omitted)'s long term strategy [...]. The feedback at the moment is that the course is still useful, in terms of how we manage to build up those*

*placements for people to do work experience and things like that.*

*It's a huge growth area there. (p. 28)*

The plan of Derek's workplace to continue developing vocational services for people with SCI showed that this process was dynamic. Although Derek spoke about this as a mission he wanted to undergo, he felt that he was doing it as part of a large group at his workplace, where his input was important.

**Master group theme 2: The essence: what vocational support services, where, how and why they are provided**

In terms of the services provided to SCI clients, all participants described the scope of their work in vocational support in terms of either actions they had taken with their SCI clients or goals they aimed to achieve with them. Participants also described different stages of their work roles, ranging from the time they first met their clients to the time they achieved goals together.

This *master group theme* is considered the core of participants' experience as it will illustrate their accounts of what they actually provided to their SCI clients. This *master group theme* is also considered the core of participants' jobs as it will report on their comprehensive descriptions of the most important tasks they carried out at their work, the forms in which those tasks took place, the methods of delivering them, and finally the perceived purpose of doing them.

This *master group theme* will split into four different themes: **(A)** (What?) The scope of vocational support services, **(B)** (Where?) Settings of vocational support services, **(C)** (How?) Mechanisms of delivering vocational support services and **(D)** (Why?) The ultimate goal of providing vocational support services.

## **A) (What?) The scope of vocational support services**

In this theme, participants described the content of the vocational support sessions they provided for their SCI clients. As this content was diverse, it required participants to take the different roles of being advisors, educators and advocates for their SCI clients.

To start with, Adam described one of the main tasks he carried out as an SCI vocational support provider:

*A lot of what we do is guidance, advice and sharing our personal experiences. (p. 3)*

He described a significant part of his role at the SCI organisation he worked for as advising his clients, where he provided a mixture of theoretical guidance (giving advice) and practical examples (sharing his personal experience of going back to work).

On the other hand, James described some of the work he did with his SCI clients in a slightly different way:

*We want people to come to us, both in a positive sense of when they want help and support and advice, but also at times of crisis, when they want help and support and advice. (p. 21)*

The advice provided during vocational sessions, from James's point of view, was focused on both times of ease and hardship for his SCI clients. He believed that his clients should be supported both when they needed motivation to RTW as well as when they faced barriers to do so.

Being more specific about the content of the advice that vocational support providers gave to their SCI clients, Derek said:

*We are also doing things on CV writing, cover letter writing, interview technique, marketing yourself, and generally trying to help people identify a way forward to returning to the workplace. (p. 3)*

The advice Derek gave his SCI clients helped prepare them for work and becoming competitive again in the job market through writing good CVs and preparing for job interviews.

Furthermore, another service that participants described as part of their work in vocational support was informing SCI clients about different resources in the community that they might find useful on their RTW journey.

For Liam, one of the most significant tasks in his job was to signpost his SCI clients to different useful community resources for work return:

*A lot of what we do anyway as mentors is signposting, so we signpost people into the right areas that could be useful for them.*  
(p. 15)

Vicky echoed Liam then described this in more detail:

*So it is looking into that and saying, right there is something called 'Access to Work', that they could look into, that can help and support them to do that job.* (p. 14)

In the above passage, Vicky gave a specific example of one of the resources that she would signpost her SCI clients to as part of giving advice regarding RTW following SCI.

In a different vein, the task of providing education was highlighted in this theme as a way of helping SCI clients present themselves in a positive way to their communities and show that they were able to work again and so be recognised as active members of those communities. Almost all participants regarded the responsibility of raising awareness about the abilities of people living with SCI to RTW as an essential part of their role as vocational support providers:

*I also do some training with staff, again in a community setting, general hospitals and spinal units, talking about the charity,*

*talking about spinal cord injury and just spreading awareness. (p. 2)*

Here, Vicky talked about the experience she had of targeting different groups to provide education and raise awareness about SCI employment; she provided training to those professionals who worked with SCI people either in the community, in general healthcare or in rehabilitation.

Vicky provided education for her clients as well:

*If I can educate other people and help other people, with a spinal cord injury, then my job is done. (p.29)*

Since providing education to her SCI clients was perceived by Vicky as the most important of her work duties, she experienced it as a task that increased her job satisfaction.

However, Derek viewed this differently:

*It does feel like it is tough work [...]. We are having to change quite a lot of perceptions out there. (p. 26)*

It can be seen here that although Derek was passionate about the work he was doing, he believed that providing education was a heavy duty. Derek believed it was not easy to change SCI people's perceptions about their own capabilities to RTW, nor was it easy to change the community and employers' negative perceptions about SCI people's ability to RTW.

Both Derek and Vicky referred to the task of raising awareness about SCI employability as one that existed in their job description. In contrast, Liam referred to it as a future goal:

*I am hoping to get more involved as I get older [...] more pushing towards that side of making sure that the voice of disabled people in society is not marginalised. (p. 17)*



Similar to his previous account of his desire to continue supporting people living with SCI, Liam saw himself being promoted in the job he was doing and therefore having more authority to provide awareness and education about the need for demonstrating that SCI people are equal to able-bodied people in terms of employment. He hoped that by doing this, his vocational support work with SCI clients would blossom and his clients would be empowered to have a strong standing in their communities.

This was a goal for Adam as well, yet with some existing challenges that he perceived as hindering its implementation:

*'The Access to Work Scheme', I know we have talked about this a few times now, but the 'Access to Work Scheme' apparently has a service where somebody can go to either an existing employer or a new employer and speak about disability, with the employer and the colleagues. And I think that is brilliant, but I have never seen it being put into action, I have never witnessed it, I do not know what they talk about. Something like that would be very, very valuable, because a lot of people just perceive a disabled person as having mental deficiencies as well. And that is often very not the case with a spinal cord injured person, and it is getting that across to people. But how we do that, to the general workforce, I do not know. It is a challenge is that. (p. 31)*

Adam believed it was important that raising awareness and providing education were actually part of vocational support services as this could improve the image of SCI people in the labour market. However, he was frustrated that this was being impeded by the lack of operation in the government system, perceiving that if awareness was not a collaborative effort, it would always be a challenge.

However, something that participants believed they could offer was advocating for clients with regard to RTW or finding a new job following SCI:

*You can talk to employees and employers [...] let them know more about what it is and what someone might need. (p. 13)*

In the above quote, Liam acknowledged his role in advocating on behalf of his SCI clients by talking to their employers and colleagues about their special requirements at work. This approach indicated the customised type of service he wanted to provide for his clients, since talking to a client's employer would be considered a service that is specific to his/her own condition and needs. There will be more on customised vocational support to follow in the next *master group theme*.

In line with this, Vicky talked about a specific client for whom she advocated, and who was successful in RTW after SCI:

*There was this one particular lady, who works [...], but she could not get the train or tubes to get to work, so we looked at that, we talked to her bosses about how she could get back to work [...] and yes she is now back at work, five days a week. (p. 24)*

Vicky felt proud sharing this example from her work; she expressed her enthusiasm about her SCI client's RTW after the injury, especially when she used the expression "yes she is now back at work, five days a week" to reflect on her contribution in this success.

Similarly, Adam perceived advocating for clients as something to strive for:

*It would be great if we were able to go in and speak to employers of newly disabled people, of newly spinal cord injured people, and let them know about what is possible and what is impossible. (p. 30)*

Here, Adam believed it would be his great pleasure to advocate for his clients in the future, since he could see the long-term benefits of this.

## **B) (Where?) Settings of vocational support services**

In this theme, participants talked about the different settings in which the above vocational tasks were usually provided.

Derek described courses as one of the settings in which he delivered different services for RTW:

*(Workplace name omitted) currently runs three courses a year to enable people to build up the confidence to return to the workplace. So they are basically two-day course. (p. 2)*

According to Derek, vocational support took the form of training, where SCI clients were able to join an intensive course during a certain time of the year.

This was the same for Adam, but because he worked for a different organisation, he had a different course structure for his SCI clients:

*It [RTW course] runs on a bi-monthly basis at (UK hospital name omitted), and we get about five or six people during a day. They spend around 45 minutes with us, so they are sourced in that manner. (p. 4)*

Here, Adam was able to describe the details about the course capacity and duration.

On the other hand, Vicky and James had a different experience; instead of running vocational training courses, they provided outreach support visits for their SCI clients.

James said:

*I was doing lots of travelling and so I was driving quite long distances, to go and see people. (p. 12)*

Instead of clients attending courses that participants ran in their organisations, James explained that he needed to travel long distances to meet his clients wherever they were based.

Overall, although the material (i.e., the content of the support services) provided to SCI clients might have been similar, the settings in which those materials were provided were different; participants either asked their clients to travel to the location of the training (i.e., a communal place) or they visited them in their own homes.

### **C) (How?) Mechanisms of delivering vocational support services**

After describing the most important services that they provided for their SCI clients and the settings where those services were carried out, participants described the mechanisms by which those tasks were effectively delivered. These included early interventions and role modelling.

Four participants (Liam, James, Derek and Adam) described their experience of providing vocational support to newly-injured clients, where carrying out early vocational interventions with SCI clients was believed to be highly important. This was clear in Adam's account:

*Just having the opportunity to sow seeds there is fantastic as well.  
So that again is a really positive side of the work that we do. (p.  
17)*

Here, Adam used the metaphor "sow the seeds" to illustrate the positive impact of carrying out early vocational interventions with SCI clients on their RTW. Adam believed that he, as a vocational support provider working at a community-based organisation, was privileged by being able to provide such a service, and that the earlier the service was provided, the better the chances were for SCI clients to achieve the goal of RTW.

Derek specified how early those interventions should be carried out:

*We know if people are not thinking about work within 6 weeks  
after their injury, then their chances of returning to work basically  
get lower all the time as time continues. So that is something that  
(workplace name omitted) is very passionate about changing as*

*well [...]. If the seed is not planted early on, then it gets harder and harder to change that perception. (p. 10 & 11)*

Similar to Adam, Derek used the metaphor of 'planting the seeds' to reflect on the importance of providing early vocational support following SCI in assisting RTW. He believed that it was important to support SCI people vocationally as early as during the first six weeks after their injuries in order to increase their chances of RTW.

In terms of how those early vocational interventions with SCI clients were implemented, different participants had different views. For example, Adam had the chance to screen for clients and provide a provisional vocational support before the start of their rehabilitation:

*When I initially meet people, if they are waiting in a district general hospital, if it seems to be an appropriate topic to talk about, I will talk about it there [...] if [...] I can tell from the things that they are saying that they might benefit from coming in, I might promote it to them then. (p. 4)*

On the other hand, James described this as a task done during the rehabilitation period which would usually be done through referrals from the SCI clients' occupational therapists:

*The idea was to go in and to spend time with somebody who was newly injured, but had expressed an interest in having a meeting, usually through the occupational therapy department or through their own OT. (p. 3)*

Beside the mechanism of providing early interventions, participants considered role modelling as an effective way of delivering their vocational support services to their SCI clients. As the nature of their work and their job title was 'peer supporters', in this theme, participants talked about how they used their personal experience of being SCI and being resilient and productive to deliver more informed vocational support to their clients. Being role models was presented in this theme as being successfully employed following SCI;

participants aimed to use their knowledge and experience to reproduce this success in SCI clients.

All participants shared their accounts, in one way or another, of perceiving themselves as role models as a result of using their personal experiences positively and conveying the message to their clients that RTW after SCI was achievable. Liam's account clearly illustrated this:

*Someone else has done it, and you can just talk them through it and how you managed it. (p. 7)*

However, Derek used his personal experience from a slightly different perspective:

*When I was first injured myself, I had to move out of the flat that I was living in and I had to give up the job that I was doing, [...] and my way out, of moving out of my parents' house, was to get a job and get myself somewhere to live, so that was one of the drivers for me, and I feel really passionate that it is a positive thing for people to be doing. (p. 10)*

At the beginning of this quote, Derek described the struggle he had when he was newly injured, and he had to leave his pre-injury job. He then described how he managed to overcome this struggle and eventually RTW. This was a successful story he was "passionate" to share with his clients, as he believed that its impact was going to be helpful in motivating them to RTW.

However, in this study, role modelling was not only about showing clients that RTW was achievable, nor was it merely about sharing personal success. It was also about using the knowledge gained from years of living with SCI to provide clients with advice that could lead them to regain their productivity after the injury:

*I have been injured for 11 years, and it is talking about life experiences and getting people to see that life will get back on*

*track for them, and just finding out what is out there for them to enable them to do that. (p. 2)*

Vicky perceived herself as someone who had knowledge, experience and resilience following SCI that could be shared with SCI clients and so signpost them to the right resources that could help them with RTW. Vicky perceived herself as an example of someone who was successful and whom clients could look up to.

James also perceived himself as a positive example to his SCI clients, but for him, this was something that could have an instant impact:

*When I go to a spinal centre, I am representing [...] a positive image of somebody who has had a spinal cord injury and got their life back on track again [...]. Because I am independent [...] that does mean I can change people's perceptions of what they can do and that is very powerful. (p. 17 & 18)*

James thought that his independence had an instant impact on clients. With no need to verbalise it, carrying out the outreach support visits independently and with no assistance enabled James to change many perceptions of clients about their own abilities to go back to work after their SCI.

#### **D) (Why?) The ultimate goal of providing vocational support services**

Following findings relating to the what, where and how of vocational support, this theme will present answers to the question 'why did vocational support providers think their services were important to SCI clients?' Findings from this theme represent the ultimate goal that participants wanted to achieve with their SCI clients.

Liam said:

*You offer them a certain amount of sessions to talk to them, and within that session you try and help them rebuild their lives following their injuries. (p. 3)*

The series of sessions that Liam ran with his SCI clients could be compared to going up a ladder, where taking the steps of advice, education and training aimed to ultimately reach life re-normalisation and re-productivity in his clients following their injuries.

Adam had the same aim, yet viewed its implementation in a different way:

*My aim is to support spinal cord injured people, their friends, families and healthcare professionals that work for them. (p. 2)*

Here, Adam explained how vocational support providers can set goals with their clients not only through considering the input of those clients, but also the input of their families, friends and healthcare team. He viewed this holistic approach as an effective one, because it would enable SCI clients to have a high quality of life (QoL) through the support of those surrounding them at home, in society and in the hospital.

Furthermore, achieving high QoL was seen by several other participants as a matter of rebuilding confidence following SCI. An example from Derek's transcript illustrated this:

*That includes helping people build up their general confidence through courses, mentoring, wheelchair skills and outreach support services. (p. 2)*

Beside the vocational training courses that Derek mentioned before, which aimed to help his SCI clients be prepared for work return, he emphasised that there were a range of other services that his workplace provided to those clients. One example of this was physical training, which aimed to improve the confidence of his clients, and therefore enabled them to be active and productive members of society.

### **Master group theme 3: Looking through the lens of SCI clients when providing them with vocational support; the approach of individuality**

All participants talked about how they perceived their clients and how they approached them when providing them with vocational support services. Participants believed that each of their clients was unique in his or her character, story, needs and challenges, and



therefore required customised support, which was influenced by empathy and sympathy. They also believed that each of their SCI clients was a unique contributor to his or her own vocational goal.

To demonstrate this notion of individuality and see things through the lenses of those who receive support instead of those who provide it, this *master group theme* will split into four themes: **(A)** Providing bespoke vocational support to SCI clients, **(B)** Engaging SCI clients in the vocational programme by acknowledging their role in achieving their own goals of RTW, **(C)** Empathy as a clear sign of implementing individuality at work and **(D)** Looking through the eyes of SCI clients is to feel for their pain.

### **A) Providing bespoke vocational support to SCI clients**

Four out of the total five participants (i.e., Liam, Derek, Vicky and Adam) talked about providing bespoke vocational support for their SCI clients, meaning that the latter's individual needs were considered. We have already seen that participants spoke about running RTW courses and vocational clinics, where they usually approached their SCI clients in groups. They also spoke about running outreach support sessions, in which SCI clients were usually approached individually. In both settings, participants spoke about providing customised vocational support, where their clients' individual backgrounds and needs were considered.

Participants referred to this type of service using different terms; Adam and Vicky referred to it as "*on a one-to-one basis*" and "*individual basis*" respectively, whereas Liam referred to it as "*peer to peer*". All of these terms referred to looking at SCI clients as individuals who had different needs, rather than providing a fixed and a pre-made material during vocational support sessions. An example of this came from Vicky:

*I would not have a 'one cap fits all' approach to everybody that I see; it really is an individual basis, on whatever we are going to talk about. (p. 23)*

Although it could be argued that Vicky's clients were all similar to herself and to each other by being SCI, she wanted to look beyond this by trying to provide the appropriate type of support for each client. She described how she had to keep changing the lens through which she saw her clients every time she met a different one.

The use of this approach was well-justified elsewhere in Vicky's transcript:

*It is people specific, and how we manage it, depends on their scenario, their injury, and yes, their situation. (p. 16)*

Vicky acknowledged that each client had a different story, physical abilities, needs and case in terms of work status. She therefore believed that achieving realistic goals would be more feasible by providing tailored support.

*A big chunk who return to jobs that they were doing before, [...]. There is also a group who were maybe unemployed beforehand [...] then there is the people on the fence I guess, who are less sure about what they are going to do. (p. 7)*

In keeping with the approach of individuality, this extract from Derek demonstrated an awareness of the different goals his SCI clients wanted to achieve in terms of employment after the injury, which therefore indicated the requirement to customise his vocational support.

#### **B) Engaging SCI clients in the vocational programme by acknowledging their role in achieving their own goals of RTW**

Participants believed that achieving realistic goals was a task that was shared between vocational support providers and their SCI clients. All participants acknowledged the role of their SCI clients during the vocational support programme. Clients set their own goals, and participants supported them to achieve those goals. Derek said:

*We are not giving people jobs [...], we are just working with them to help them achieve what they want to achieve. (p. 27)*

Derek emphasised that his role was not to hand jobs to SCI clients. Instead, he expected his clients to think about what they wanted to do after the injury and use the knowledge provided during the support sessions to achieve it.

James referred to this as giving his SCI clients clues:

*Giving people direction, but not necessarily giving them all the answers. (p. 7)*

In this context, providing guidance about work return was perceived by James as his responsibility, whereas using this guidance to achieve the goals of RTW was delegated to his SCI clients. In other words, the role of vocational support providers was seen by James as giving SCI clients the key to success; it was then up to the clients to pursue that success.

Adam also talked about this delegation to his SCI clients. However, he perceived that his clients had the choice to either accept or reject this delegation:

*We will give them the guidance, the pointers and the action plans, but it is down to that person to then follow through. (p. 16)*

Adam gave his SCI clients the freedom to decide whether to accept or reject an informed delegation of responsibility. Adam perceived his SCI clients as individuals who were able to decide for themselves, because the vocational programme was flexible enough to enable them to see things with their own lens rather than the vocational support provider deciding their goals on their behalf.

Furthermore, it was demonstrated that participants felt SCI clients should have a sense of agency when it came to achieving vocational goals, which emphasised a higher level of individuality for those clients. Vicky talked about this:

*Getting them to come to their own conclusions, rather than you suggesting [...]. I think that is really important for them to think, that they have got to do that bit themselves, just with a little bit of guidance. (p. 17)*

Like the other participants, Vicky emphasised the importance of engaging SCI clients in the vocational programme. However, she particularly emphasised her SCI clients' sense of agency; she believed her clients should take the initiative to decide what was suited for them vocationally and how they wanted to achieve it. She believed that this sense of agency meant that her contribution to this process was minor, while the major responsibility was on SCI clients.

On the other hand, Liam described what can be considered as the highest level of individuality when approaching SCI clients in vocational support sessions:

*You offer them a certain amount of sessions [...] in a way that is led by them really. So, they take the lead. (p. 3)*

For Liam, it was not only a matter of SCI clients having a sense of agency or freedom to accept or reject delegations from vocational support providers to achieve RTW goals, but it was a matter of giving them the full control to lead the vocational programme in the direction they felt was most suitable for them. Liam provided a vocational service in which his role could hardly be mentioned, because he believed his clients were the experts in identifying their potentials, setting their own goals and working towards achieving them.

### **C) Empathy as a clear sign of implementing individuality at work**

Some participants considered their SCI clients' challenges with a great amount of empathy. James, Derek and Adam demonstrated understanding of their clients' negative emotions as stemming from the difficult situations that arose after acquiring SCI. Derek said:

*People are scared of that change, or of their lives being ... having to make a big change in their life or ... it is scary for people. (p. 17)*

Derek acknowledged how his clients felt after acquiring SCI and how scary it was for them to change their career path. This acknowledgement was influenced by his own injury and affected how he approached his clients in terms of recognising their individualised challenges rather than expecting that they would all have the same type of challenges.

Adam explicitly associated himself with his clients as an SCI sufferer (i.e., as a peer), and was empathic with his clients because he had been through similar difficulties to theirs:

*And I know that from personal experience, because when I finally realised that I could not go back to the job that I had, I really struggled to think which way am I going to go now? [...]. So then I was lost in the system myself. And I can see that going on in people's minds when I am talking about which ways to go. So that is quite difficult. (p. 13)*

Talking about the specific experience of losing work after SCI and having to recommence the journey of employment, Adam felt he was able to imagine what was going through his clients' minds when they came to his vocational support sessions, because he could feel that they were going through the same struggle he went through when he was newly injured.

James was empathic too, but his sense of empathy was slightly different to Adam and Derek:

*And his mum was with him when I saw him and I think it was probably the reaction of his mum, you know, as a parent, and I am a parent as well, where you could see that she was just about holding it all together, for her son, but I should imagine that every time she left the ward, she was in bits. (p. 8)*

Here, James gave an example of a young client he had worked with, and his empathy for that client's mother. This was because the mother emotionally suffered after her child acquired SCI, and James could relate to this due to his status of being a parent, although his child had not been injured. James could feel what the mother felt, because he tried to put himself in her shoes and see things through her lens; this was demonstrated when he used the phrase "I should imagine". Hence, he showed a high level of approaching clients on an individual level rather than distancing himself from them.

Finally, not only was empathy viewed as a demonstration of implementing individuality with SCI clients, but also as an important quality that supporters believed they should have:

*People get a spinal cord injury in such simple, silly, ridiculous ways. And I think it is good to be mindful of that. (p. 9)*

The term “*mindful*” that James used in the above quote was powerful in illustrating his belief that understanding clients’ pain and devastation was important for providing high quality vocational support.

#### **D) Looking through the eyes of SCI clients is to feel for their emotional pain**

Another quality that some participants described as important when providing vocational support to SCI clients was to be sympathetic. Adam described this:

*There is certain things about this job that, as much as you try to put on a brave face, it is in the back of your mind that this person is going through that right now [...]. I do feel that having that type of quality is important to this role as well. If you were able to completely switch off from all feelings for people, then I do not think you would be the right sort of person for the role. (p. 19 & 20)*

Being sympathetic meant being emotionally affected by clients’ emotional pain, and for Adam this was unescapable. Adam viewed his job in vocational support as requiring feelings of sympathy, and if this requirement is not met, he believed supporters should be disqualified from doing their job.

Sympathy in this context was presented as participants’ approach to their clients, where they viewed pain and difficulties as the unique and individualised experiences of clients. Vicky described this:

*If someone has had their injury through, silly is the wrong word, but, something that really could have been avoided [...]. There is a*

*general frustration about people getting the right care [...],  
because at the end of the day, these people are humans. (p. 7 &  
12)*

Vicky felt the agony of her SCI clients for not being given the appropriate care; she felt that they have been marginalised because of their injury although it was not their fault that they acquired it in the first place. As she was trying to see each client through his or her own lens, Vicky sounded as frustrated as her clients may be when it came to them not receiving the right care.

#### **Master group theme 4: Looking after oneself as a determinant of perceiving and approaching difficult cases at work**

All participants except Derek talked about the ways they coped with different emotional challenges stemming from dealing with difficult cases at work. Those cases were either overwhelmingly devastating or overwhelming demanding, and participants had to learn to manage working with them.

Participants' experiences of approaching the cases in this *master group theme* were influenced by their sense of looking after themselves, where they had to make sure they were not left with negative feelings. The following three themes demonstrated participants' ability to manage emotionally difficult cases when providing vocational support: **(A)** Demonstrating the ability to show balanced sympathy to SCI clients, **(B)** Demonstrating the ability to manage negative emotions stemming from working with difficult cases and **(C)** Demonstrating the ability to reconcile with self for being limited in what to offer as a vocational support provider.

##### **A) Demonstrating the ability to show balanced sympathy to SCI clients**

Whereas participants' feelings of sympathy towards the pain of their SCI clients were presented as a positive aspect in the previous *master group theme* (because they reflected an approach of identifying clients' uniqueness), these feelings will be presented in this *master group theme* as an aspect that could only be positive if they were balanced with

reality. This is because excessive sympathy was perceived as having a negative effect on both participants and their clients.

Liam and Adam, for example, talked about their initial experience of being emotionally impacted by their SCI clients' stories, but how they were able to overcome this later on:

*I think if you are a caring and empathetic person anyway, which I sort of am, it is hard to separate the two anyway [...], but you have to be able to switch off as well at times [...]. I think I have developed quite good coping mechanisms for being able to get away from. (p. 24)*

*In the past, unfortunately, I have had several cases that have been very, very difficult and hard to switch off from. But again, because I have been doing it for so long, I think I have learnt methods for being able to deal with it. (p. 20)*

In these passages, it was not the case that Liam and Adam stopped being sympathetic after working for a number of years with clients with SCI, but rather that they learned to manage the negative emotions stemming from having excessive sympathy.

Liam and Adam realised that their sympathy was excessive when it started affecting them emotionally and interfering with their personal life outside work. Following this, they understood that it was important to learn coping mechanisms to help them separate professional life from personal life, while maintaining their moderated sense of sympathy for their SCI clients.

On a different level, Vicky talked about how she had to fight the feeling of guilt for not having excessive sympathy for her clients, because she realised that being too sympathetic could negatively affect her clients' ability to achieve realistic vocational goals:

*So it is being sensitive about people's expectations, but also being realistic [...]; it makes me sound really callous does not it? but I have to not, let it bother me. (p. 15 & 8)*



While having a balanced sympathy was beneficial for Vicky' clients, it was also beneficial for her, because it allowed her to overcome her sense of guilt. In other words, because Vicky maintained a moderated sense of sympathy towards her SCI clients while at the same time setting realistic goals with them that matched their abilities and situations, she was able to feel at ease.

**B) Demonstrating the ability to manage negative emotions stemming from working with difficult cases**

Another demonstration of ways in which participants looked after themselves was their ability to overcome the negative emotions transferred to them from their SCI clients.

James described how he felt towards SCI clients who lost their jobs following their injuries:

*I found it difficult at times. You are talking to someone who, you know, let's say they were in the army and they are not able to go back to that role – that is very difficult. You know, if you have got somebody who has only ever done that job and who grew up thinking that is what I want to be when I grow up, for them to have that taken away, quite often through no fault of their own, psychologically that is difficult for them to process and it is difficult for me to provide that support without being affected by it. (p. 6)*

Note the repetition of the word “difficult” in James’s quote, which indicated that he was sympathetic with his SCI clients’ loss of jobs, but more importantly that he was emotionally devastated by it.

However, he was able to manage this feeling of devastation through doing the following:

*I used to think about my car as my little decompression chamber [...]. I do not feel like I bottle things up, because I am always happy to talk about them. (p. 6)*

The metaphor that James used here of his car being “*my little decompression chamber*” was very powerful in illustrating how he used to immediately let out all the negative feelings he accumulated following overwhelming support sessions. This metaphor gave the impression that James would cry or talk in a loud voice inside the car to instantly pour his heart out instead of bottling things up. This instant coping mechanism helped James be in control of the rest of his day at home after coming back from work.

On the other hand, Vicky and Adam believed that they were able to develop a different coping mechanism when listening to their clients’ sad stories and challenges. Although those experiences were similar to the ones that Vicky and Adam experienced when they were newly injured, those two participants were successful in not being triggered by them:

*I have been injured for 11 years, so I am over my story, if that makes sense, so no, I cannot think of anything that would be comparable [...]. Once I am not at work, it does not mean to say I do not think about it, but I cannot let it overtake the world. (p. 10)*

*It brings back the memories that I have and the thoughts and feelings that I had. But because I have been doing this so long, I can kind of switch that side of it off, my personal side of it. (p. 18)*

Both Vicky and Adam acknowledged that dealing with clients that were mutually injured could be emotionally overwhelming. However, the phrases “*I cannot let it overtake the world*” and “*I can kind of switch that side of it off*” showed that they were proud of their ability to overcome these emotions. They both believed that the factor of time was vital in this regard, meaning the more experienced they became in their work, the more they were able to avoid being personally triggered by clients’ challenges that were similar to theirs.

### **C) Demonstrating the ability to reconcile with self for being limited in what to offer as a vocational support provider**

Participants also talked about their experience of emotional struggle with some clients who were demanding in terms of what they expected from the vocational support programme. As some SCI clients had unrealistic expectations about what vocational support providers could offer them, participants initially felt frustrated for not being able to meet those expectations. However, time and experience were important factors that enabled the participants to reach a level of self-reconciliation with what they were able to offer. Liam and Vicky put it this way:

*We are limited to what we can do for people [...] ethically you cannot really do that, but you know that is what ... in your heart you want to do stuff for people and help people more [...]. You need to, yeah, I think it is important [to maintain a professional relationship with clients]. (p. 23)*

*Well, but that is a frustration and I am not going to change the world unfortunately, it is all about who is got the money and who is going to pay for it. So that is a frustration, but it is one that is a reality unfortunately. (p. 13)*

Both of these quotes illustrated how Liam and Vicky initially wished that they could meet their clients' unrealistic expectations and how they felt frustrated for not being able to do so. However, with time, they accepted the fact that they were giving the maximum effort they could during vocational sessions and that this was sufficient for them not to feel guilty.

On the other hand, James did not experience frustration about this. He never believed that he was ethically expected to offer support beyond his abilities and responsibilities, which always put him at ease:

*I think the difficulty would have been if I thought that my job was about fixing them or doing it all for them. (p. 10)*

Although James was similar to Liam and Vicky in that he wanted to offer the maximum he could to his clients, he was confident that it had never been his job to offer more than he already did. Regardless of what his clients expected from him, James was satisfied that he did his best and he was glad that he did not overwhelm himself with unnecessary guilt.

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## Chapter 10: Discussion and conclusion

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### Introduction

The second study of this thesis aimed to explore the personal experience of five participants who provided vocational support to individuals with spinal cord injury (SCI) as part of their work at UK-based SCI community organisations.

The first section of this chapter will briefly provide a general discussion about the findings from the second study, and how they integrated. The next section will discuss these findings in relation to existing literature, and the final sections will present the study's contribution to knowledge and implications, as well as suggestions for future research. The chapter will finally highlight the researcher's reflections and reflexivity.

### General discussion

All participants in the second study were peer supporters who provided vocational services to people living with SCI as part of their job. As most of the SCI vocational support work in UK community organisations is provided by peer supporters, the sample available for this study was entirely from this group.

Mutuality being present as a theme in the first *master group theme* influenced the analysis of participants' accounts across the four *master group themes*. Firstly, mutuality helped set the scene for the first *master group theme* in terms of how participants viewed their relationships with their SCI clients. Secondly, it influenced the remaining three *master group themes* in terms of how participants approached their clients and how they dealt with emotionally difficult cases. In other words, being a peer and sharing a similar health condition with clients influenced participants' accounts of doing vocational support in various aspects.

Generally, Figure 13 illustrates how the four *master group themes* in the second study were integrated.

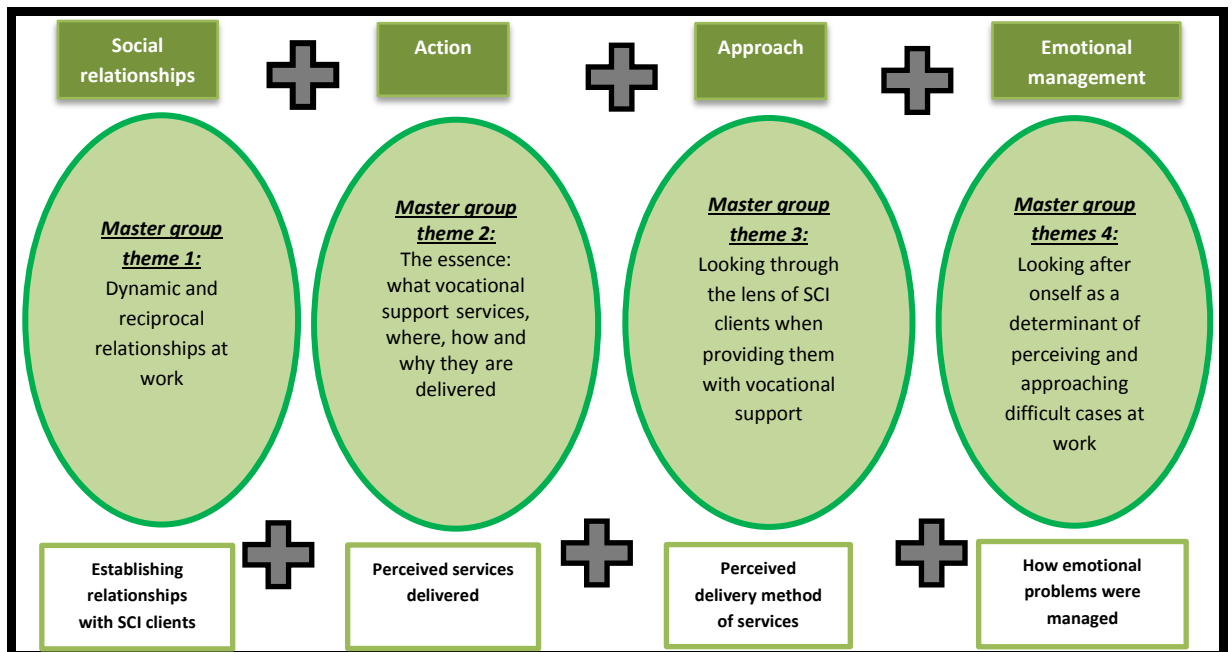


Figure 13. The different aspects of the experience that connect *master group themes* in the second study

The following section of the chapter will comprise a discussion of the findings in each *master group theme* and how they were related to the existing literature in order to show where they supported, differentiated or added to what has already been found.

### Discussion of each master group theme

#### **Master group theme 1: Dynamic and reciprocal relationships at work**

This *master group theme* could be seen as a good starting point for presenting the analysis of this study, because it included information about how participants were able to form positive relationships with their SCI clients when providing vocational support. On the other hand, this *master group theme* was able to reflect on the reason why some participants started working in the domain of community support in order to give voice to people with SCI.

Peer support was described by participants in this study as an essential element of the vocational support programme. According to the literature, the term 'peer support' usually refers to the phenomenon of relating to others who have had a like experience, where empathy and validation can emerge (Mead & MacNeil, 2006). The main idea behind implementing a peer support approach is usually to offer advice as well as practical support that other professionals may not be able to offer (Mead & MacNeil, 2006).

Core to the concept of peer support in this study was mutuality; participants believed that sharing the experience of SCI with their clients played an important role in how they viewed their work experience as a whole. To elaborate, besides mutuality being key to establishing interpersonal relationships with SCI clients, having this shared experience was also an aspect that shaped the services provided to clients and influenced the professional approach to challenges faced at work.

Whittemore, Rankin, Callahan, Leder, and Carroll (2000) reported that mutual sharing with clients characterised the experience of peer supporters of individuals with myocardial infraction and allowed them to offer a unique type of support that was consistent with mainstream health practices. In addition, Munce and colleagues (2014) interviewed individuals with traumatic SCI in order to explore their perceived facilitators and barriers to self-management and found that peer support was a facilitator that was valued by most participants. This value of mutuality was similarly found in the second study; yet, it was uniquely reported from the perspective of support providers rather than recipients.

In the second study, matching an SCI client with a peer supporter in terms of age and level of injury was considered by the majority of participants to be an important element of the vocational support programme. Participants felt it was logical for clients and supporters to share personally relevant experiences. In Munce and colleagues' (2014) study, SCI mentees emphasised the need to be matched with mentors who were similar to them in age and level of injury. Similarly, Veith, Sherman, Pellino, and Yasui (2006) conducted a grounded theory (GT) study in which they interviewed SCI clients who received a mentoring service from peers and found that mutuality in age and level of injury were salient factors affecting the mentoring relationship. Although those two studies were similar to the second study in

that they both had a qualitative design, their findings about mutuality were again reported from the perspective of mentees rather than mentors, which gave a valuable, yet different insight.

Moreover, the second study referred to participants' experiences of establishing rapport with their SCI clients as an important aspect of doing vocational support. There are many definitions cited in the literature for the term 'rapport', but most refer to it as the 'quality of the relationship' (e.g., Coan Jr, 1984; Haryati Shaikh Ali & Oly Ndubisi, 2011). In healthcare, this term has been widely used to describe the quality of the relationship between patients and practitioners. For example, according to occupational therapists in Guidetti and Tham's (2002) work, it was important to establish trust and communication with patients in order to achieve rehabilitation goals. In studies related to peer support, Veith and colleagues (2006) found that, according to SCI mentees, friendliness was an important factor that affected the quality of the mentoring relationship. Similarly, those with chronic kidney disease expressed the importance of establishing rapport with their peer supporters in order for the relationship to work (Taylor, Gutteridge, & Willis, 2016).

On the other hand, with regard to studies exploring service providers' views, Boschen, Tonack, and Gargaro (2005) reported that support providers for people living with SCI believed that their relationships with their clients were dynamic and that maintaining good quality relationships was the key to successful experience in rehabilitation and community reintegration. Similarly, Westby and Backman (2010) interviewed healthcare providers working with patients living with total hip arthroplasty and found that a good patient-provider relationship was believed to lead to recovery, whereas a negative patient-provider relationship, described as having either poor or absent communication, was believed to decrease both collaboration and effectiveness of the treatment. However, Moran, Russinova, Gidugu, Yim, and Sprague (2011) stated that peer supporters of patients with psychiatric illnesses believed that engaging in a positive relationship with patients enhanced their own interpersonal skills, demonstrating a benefit for supporters rather than clients.



The current findings were similar to the above literature in that they shed light on being satisfied about the ability to establish rapport with SCI clients as well as being challenged with the barriers that hindered this establishment and the impact of this on the delivery of services and the self-image of supporters.

Underlying the term 'rapport' is 'reciprocation' (Leach, 2005). This was true for the current study; for example, Derek talked about a group of SCI individuals who received mentoring through his community organisation, including vocational support, and who, as a sign of existing rapport and reciprocation, started working in that organisation and helping other people with a similar injury.

The term 'reciprocation' can be defined as *"an ongoing process of exchange with the aim of establishing and maintaining equality between parties"* (Maiter, Simich, Jacobson, & Wise, 2008, p. 305). Many studies in the literature reported that reciprocation from clients was one of the positive experiences of providing support. For example, results from a study by Bracke, Christiaens, and Verhaeghe (2008) reported that, for peer supporters of individuals with mental health conditions, it was more beneficial to provide support than receive it. Another example is by Moran and colleagues (2011), who found that peer supporters of people with psychiatric illnesses felt 'rewarded' for the achievements they had with their clients. Similarly, a sample of vocational rehabilitation (VR) providers working with previous veterans with current polytrauma in the US was proud of serving such *"heroes"* and found this work *"deeply rewarding"* (Friedemann-Sanchez et al., 2008). In the same vein, receiving appreciation and positive feedback from clients was found to reflect peer supporters' sense of being respected (Moran et al., 2011). Further, a literature review stated that peer supporters of people with mental health difficulties reported that receiving positive responses from their clients about their peer support experience was one of the most rewarding aspects of their job (Miyamoto & Sono, 2012).

Current participants' accounts supported the above findings; however, they added to the picture by discussing the particular experience of providing vocational support. Participants were able to give examples of clients they helped to return to work (RTW) and describe how rewarding this was for them.

While the previously mentioned work by Wittig and colleagues (2003) showed that job satisfaction among long-term care providers was influenced by feelings of appreciation from employers, the current study reported job satisfaction among providers as being influenced by appreciation from clients.

From a different point of view, some participants in the current study felt that their work in supporting mutually SCI persons was a sign of giving back to their workplaces, which had once supported them when they were newly injured themselves. Eisenberger, Armeli, Rexwinkel, Lynch, and Rhoades (2001) found that organisational support was reciprocated by employees feeling obliged to help achieve the objectives of their organisation. Similarly, Moran and colleagues (2011) found that peer supporters expressed their gratitude to their organisation through giving back to their clients and supporting them.

While the current participants described their relationships with their clients and workplace as dynamic, they also described a desire for those relationships to continue. The passion to continue supporting people with SCI and providing them with different vocational services was expressed as either a personal plan (Liam and James) or as an organisational plan with a personal contribution (Derek). Similar studies have noted that peer support was seen as a 'mission' (Moran et al., 2011) that led individuals to take initiatives (Miyamoto & Sono, 2012).

Consistent with the above studies, the current participants were passionate about continuing to work with people with SCI, which reflected their satisfaction with their work. Similar findings were noted in Wilding, Curtin, and Whiteford's (2012) study, where opportunities for professional development for a sample of rehabilitation staff could lead to increased satisfaction at work.

### **Master group theme 2: The essence: what vocational support services, where, how and why they are provided**

Participants' accounts in the current study comprehensively portrayed the nature of their jobs as vocational support providers. They outlined the type of services they provided to their SCI clients, but also where, how and why they provided these services.

As vocational support providers, participants talked about the different services they provided to their SCI clients to help them with employment options following their injuries. These accounts corresponded with the definition of VR services by the Department for Work and Pensions (2004) in the UK in terms of the tasks that specialists carry out. For example, both the definition and the current participants mention giving advice about adjustments at work, providing education to clients and members of the public, communicating with employers and rebuilding capacity for work. It is interesting to note that although the participants were originally peer supporters who provided VR as part of their job, they had very similar accounts of the services they provided to the ones provided by VR specialists.

Fundamental to the services that the participants provided during their vocational support sessions was giving advice to SCI clients on different life aspects, including work. This was in line with what Ottomanelli and Lind (2009) described as 'SCI supported-employment', in which counselling and giving advice was a fundamental element. It was also in line with the elements that Leahy and colleagues (2003) identified as job functions in rehabilitation, where career counselling was at the top of the list.

Similar to the current study, previous studies reported that people with disabilities preferred to be advised on how to manage work after disability (Sweetland, Riazi, Cano, & Playford, 2007) and to receive practical advice from peer supporters (Haas et al., 2013). However, where those previous studies reported this from the perspective of the advice recipients, the current study reported it from the perspective of the advice providers, which allowed further description of the different types of advice given to clients as well as examples of the content of the advice sessions.

In addition, signposting SCI clients to different job placement, job modification and community resources were among the tasks the current participants carried out during vocational support sessions. Previous research suggested that being knowledgeable about different agencies and the changes in various systems was an important competency of VR providers (Defur & Taymans, 1995). More specifically, peer supporters were found to be more knowledgeable than non-peer supporters in terms of community resources, and

more willing to share those resources with SCI clients (Kelly, 2007). While a small number of studies (e.g., Hass et al., 2013), touched briefly on the value of being signposted by peer supporters to resources that could help with living a better life after SCI, there were not many studies in the literature that recognised the significance of the task of signposting in job descriptions of VR supporters.

Highlighting important aspects related to the human rights model of disability and raising awareness through providing education about the ability to RTW of people living with SCI were among the main tasks that participants carried out as part of their work in vocational support. This also supported recommendations from the World Health Organisation and International Spinal Cord Society (2013) that awareness is raised about SCI and that this should be one of the main tasks for support providers to carry out. Consistent with the current findings, Westby and Backman (2010) reported that rehabilitation providers viewed the task of providing education as a way of empowering their clients.

In a similar vein, while some studies (Crudden, Sansing, & Butler, 2005; Moran et al., 2011) reported that receiving education after acquiring a disability was beneficial for overall well-being, the current study reported that education was beneficial for those who provide it as well. The current participants reported that providing education about SCI helped them feel satisfied about their job and have ambitions to give more to people with SCI.

Whereas the literature on peer supporters included challenges, such as being labelled as a peer (i.e., having a “*peer persona*”) (Moran, Russinova, Gidugu, & Gagne, 2013, p. 287) and being stressed due to the responsibility of educating colleagues and members of the public about SCI (Friedemann-Sanchez et al., 2008), the current study reported a different challenge, in which the difficulty was in convincing people living with SCI and the community to change their negative perceptions about the ability to work following SCI.

While this was not surprising, given that ableism still exists in our societies, the current participants’ role in fighting this negative concept reflected the human rights model of disability. Participants in the current study talked about their role in advocating for their SCI clients through communicating with their employers and colleagues regarding their RTW. A literature review by Shaw and colleagues (2008) reported that mediating with employers

was among the most important competencies identified for RTW coordinators for disabled people. In other studies (McCarthy & Leierer, 2001; Sweetland et al., 2007), clients expressed a need for their counsellors and vocational support providers to be committed to advocate on their behalf in different aspects affecting their disability.

A study by Koletsi and colleagues (2009) reported positive responses from clients with mental health conditions, who were advocated for by vocational support providers, and gave an example of a client who expressed gratitude towards a vocational support provider for taking the role of mediating with an employer and eventually helped with recruitment. However, while the current study reported a similar finding, it demonstrated the positive response from the advocate instead of the client; enthusiasm about communicating with a client's employer and succeeding in helping this client RTW was a major positive response for the current participants.

In a different vein, the current study was able to shed light on the locations where participants usually provided their vocational support. Although participants were identified as community supporters, they still provided their support, including helping with employment following SCI, in rehabilitation settings. Vocational clinics conducted in both spinal units and outreach support programmes were considered formal settings, where clients met with their peer supporters to receive professional support during rehabilitation and after they were discharged to the community. This contradicted studies like Sherman, DeVinney, and Sperling (2004) and Mead and MacNeil (2006), where non-professional and informal meetings with peer supporters took place. It also contradicted Kroll (2008), where VR professionals felt constrained by the short length of stay of SCI patients in rehabilitation hospitals since they could not provide clients with support after their discharge.

Since participants in the current study used SCI rehabilitation units as one of the main settings of their work, they were able to deliver early vocational interventions. They sometimes delivered those interventions as early as during the acute stage of SCI, so before their clients joined rehabilitation. However, while studies like Ljungberg, Kroll, Libin, and Gordon's (2011) echoed the current study in terms of the importance of providing

education through peer support and during the SCI acute stage, many others (Haas et al., 2013; Hay-Smith et al., 2013; Munce et al., 2014) disagreed, stating that clients were usually not physically or psychologically ready to discuss work when they were newly injured.

As well as early intervention, role modelling was also implemented by the current participants as a way of delivering VR services to SCI clients. Role modelling in the current study was based on the notion of mutuality, where the belief was that: *“someone else has done it”* (Liam, p. 7). Veith and colleagues (2006) and Isaksson and Hellman (2012) emphasised this, where role modelling for people living with SCI was believed to be best presented by peer supporters. Nevertheless, as the current study looked at the particular experience of providing SCI vocational support, it was important for participants to share their particular experience of work following the injury with their clients. Relevant findings in the literature showed that having good role models was important in the RTW process following SCI (Dekkers-Sánchez et al., 2011).

As supporters, sharing successful stories about RTW was something about which the current participants felt passionate. Similarly, Moran and colleagues (2011) noted that peer supporters of individuals with SCI were motivated to present themselves in ways that reflected their keenness to live up to their own responsibilities, because they knew that their clients perceived them as someone to look up to. This was consistent with Vicky’s feelings about being a role model for her clients. Furthermore, similar to findings in Haas and colleagues’ (2013), being perceived by clients as an independent person was an indirect, non-verbally role modelling mechanism used by participants in the current study.

However, what was unique about findings relevant to role modelling in the current study was that participants did not only use their personal success to become role models for their SCI clients, but also shared the experiences throughout the years after their injury which had led them to succeed in their work.

Furthermore, the VR literature showed that teaching comprehensive skills is more effective than just teaching job-orientated skills in helping individuals RTW (Hammond, 2008).

Consistent with this, participants’ ultimate aim for providing vocational support to their SCI

clients was to enable them to rebuild their lives after SCI, including their ability to regain employment. Supporting findings were noted in Westby and Backman's (2010) work, where patients' aims to go back to their normal lives after having knee or hip surgery were expressed more repeatedly than the aim of walking again or being free from pain.

The fact that participants were peer supporters might have influenced how broad the goals they wanted to achieve with their clients were. In other words, since participants provided different types of support to their SCI clients, and not merely vocational support, their aim was to help them improve their lives in general rather than just place them in jobs.

Supporting findings in the literature linked the peer support role with the goal of re-normalising the SCI experience (Veith et al., 2006) and being able to adjust to life after traumatic SCI (Arya et al., 2016; Haas et al., 2013), including regaining confidence (Kroll, 2008; Miyamoto & Sono, 2012), social participation and employment (Sweet, Noreau, Leblond, & Martin Ginis, 2016).

### **Master group theme 3: Looking through the lens of SCI clients when providing them with vocational support; the approach of individuality**

As part of their experience of delivering vocational support, participants described in the third *master group theme* how they viewed their SCI clients and how they approached them during support sessions. Participants adopted the approach of individuality, in which they viewed their clients as unique individuals, and in which clients' needs, feelings and goals were seen through their own lens. This approach was personally meaningful to the researcher as she had always challenged the limited implementation of individuality in her previous role in VR. Hence, she perceived current participants' accounts in implementing this approach as applaudable and worth including as a separate theme in the study.

This approach of individuality was similar to the 'client-centred approach' in three main areas (i.e., client-involvement, customised support and empathy). Firstly, the 'client-centred approach', built on the work of Carl Rogers (1902- 1987), is considered facilitative, yet non-directive (Bower, 2001), meaning the client has a direct involvement in setting his

or her individualised goals and an active role in achieving this goal (Doig, Fleming, Cornwell, & Kuipers, 2009). Participants in the current study adopted this approach, and therefore emphasised previous findings around the promotion of client-centred practice due to its importance in the rehabilitation of different conditions (S. Parker et al., 2017), including SCI (Hammell, 1995). Further, the current study complemented the previous work of Job, Anstey, and Hopkinson (2016) in recognising the expected long-term benefits of teaching healthcare students the importance of working collaboratively with patients who have long-term conditions by focusing on patient experience and considering it a fundamental element when providing patient education.

In the current study, participants spoke about different forms of engaging their SCI clients in the vocational support programme. For example, while Derek expected his clients to work with him to set their vocational goals before achieving those goals themselves, James viewed his main role as giving his clients tips that could guide them to achieve their vocational goals. However, for both Derek and James, vocational support was provided mainly during the initial period of job preparation, while applying for jobs and going for interviews was the sole responsibility of SCI clients. Similar findings (Crudden et al., 2005) have shown that rehabilitation professionals did not tend to accompany their clients to job interviews, but rather encouraged them to present themselves to potential employers as independent individuals.

Another example was current participant Adam, who described his implementation of individuality in his support sessions as similar to that of participants in Kroll's (2008) study, where SCI clients received information about their role in the sessions as well as an offer of being active participants in achieving their own goals. However, in the current study, Adam gave his clients the freedom to either accept or reject this offer based on the belief that they were adults who were able to make an informed decision.

Vicky adopted a different form of the approach of individuality by giving her clients a sense of agency as they discovered what employment options were suitable for them following SCI and made decisions that embraced those options. Vicky felt that her role was minimal compared to that of her SCI clients in this process. Previous research from Isaksson and



Hellman (2012) showed similar results, where occupational therapists tended to balance the amount of support they gave to their SCI patients in order to enhance their independence.

The client-centred approach also encourages customised services based on individualised needs (Cott, 2004), as does the approach of individuality in the current study. Consistent with those two approaches as well as Hammond's (2008) description of VR services, current participants delivered both group and individual vocational support sessions to their SCI clients. In both types of sessions, participants provided bespoke services, depending on each client's level of injury, ability, background and vocational goals. Previous research showed that, according to occupational therapists, considering SCI patients' pre-injury experience and identifying post-injury challenges related to their abilities was important for the former to perform activities related to self-care (Guidetti & Tham, 2002). Other research also showed that rehabilitation professionals believed that providing tailored interventions for people with SCI was important in achieving vocational goals (Dekkers-Sánchez et al., 2011).

Thirdly, the current approach of individuality and the client-centred approach shared the principle of empathy. Defined as the attempt to willingly comprehend another person's negative or positive experiences in a non-judgemental way (Wispé, 1986) and rather experience them (Jeffrey, 2016), empathy is considered an important quality for professionals adopting the client-centred approach (Rowe, 2017). However, more generally, Stebnicki (2000) argued that all rehabilitation counsellors, whether they adopted the client-centred approach or not, are required to deliver their services with a great amount of empathy for their clients and family members. While the current study supported both of the above arguments, it also supported the observation that empathy is a required quality when delivering vocational support and RTW services particularly.

Previous research (Dekkers-Sánchez et al., 2011; Haas et al., 2013; Sells, Black, Davidson, & Rowe, 2008; Veith et al., 2006) has emphasised the importance and benefits of having empathic peer supporters working in the rehabilitation of people with different conditions due to their meaningful ability to understand the challenges of their clients. Nevertheless,

the current study was able to contribute to the literature by showing that peer supporters could also feel empathic about issues not necessarily related to their mutual injury with their clients.

Also, the approach of individuality in this study was able to uniquely adopt the notion of sympathy. In the literature, sympathy is seen as a broad term that refers to having a similar feeling to that of another person's, because of an unpleasant event in that person's life (Jeffrey, 2016). Although some literature associate sympathy with feelings of pettiness (Jeffrey, 2016), in the current study, sympathy was presented as a sign of being aware of SCI clients' suffering when delivering support services to them.

In the current study, sympathy was sometimes inevitable; Adam talked about how it was difficult for him to switch off from thinking of his clients' struggle. While some research identified sympathy as a challenge (Moran et al., 2013), the current study identified it as a positive aspect and a requirement for providing support.

Finally, being sympathetic in the current study was demonstrated in viewing SCI clients as valuable and dignified individuals. As in findings noted in Brackett and colleagues' (1984) work, where dignity, value and importance were principles for providing emotional care to SCI patients, Vicky, reflecting on the human rights model of disability, was sympathetic with SCI clients who did not receive appropriate care as well as believing that this was against their basic rights as humans.

#### **Master group theme 4: Looking after oneself as a determinant of perceiving and approaching difficult cases at work**

While the above three *master group themes* presented participants' experiences of providing vocational support from three different perspectives (i.e. social relationships, action and approach), the fourth *master group theme* presented it from the perspective of emotional management at work. It can be said that the fourth *master group theme* was the most illustrative of participants' overall positive experience of providing SCI vocational support, since rather than focusing on negative emotions and challenges, it focused on how these challenges were overcome. This might have been influenced by the

researcher's own experience of providing VR support to SCI individuals, which was mainly positive. Although, as mentioned earlier, the importance of VR services was frequently neglected by other rehabilitation workers in the researcher's previous workplace, her overall experience as a VR support provider was positive. The researcher, whose experiences resonated with participants in this study, could see that the positive aspects of doing SCI VR outweighed the negative aspects.

The current study can be compared to previous research that has supported the link between the experience of providing vocational and peer support and the development of a general sense of self-confidence and self-efficacy (Bracke et al., 2008; Miyamoto & Sono, 2012; Schwartz & Sendor, 1999). However, the current study was more focused on participants' ability to create a sense of looking after their own well-being and developing that further in order to overcome challenges related to working with demanding and emotionally difficult cases.

Liam and Adam talked about how, during the period of initially starting their jobs as supporters, their sympathy with their clients was excessive and so impacted their emotions. They then talked about being able to establish more moderate amounts of sympathy with their SCI clients, so being able to maintain their sensitivity to their clients' emotional struggle, while at the same time not letting that affect their personal lives negatively. These participants regarded their years of work experience as the main factor that helped them learn strategies to balance their sympathy. These findings agreed with the literature, which suggests that the more experienced the supporter is, the better he or she becomes at protecting themselves from burnout caused by working with people with devastating medical conditions (Stebnicki, 2000).

Nevertheless, the current findings also demonstrated how this adaptation did not eliminate the sense of sympathy. Vicky talked about her ability to establish a balance between maintaining sensitivity to her SCI clients' expectations and setting realistic vocational goals with them, which was a finding consistent with those cited in Dekkers-Sánchez and colleagues' (2011) work. Yet, interestingly, Vicky reflected on how this balanced sympathy

initially created a sense of guilt that she had to fight in order to maintain her emotional well-being and to be productive in her work with her clients.

Furthermore, the majority of the current participants spoke about their experience of working with cases that were emotionally taxing, and how they were able to cope with that. For example, James felt that the negative emotions of his SCI clients connected to losing jobs that were personally valued were unintentionally being transferred to him. Although this resonated with findings from Friedemann-Sanchez and colleagues (2008), it is important not to confuse James's emotions with sympathy, since in this case, James viewed his emotion as temporary and negative, and therefore strived to overcome it. James was able to develop resilience at work that was enforced by his desire to be stress-free. By doing this, he echoed the strategy identified by Jackson, Firtko, and Edenborough (2007) of being emotionally insightful when working in healthcare settings. Here, James used a specific mechanism to develop his resilience, in which he was able to instantly and effectively unload his stress to avoid it accumulating.

Similarly, Vicky and Adam initially found it difficult to deal with SCI clients whose stories reminded them of their own. Nevertheless, time and experience helped these two participants overcome this difficulty. Moran and colleagues (2011) associated time with resilience, where the more frequently peer supporters told their clients the stories of their injuries, the more those supporters felt they were 'recovery' stories rather than 'illness' stories. Although this association existed in the current study, it was presented in a way which suggested that the more experienced the participants were in their work, the more detached they felt from their stories, which resulted in them no longer comparing their own stories to their clients'.

Finally, the current study showed participants' ability to develop a sense of looking after the self through reconciling with what they were able to offer to their SCI clients. In other words, although participants felt that some of their clients had higher expectations from the vocational support sessions than their capacity, they had not to let this make them feel guilty. Liam and Vicky initially felt frustrated that they were not able to provide what some of their clients wanted from their vocational sessions, but eventually came to terms with

this, because they came to the conclusion that those demands were either unethical or unrealistic. This feeling of self-reconciliation is similar to the self-acceptance identified by previous research, where the more experienced peer supporters were in their job, the more they found themselves able to manage life difficulties (Moran et al., 2011; Schwartz & Sendor, 1999). Meanwhile, James was always satisfied that he offered his maximum support, and it was never a problem for him if his SCI clients had unrealistic expectations. This is similar to the work of Boschen, Tonack, and Gargaro (2005), where support providers of people with SCI found their internal locus of control correlating with their sense of satisfaction.

### **Contribution to knowledge**

Whereas previous research has focused on particular variables in the experience of providing support for people living with SCI, such as job burnout, the second study produced a more comprehensive, detailed overview of this experience. The four *master group themes* were able to reflect, in detail, on the different variables of social relationships, tasks at work, approach to clients and emotional management when providing SCI vocational support.

In a different vein, although both negative and positive experiences of participants in the second study were noted, negative experiences were not the main experience that participants wanted to convey in their interviews and therefore were not reflected upon separately. Rather, those negative experiences were referred to by participants as either a way of describing the nature of their work or to explain how some challenging cases at work could eventually be managed. In other words, negative emotions were integrated into participants' experiences but did not define them.

The fact that all participants were peer supporters enriched the data in more than one way. Firstly, mutuality between participants and their clients in terms of injury was unique to the experience of providing SCI vocational support, where empathy played an important role in approaching clients and where perceiving the self as a role model highlighted the delivery of support on RTW. Secondly, a unique observation in this study was that vocational

support for people with SCI in UK specialised community organisations is usually provided through peer supporters, which might not be the case in other countries. This observation can contribute to the literature of SCI, meaning that studies conducted in countries other than the UK can report their observations and compare them to the current one. Finally, while The World Health Organisation and International Spinal Cord Society (2013) recommend that VR services should be provided in both rehabilitation and community settings, this study demonstrated that peer supporters are the main providers of those services in both settings. That is, the current participants carried out early interventions during SCI rehabilitation programmes and at the same time conducted outreach visits in the community following rehabilitation discharge.

In addition, the second study was able to produce detailed accounts of the different types of vocational support services that participants provided for their SCI clients (such as advice, signposting, education and advocacy). This was a unique finding because, unlike existing literature, those accounts were reported from the perspective of support providers rather than recipients. Also, the fact that those services were carried out by peer supporters rather than vocational specialists or rehabilitation counsellors gave the data a different aspect.

In terms of the approaches for delivering those services, the ability to provide a customised vocational support as part of the community services from charity organisations was a meaningful finding. To elaborate, although some research has shown that tailored VR services for people with SCI are warranted, being able to demonstrate this during vocational sessions carried out by peer supporters, where the demand on community organisations is usually high and the number of SCI service users in the community is large, is a unique finding of the second study.

Finally, while a passion for work has been highlighted in previous studies looking at the experience of peer supporters (Moran et al., 2011), the second study was able to highlight this in terms of the particular experience of providing SCI vocational support by embracing the concepts of job development and job satisfaction. Being able to highlight a sense of

striving for job development when providing vocational support, regardless of whether this job was voluntary or paid, is considered a contribution to the literature of SCI VR.

### **Implications and future research**

Most aspects of work experience that participants drew on in the second study were positive. From the relational aspects of work (that is, mutuality, rapport and reciprocation) and going through the description of the work (which offered diverse services), the approach of valuing clients as individuals (that is, uniqueness of clients, empathy and sympathy) and finally the ability to manage emotional difficulties at work (through balanced sympathy and self-reconciliation), findings were mostly positive. This positive experience can encourage SCI community organisations that have not yet implemented vocational programmes to do so, while it can encourage others to continue to show more appreciation, encouragement and support to vocational support providers.

In the second study, the notion of reciprocation was important for those participants who wanted to do the job of peer and vocational support as a result of their appreciation of what the workplace has provided to them earlier. This finding can help SCI community organisations to recruit more peer supporters who have been supported previously, as their motivations may be morally-oriented more than financially-oriented.

This means that findings which relate to participants' sense of passion, satisfaction and ambitions for job development are a way to give voice, rights and position to people with SCI and to help fight social stigma through RTW. As this is a unique finding in the second study, which is influenced by the human rights model of disability, it is recommended that future research explore this further to help understand whether this is specific to peer supporters who are SCI themselves or if it is a positive sense that can be noted among vocational support providers in general.

Participants' length of experience in the job varied between two and nine years. While the literature showed that time and experience are positively related to resilience in rehabilitation and support providers (e.g., Moran et al., 2011), future research recruiting a

more homogenous sample than the current study in terms of years of experience could help understand this relationship better.

Although participants' experiences were mainly positive, this did not mean they were not faced with challenges. For example, struggling to raise awareness among employers due to existing ableism and negative perceptions about SCI as well as being frustrated due to unmet needs of SCI clients were challenges reported by participants in the second study. While participants considered these challenges and some others as minor in face of the whole experience, they are still valuable to the human rights model of disability and are worth consideration from future researchers in order to reach a more detailed understanding of those challenges so that they can be overcome.

While the above challenges were ongoing at the time of interview, participants spoke about other challenges they had experienced in the past, and which they were able to overcome with time and experience. Those were challenges related to being too sympathetic, being emotionally triggered by clients' stories and feeling overwhelmed by their unrealistic expectations about the vocational programme. However, because participants' years of experience, which influenced their ability to overcome those challenges, varied in the study, it is worth investigating whether resilience in the work of SCI vocational support is associated with a certain number of years' experience. It is also worth investigating whether there are factors other than time and experience that can help with resilience in this type of work.

Reaching a high level of life re-normalisation after SCI was a comprehensive aim that participants wanted to achieve with their clients. Participants indicated that RTW was incorporated into this aim instead of being the sole aim of vocational support. This finding complements the human rights model of disability, as it encourages vocational support providers to look beyond SCI employment for their clients and to consider quality of life (QoL) as a broad goal.

With regard to the general approach of individuality that was adopted by the participants in this study, despite its existence as a notion in the literature, this study was able to show its different manifestations. Service customisation, clients' engagement, empathy and



sympathy were all illustrations of the notion of individuality in this study, which can be seen as potential foundations to develop a framework or model for delivering vocational support services for people with SCI.

Finally, a meaningful finding from the second study is that of the relevance of carrying out vocational interventions for people with SCI as early as during the pre-rehabilitation phase. While the literature mostly suggests that interventions of this type are not very constructive, this study showed that they are often delivered in the UK via community organisations based on the belief that they can be beneficial for people with SCI. Thus, it would be worth conducting further research to measure the impact of these interventions on SCI clients who receive them during an early phase of their injury.

### **Considerations and reflections**

As in the first study, the researcher critically reflected on the overall work of the second study. Firstly, all participants in this second study had a job title of peer supporter, which meant that providing vocational support was part of their role rather than the main one. Although powerful, this might have influenced their experiential accounts of providing vocational support compared to non-peer supporters (e.g., VR specialists). However, as this study was based on how vocational support is delivered specifically in UK community organisations, it was unique in drawing on personal accounts of participants who had the dual role of providing peer and vocational support.

Secondly, recruiting participants in the second study was done using the technique of snowballing, which has potential limitations. Despite being a valid option for interpretative phenomenological analysis (IPA) research and the most logical route for recruiting participants for the second study, some participants' agreement to take part might have been influenced by what their colleagues told them about the study before the researcher approached them. In other words, since some participants were interviewed before suggesting other participants to the researcher, they might have passed their personal impressions about their own interviews to their colleagues before the latter's interviews. However, the researcher made sure that each participant read and understood all the

documents sent to him/her before agreeing to take part and that a brief chat with each participant took place before participation to allow questions to be answered.

Finally, there are not many SCI community organisations based in the UK, meaning there could be a risk that participants' identities might be recognisable. However, the researcher ensured that any information that can lead to identifying the participants were omitted or changed (e.g., names, locations, workplaces and so on) from transcripts, analysis, results, discussion and conclusion.

### **A reflexivity note**

The following section contains the researcher's brief thoughts on reflexivity in relation to the second study. As mentioned earlier, the researcher, as a fellow VR service provider, felt she was able to establish rapport with participants in this study easily and that she was familiar with a number of their accounts. However, the researcher sometimes perceived that participants in this study were the true experts in what they discussed in their interviews, as they were SCI sufferers themselves. This occasionally limited requests for elaboration by the researcher, such as when Liam talked about how having a client with the same level of injury was effective, or when Adam and Vicky talked about their resilience years after acquiring SCI.

Participants James and Derek, who were employed by their SCI community organisations as RTW programme managers, while still being peer supporters, were inevitably viewed by the researcher as more enthusiastic about their experiences. Their accounts were also richer than other participants. To elaborate, since James and Derek both had a main role of being RTW programme managers at their workplaces rather than peer supporters, they were perceived by the researcher as being more engaged in the interviews than other participants due to their rich background in this topic. However, this could be the unavoidable result of the researcher feeling that James and Derek had the same knowledge and skills that she had at her previous work, and therefore, for her, their identity as vocational support providers subconsciously outweighed their identities as peer supporters.

Nevertheless, drawing on the experiences of vocational support providers who were also peer supporters generally turned out to be a powerful position for the second study, since recruiting such a sample added to the quality of the data. In other words, mutuality between supporters and their clients in terms of injury was an important theme that ran through the experiential accounts of those providing vocational support; empathy, rapport and reciprocity were all important elements that were relevant to this mutuality.

## PART C

### Looking at the two studies together

Study 1	Study 2
<p><i>"I have got to rely on a lot of other people doing even silly minor tasks that you would do yourself".</i></p> <p>(Participant Andy, p. 7)</p>	<p><i>"People get a spinal cord injury in such simple, silly, ridiculous ways. And I think it is good to be mindful of that".</i></p> <p>(Participant James, p. 9)</p>

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## Chapter 11: Linking the two studies

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The thesis consisted of two separate studies which aimed to answer the following overarching question:

**What is the meaning and experience of work and/or lack of work for men who have suffered spinal cord injury (SCI)?**

The two studies aimed to understand firstly how those living with SCI who had transitioned from employment to unemployment following their injuries made sense of their experiences, and secondly how those who provide community vocational support to people living with SCI to help them transition from unemployment to employment following their injuries made sense of their experiences.

While the two studies were conducted separately and the two groups of participants were not related to each other in any way, it was important to link them to each other in order to answer the above overarching research question of the thesis. In other words, the findings of studies one and two were linked through identifying patterns between those findings which aided the understanding of the meaning of work and/or lack of work following SCI.

The process of identifying the patterns was carried out by writing down all *group themes* from both studies then writing the topics discussed under them in small pieces of paper. For example, in the first study, the *group theme* 'Living with a physically reduced quality of life (QoL) following the injury' had the topics 'Dependency on others' and 'Medical complications'; while in the second study the *group theme* 'Looking through the eyes of SCI clients is to feel for their emotional pain' had the topic 'Sympathy'. The identification of patterns took place at the level of those topics as their contents were more specific than the *group themes*, especially when it came to looking at quotes from participants' accounts.

Whenever a topic from study one matched a topic from study two (either because they echoed each other or because one worked as a response for the other), the link between them was given a relevant name. For example, the topic *'Dependency on other'* from study one matched the topic *'Sympathy'* from study two; the latter was a response from vocational support providers to the feelings of unemployed SCI individuals in the former and thus the link between them was named *'Emotional support'*.

Working through all the topics from studies one and two, more of these sorts of links were identified, while some topics were dropped as they did not have a match. The next step involved creating patterns from grouping identified links; for example, *'Emotional support'* was grouped with other identified links under the general pattern of *'Support'* in the thesis.

Four such patterns were created by comparing studies one and two: *The meaning of work*, *Emotional management*, *Support* and *Vocational goals*. Together, these combined to present a holistic view on the meaning of work and/or lack of work following SCI. In fact, these four patterns in turn cluster into two groups:

**Common Accounts:** Material from both study one and study two which was relevant to *The meaning of work* and *Emotional management* was linked by echoing each other; the participants in each study were talking about similar concerns.

**Need and response:** Material which was relevant to *Support* and *Vocational goals* was linked because the needs identified by participants in study one were picked up as needs to which the participants in study two felt they had to respond.

Before presenting each of those two clusters of **'Common accounts'** and **'Need and response'** in the rest of this chapter, Table 16 below gives an overview of them.

Table 16

Overview of how studies one and two are linked

Patterns		Study 1	Study 2	
<b><u>Common accounts</u></b>	<b>The meaning of work</b>	<i>Positive views about work</i>	Nostalgia to pre- SCI work + plans to return to work (RTW)	Desire to continue work and help people with SCI
	<b>Emotional management</b>	<i>Self-reconciliation</i>	Accepting own limited ability to do certain jobs post-SCI	Accepting own limited capacity when offering support
<b><u>Need and response</u></b>	<b>Support</b>	<i>Emotional support</i>	Struggling to RTW	Sympathy /empathy with SCI clients
		<i>Importance of support</i>	Accentuated support from family and friends	Included family and friends when providing support
		<i>Customised support</i>	Lack of specialised care	Bespoke approach
		<i>Early vocational interventions</i>	No acknowledgement of early vocational support	Early vocational support as part of job responsibilities
		<i>Stigmatisation versus raising public awareness</i>	Reported facing discrimination at work because of SCI	Perceived self as having an essential role in raising public awareness for non-discriminatory employment for SCI individuals
	<b>Vocational goals</b>	<i>Sense of agency when achieving goals</i>	Able to take a personal decision about work after SCI	Encouraged SCI people to take responsibility for achieving vocational goals independently and with minimal support
		<i>Ultimate vocational goal after SCI</i>	Achieved inner peace - not necessarily through RTW	Aimed to achieve high QoL with SCI clients - including RTW

### **Common accounts**

Unemployed SCI individuals in the first study of this thesis shared common accounts with SCI vocational support providers in the second study in terms of the personal meaning of work as well as how emotional challenges relevant to SCI and work were personally managed.

#### **1) The meaning of work**

While participants in both studies differed in terms of their job status (that is, participants in the first study were unemployed while participants in the second study were current

employees), they both offered their personal accounts about the particular value of work to them as individuals.

To elaborate, participants in the first study expressed their nostalgia for the days when they were at work prior to their SCI; they perceived work as a source of enjoyment, self-fulfilment, learning from others and interaction in a social atmosphere. For example, while William generally described his nostalgia for the “*camaraderie*” (p. 15) he used to have with his work colleagues, Mathew was specifically nostalgic for “*mucking around with [...] friends*” and “*speaking to people*” (p. 22) in his previous work.

Similarly, participants in the second study showed their passion for their jobs as vocational and peer supporters, emphasised the notion of two-way reciprocation that existed in their jobs and expressed their satisfaction with the positive relationships they were able to have with their clients, which was illustrated in a quote from Adam:

*I like to think that I can get on with pretty much anybody [...], which is really vital in this type of work. (p. 25)*

In addition, participants in the first study perceived work as important following SCI. Most of them had plans to RTW; they wanted to pursue success in their vocational lives following SCI and be more recognised for their abilities than their disabilities. Mark put that beautifully when he spoke about what it meant to him to start a new job following SCI:

*I want to speak to kids in secondary school because I believe we have got a lost generation and if I can inspire and motivate even one or two, that makes my injury worthwhile. (p.14)*

Likewise, participants in the second study desired to continue working with people living with SCI by helping them become less marginalised and having their voices heard more in society. Vicky was passionate about her educational role in this regard, which framed the core meaning of her job to her:



*If I can educate other people and help other people, with a spinal cord injury, then my job is done. (p. 29)*

What might make this commonality between the two groups of participants even stronger is the observation that all participants were living with SCI. In other words, it might be that people living with SCI perceive work as having a special value, whether employed following SCI or not. However, even if there is more to the picture than these studies demonstrate, it is still of interest to note the mutuality between the two groups in terms of the deep meaning of work regardless of the injury.

## **2) Emotional management**

In this thesis, while SCI employment was perceived as highly important, the ability to emotionally manage challenges related to limited work capacity and/or work opportunities was experienced by both groups of participants and was believed to have been gained with time and resilience. Self-reconciliation was an important aspect of the experience of both groups of participants and was relevant to accepting their limited ability to perform certain tasks as well as absolving feelings of guilt.

In the first study, resilient participants overcame negative feelings to accept that there were certain jobs and life activities that were difficult to perform after their injuries. This was more marked in participants such as Andy, who did physically demanding jobs prior to their SCI:

*I am still pushing myself, but you can only push yourself as far as your body will let it go. With the damage that is there, it is never going to be 100% now I do not think. (p. 36)*

Similarly, in the second study, with time and experience, participants were able to overcome their feelings of guilt for not being able to live up to their clients' unrealistic expectations when delivering vocational support. As vocational support providers, participants in the second study believed they were working at their maximum capacity for

helping their SCI clients RTW. For example, Liam illustrated this self-reconciliation in his following quote:

*We are limited to what we can do for people [...] ethically you cannot really do that, but you know that is what ... in your heart you want to do stuff for people and help people more. (p. 23)*

This sense of self-reconciliation helped both groups achieve inner peace and move forward with vocational life by continuing to be productive.

### **Need and response**

In addition to the mutual accounts between participants in the two studies, whenever there was a personal need and/or challenge presented by participants in the first study, participants' accounts in the second study can be seen as responses to those needs and/or challenges. This need and response observation was mainly related to aspects of support and achieving vocational goals following SCI.

#### **1) Support**

In this thesis, fundamental to the meaning of SCI employment was support, which was manifested in both studies. Participants in the first study expressed bitter feelings both over their absence from work following SCI and their struggle with being independent. Where his environment was not fully adapted to his injury, Andy struggled with independently doing simple daily activities after his injury, let alone going back to his previous job as a truck driver and providing for himself and his family:

*I have got to rely on a lot of other people doing even silly minor tasks that you would do yourself, like making a cup of tea or whatever you know [...]. It takes a lot of self-respect away from yourself, knowing that you cannot provide for people, or yourself even. (p. 7 & 30)*

At the same time, as vocational and peer supporters of people with SCI, participants in the second study had sympathy for those people living with SCI who went through such suffering. Echoing Andy from study one, James in study two also used the term 'silly' to express his thoughts about the ways in which his clients were injured:

*People get a spinal cord injury in such simple, silly, ridiculous ways. And I think it is good to be mindful of that. (p. 9)*

Group two participants also had empathy for their SCI clients as part of their job role, as they felt personally able to understand what it is like for people with SCI to think about work. This took the form of either seeing SCI clients as unique individuals or as mutually injured and hence fellow sufferers.

Overall, it can be concluded that where the first group suffered emotionally from leaving work post-SCI, the second group responded to this through acknowledging this suffering and showing emotional support. However, considering the social model of disability, it would have been valuable if the first group had actually had this input from a source of professional support such as the second group, who were not only supporters, but fellow SCI individuals as well. In other words, both sympathy and empathy from professionals in the second group could have eliminated social barriers faced by SCI individuals in the first group in terms of independence and productivity following their injuries.

Another link between the two studies in relation to support after SCI is that of support from family and friends. This was noted in both studies as an important aspect of accepting the injury and contemplating employment recommencement following SCI. While participants in the first study discussed the importance of support from their family (such as when Simon described his family as *"encouraging"* p. 31) and friends for achieving their vocational goals, participants in the second study believed it was important to involve the family and friends of SCI individuals in vocational programmes to fulfil the aim of providing a comprehensive service (e.g. Adam advised that his aim at work was to *"to support spinal cord injured people, their friends, families [...]"* p. 2).

Further to this, both studies shed light on the importance of delivering care that was appropriate to the specific needs of each SCI individual. Participants in the first study described negative experiences of receiving inadequate medical care following their injuries, where healthcare teams *“knew nothing about spinal cord”* (Jack, p. 11). These negative experiences were completely different when the same participants were transferred to specialised physical rehabilitation wards and were looked after by SCI professionals, which enabled some to RTW for a while. While this showed how important it was to receive SCI customised support, participants in the second study emphasised this and believed that, as service providers, an identical pattern of support cannot be delivered to all SCI clients, but rather must be *“people specific”* (Vicky, p. 16).

Both customised support which is tailored to individual needs following SCI and the role of family and friends of SCI people in their plan to RTW have meaningful implications, as they were not only emphasised by people living with SCI but by SCI vocational support providers as well, which should receive more attention by community organisations. To elaborate, considering the human rights model of disability, both of those elements of customised care and support from family and friends seem important in the vocational journey following SCI, and thus need to be considered, perhaps after further exploration and research, when evaluating vocational services in the community.

In addition, it was noteworthy that participants in the second study described how part of their work in vocational and peer support was conducting early interventions with SCI clients during an acute medical stage, which was something that participants in the first study lacked in their experience of initial treatment for SCI. To elaborate, participants' accounts in the first study echoed those in the second study in terms of the importance of support. However, participants' accounts in the first study did not reflect being engaged in support to RTW whilst in hospital and rehabilitation following their injuries. Even Henry, who was able to RTW following his first episode of spinal stroke, attributed his ability to do so to the high level of physical rehabilitation he received at that time. As a result, it can be said that while participants in the second study confirmed that early vocational support services are available for people with SCI at their rehabilitation centres in the UK under the belief that *“if the seed is not planted early on, then it gets harder and harder to change that*

*perception*” (Derek, p. 11), participants in the first study did not recollect this being part of their rehabilitation experience.

These contrasting findings have valuable implications which are relevant to the human rights model of disability, as they reflect the need to make early vocational support in SCI rehabilitation centres more recognisable for patients, which could make it easier and quicker for them to go back to work following their injuries.

Finally, social stigma about the ability to RTW was a challenge that SCI participants drew on in the first study, while working on combatting this stigma was a task that participants in the second study felt they needed to do. To elaborate, participants in the first study expressed bitter feelings over perceived discrimination from job agencies or their pre-injury employers over their ability to work. Jack expressed his frustration in the following words:

*People look at me and they go ‘you have done great things for this, you have done great things for that’, but when you talk about work they go ‘oh it is because you are in a wheelchair’. (p. 43)*

At the same time, participants in the second study expressed their motivation to use their positions in community organisations to push *“towards that side of making sure that the voice of disabled people in society is not marginalised”* (Liam, p. 17) as well as to advocate for them to fight for their right to RTW and remain productive following their injuries. This desire to combat stigma is perhaps more powerful when one considers that study two participants were also people living with SCI.

However, having access to such community services could have been valuable in improving the experiences of participants in the first study as well as making the services provided by participants in the second study more worthwhile, a finding which has implications relevant to the human rights model of disability.

## 2) Vocational goals

Finally, the meaning of work and/or lack of work following SCI was significantly manifested in how the two groups in this thesis viewed vocational goals. Firstly, the ability to take the decision on what was suitable in terms of work following SCI was an important aspect of the experience of participants in the first study, the importance of which was echoed by participants in second study. For example, William took the decision not to work in the aircraft industry anymore for the following reasons:

*It was my decision. I cannot sit in an office for eight hours a day [...] there are lots of things I cannot do in the aircraft industry. (p. 11)*

Additionally, in the first study of this thesis, while participants spoke about their ability to consider a new chapter in their vocational lives (some had concrete plans for work, while others had made an actual start), they did not discuss on any vocational support that they received from rehabilitation or community organisations. As a perceived response to this, participants in the second study expected their clients to take a major role in planning and achieving employment goals. While those participants believed that they could minimally share this responsibility with their clients, they identified their clients' freedom to accept advice and their ability to *"come to their own conclusions"* (Vicky, p. 17).

Nevertheless, emphasising the importance of professional support from community organisations, it could have been different if participants in the first study were guided by community supporters, like those in the second study, before reaching conclusions about what they wanted to do vocationally following their SCI. In other words, it could have been beneficial for participants in the first study to receive a codified service of vocational guidance, counselling and signposting so that their vocational decisions could have been more professionally-informed.

Secondly, participants in both studies reflected that having a comprehensively successful life after SCI was down to more than just having a job. In the final *master group theme* of the first study, after a long journey of suffering, some participants reported that they

reached inner peace; not necessarily or solely through RTW, but through experiencing improved confidence and a strong self-image as men, fathers and breadwinners following SCI. For example, Chris's aim was not only to RTW after his injury, but to do so while feeling confident:

*To be honest to be returning to work I would not want a label [...]. I wanted to be equal to everybody else. (p. 17)*

In what could be seen as a response to this, participants in the second study emphasised that by providing vocational support, they aimed to prepare their SCI clients for work following their injuries, but more importantly, and in light of the human rights model of disability, to help them *“build up their general confidence”* (Derek, p. 2) and *“get on with their lives”* (Vicky, p. 6). This could have important implications in terms of understanding the core of the vocational programmes provided and being on the same page with SCI clients when providing those programmes.

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## Chapter 12: Validity and quality of the two studies

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The validity and quality of research can be considered on different levels. In this final chapter, the assessment criteria of Yardley (2000) for qualitative research as well as the criteria of Smith (2011) for research using interpretative phenomenological analysis (IPA) were deemed to be the most suitable frameworks for assessing the quality of this thesis (comprising studies one and two). Since those criteria can sometimes overlap, the principles of the broader criteria of Yardley (2000) will be presented below, while the specific criteria of IPA by Smith (2011) will be drawn upon where relevant.

According to Yardley (2000), the core considerations when evaluating the validity of qualitative research in psychology are: **(1)** Sensitivity to context, **(2)** Commitment, rigour, transparency and coherence, and finally **(3)** Impact and importance.

Each of the points above will be discussed below in relation to this thesis.

### Sensitivity to context

Yardley's (2000) first consideration when assessing the quality of research is the demonstration of sensitivity to context. This can be through demonstrating familiarity with the existing literature relevant to the topic under investigation, but for qualitative literature in particular, this should also be through demonstrating an awareness of data interpretation in previous empirical work (Yardley, 2000). As both studies one and two in this thesis were phenomenological, sections in the literature review chapters were included which reviewed experiential studies relevant to the topics under investigation in order to enhance the justification and formulation of the current research questions.

Further to this, according to Yardley (2000), sensitivity to context in studies using approaches such as phenomenology should be demonstrated through grounding the research in the philosophy of the approach and the different perspectives considered,



which will help produce profound analysis. Indeed, Smith (2011) sets out that for IPA research to be acceptable it should subscribe to the three theoretical underpinnings of phenomenology, hermeneutics and idiography. In both studies one and two in this thesis, the three theoretical underpinnings of IPA were demonstrated in the research questions, methods of data collection and analysis as well as in the presentation of the findings. Also, IPA matched the methodological and theoretical rationales of the two studies and the researcher's epistemological position in the thesis. Finally, the researcher demonstrated an awareness of the different qualitative approaches in psychology and how IPA, as the chosen approach in this thesis, stood out in answering the two current research questions.

In a different vein, Yardley's (2000) criteria draw attention to the importance of reflexivity by being sensitive to the beliefs and norms of both the researcher and the participants as well as the characteristics of the researcher, such as his or her gender, or status as a professional or a fellow in the topic under investigation. Those characteristics can influence how power is balanced between researcher and participants (Yardley, 2000).

This section will now illustrate how the four types of reflexivity mentioned in chapter three (that is, personal, critical, epistemological and feminist) were embedded in and throughout this thesis.

As mentioned earlier, reflexivity is about the personal involvement of the researcher through his or her choices, experiences and values which inform the research. In this thesis, the researcher demonstrated personal reflexivity mainly due to her career background in vocational rehabilitation (VR) for people living with spinal cord injury (SCI). The researcher demonstrated this through reflecting both on her experience in working with SCI people and in being a fellow VR service provider. Her work experience in Saudi Arabia together with the passion and beliefs she gained during the time she did this job had impacted the way she worked throughout this thesis from designing it (e.g. research question, recruitment and research method) until writing its outcomes. For example, in the second study, the researcher interpreted the overall experience of participants

engaged in SCI vocational support as positive. Although this was evident in the accounts participants provided during their interviews and was audited by the academic supervisor, these interpretations could also have been influenced by the researcher's personal experience of doing the same job.

The researcher also demonstrated personal reflexivity through reflecting on her personal, social and cultural beliefs, which were influenced by the family environment in which she grew up as well as her personal experiences. All of this impacted on how she interpreted participants' accounts in the two studies of this thesis. A good example here is the personal resonance that the researcher felt, due to her studies interruption, with Simon's experience of leaving a high-profile job and at the same time struggling to maintain a positive self-image. While this resonance felt inevitable, Simon's case analysis was audited by the academic supervisor to alleviate any over-interpretation by the researcher.

Furthermore, critical reflexivity is about the researcher's critical evaluation of the social and cultural constructs which shape the research. In this thesis, critical reflexivity was present through a reflection of the researcher's knowledge of social and cultural constraints for people with SCI and/or their support providers as well as issues related to marginalisation or underestimation of those two groups. For example, the researcher reflected on the unheard voices of unemployed individuals living with SCI that motivated the completion of the first study. The two main motivations for this thesis were the researcher's previous workplace observation of the neglect of the voices of unemployed individuals who did not verbalise an intention to return to work (RTW) after SCI and the discovery that existing literature focusing on this population was lacking.

Epistemological reflexivity, on the other hand, is about the researcher's theoretical and epistemological position as well as the evaluation of how the design of the research can help understand the investigated phenomenon. In this thesis, the researcher believed in knowledge creation through giving voice to participants. While using IPA to create knowledge in this thesis meant that the researcher had an essential role in interpreting those voices, the researcher recognised participants as embodied agents who were able

to make sense of their own experiences in the first place. A good example here is of the researcher's initial over-interpretation of some of the participants' accounts of anger and helplessness in the first study as demonstrating hatred of their conditions rather than bitter feelings; this was alleviated by the academic supervisor's audit, which ensured that the researcher's voice was not higher than the participants'. In other words, epistemological reflexivity was demonstrated through the researcher's learnt balance between her analytical voice and those of her participants.

Finally, feminist reflexivity refers to the impact of the perceptions of gender differences on the research, of which the researcher should be aware. In a number of occasions in the first study, feminist reflexivity demonstrated by the researcher impacted how the interview schedule was devised and how some of the interview questions were asked. For instance, as mentioned before, the researcher did not include questions related to masculinity in the interview schedule of the first study in this thesis. This was because, as a female from a different culture, the researcher did not want to colour her participants' experiences with her own perception of masculinity. Instead, she believed that this topic would emerge naturally if it was important to participants, which it did; participants drew widely on the effect of SCI, and particularly losing work, on their self and social images as tough men, fathers and/or family breadwinners.

### **Commitment, rigour, transparency and coherence**

The second consideration in Yardley's (2000) criteria is relevant to commitment, rigour, transparency and coherence. Commitment refers to the researcher's demonstration of skills and competences to use the methods chosen for the research project as well as to his or her engagement with the topic under investigation (Yardley, 2000). The researcher's stance in this IPA work was committed to experiential research, which is evident from the research design for both studies. Furthermore, this commitment was shown through the researcher's attentiveness to the idiographic experiences of participants as single cases in both studies during data collection and analysis. Finally, the researcher was committed to the experiences of participants not only as an IPA researcher, but also as a professional and a fellow VR service provider.

Rigour, in Yardley's (2002) criteria, refers to the appropriateness of the sample for answering the research question and its suitability for producing an in-depth analysis that constructs different levels. In studies one and two, the samples were small, homogeneous and purposive, which met the criteria for in-depth IPA initial idiographic analysis, followed by analysis across cases where convergences and divergences were presented within each theme. Smith's (2011) suggestion for measuring the prevalence of extracts among participants for each theme as a means of evaluating the quality of the IPA analysis guided the inclusion of themes at different levels of the current analyses. Each theme presented in the current cross-case analyses was elaborated on in-depth, which allowed interpretative analysis to be conducted.

Furthermore, both Yardley (2000) and Smith (2011) include transparency and coherence in their criteria for assessing the quality and validity of qualitative research. Transparency refers to the degree of disclosure by the researcher about how all the stages of the research process were carried out, meaning that these stages need to be clearly written up in the research report (Yardley, 2000). In this thesis, transparency was enhanced by detailing how the research questions were rationalised, how participants were carefully recruited, how the interview schedules were devised and how interviews were analysed both individually and across cases (this was supported by examples in tables and figures in the method sections of both studies).

As part of being transparent, Yardley (2000) emphasises that the researcher needs to be reflexive, especially with regards to how his or her own experiences affected motivations for the research and how external constraints affected research choices. In this thesis, the researcher detailed how her personal passion for the topic developed and how her personal beliefs about the importance of work affected the design as well as the analysis of the data in both studies. Moreover, constraints with regards to recruitment sites as well as certain inclusion criteria for participants were documented.

Coherence in qualitative reach refers to the clarity of how the research question matches the method of analysis and the philosophy adopted (Yardley, 2000). This was evident in the previously mentioned commitment of the thesis to the three theoretical

underpinnings of IPA. In this thesis, the two research questions were open, experiential and exploratory.

According to Yardley (2000), coherence also refers to the quality of the narrative and the production of reality that is meaningful to participants. Narratives in both of the current studies included issues that were directly relevant and meaningful to participants' personal experiences. Participants in the first study were interviewed about a significantly life-changing event that happened to them. In addition, the aim of interviewing participants in the second study was to explore their personal experiential accounts about their work as VR support providers rather than what they thought about the experiences of their SCI clients who use VR services.

### **Impact and importance**

The third and final consideration in the criteria of Yardley (2000) is impact and importance of qualitative research. According to these criteria, for research to be important it should help understand a topic in a new way and allow a wider impact through further research (Yardley, 2000). This thesis explored new experiential perspectives on the meaning of employment and/or lack of employment following SCI. The importance of this thesis is that it offers rich experiential data which compliments, enhances and adds to existing literature. It also encourages future researchers to explore issues relevant to this topic in light of the current outcomes.

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## Appendix (1): Ethics approval letters for the first study



### **Health Research Authority**

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01 July 2016

**Miss Wafa Turkistani  
IPA Research Group  
Birkbeck  
University of London  
Malet Street  
London  
WC1E 7HX**

Dear Miss Turkistani

**Study title:** Exploring the Personal Experience of Transitioning from Employment to Unemployment following Spinal Cord Injury: an Interpretative Phenomenological Analysis  
**REC reference:** 16/LO/0852  
**Protocol number:** n/a  
**IRAS project ID:** 178895

Thank you for your letter of 08 June 2016, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information was considered in correspondence by a Sub-Committee of the REC. A list of the Sub-Committee members is attached.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Mrs Kieran Hall, [nrescommittee.london-bloomsbury@nhs.net](mailto:nrescommittee.london-bloomsbury@nhs.net).

#### **Confirmation of ethical opinion**

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

The Sub-Committee *suggest* that you make it explicitly clear that the participants will receive no remuneration.

The Sub-Committee also *suggest* that you reconsider how long the recorded data be stored, for instance, could it be destroyed after transcription.

They also *suggest* that you provide the number for PALS as an additional signpost on the PIS.

A Research Ethics Committee established by the Health Research Authority

## Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

## Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett ([catherineblewett@nhs.net](mailto:catherineblewett@nhs.net)), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

## Ethical review of research sites

### NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

## Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Covering letter on headed paper ]		23 March 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Indemnity letter ]		23 July 2015
Interview schedules or topic guides for participants [Interview Schedule ]	1.0	22 March 2016
IRAS Checklist XML [Checklist_24032016]		24 March 2016
IRAS Checklist XML [Checklist_13062016]		13 June 2016
Letters of invitation to participant [Letter of invitation to participants ]	1.0	22 March 2016
Other [Letter from the on-site supervisor at the hosting NHS Trust (NISC approval)]		03 March 2016
Other [Summary CV for on-site supervisor at hosting NHS Trust [Principle Investigator (PI)]]		10 March 2016
Other [Debrief form ]	1.0	22 March 2016
Other [Honorary contract with Buckinghamshire Healthcare Trust ]		17 February 2016
Other [Good Clinical Practice Certificate ]	n/a	09 April 2016
Other [Favourable opinion letter Masters degree 2013]	n/a	28 June 2013
Other [RESPONSE TO PROVISIONAL OPINION LETTER]	n/a	08 June 2016
Other [Email clarification re: Lone Worker Policy]		27 June 2016
Participant consent form [Revised consent form ]	1.1	08 June 2016
Participant information sheet (PIS) [Revised PIS]	1.1	08 June 2016
REC Application Form [REC_Form_13062016]		13 June 2016
Research protocol or project proposal [Revised Research Protocol ]	1.1	08 June 2016
Summary CV for Chief Investigator (CI) [Summary CV for Chief Investigator (CI) ]		12 March 2016
Summary CV for Chief Investigator (CI) [Revised Summary CV CI version 1.1]	1.1	30 May 2016
Summary CV for student [Summary CV for student ]		12 March 2016
Summary CV for student [CV summary for student ]	1.1	30 May 2016
Summary CV for supervisor (student research) [Academic supervisor's summary CV]		12 March 2016

## Statement of compliance

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

## After ethical review

### Reporting requirements



The attached document “*After ethical review – guidance for researchers*” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### **HRA Training**

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

<b>16/LO/0852</b>	<b>Please quote this number on all correspondence</b>
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With the Committee’s best wishes for the success of this project.

Yours sincerely



**On behalf of  
Reverend Jim Linthicum  
Chair**

**Email:** [nrescommittee.london-bloomsbury@nhs.net](mailto:nrescommittee.london-bloomsbury@nhs.net)

**Enclosures:** List of names and professions of members who were present at the meeting and those who submitted written comments

“After ethical review – guidance for researchers”

**Copy to:** Dr Sarah Lee  
  
Denise Watson,  
Research and Development

**London - Bloomsbury Research Ethics Committee**

**Attendance at Sub-Committee of the REC meeting**

**Committee Members:**

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Reverend Jim Linthicum <b>Chair</b>	Lay member - Hospital Chaplain	Yes	
Dr Nabila Youssouf	Research Fellow in Clinical Trials	Yes	

**Also in attendance:**

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Ewa Grzegorska	REC Assistant



## Health Research Authority

Miss Wafa Turkistani  
IPA Research Group, Birkbeck, University of London  
Malet Street  
London  
WC1E 7HX

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

10 August 2016

Dear Miss Turkistani

**Letter of HRA Approval for a study processed  
through pre-HRA Approval systems**

**Study title:** Exploring the Personal Experience of Transitioning from Employment to Unemployment following Spinal Cord Injury: an Interpretative Phenomenological Analysis

**IRAS project ID:** 178895

**Sponsor:** Birkbeck, University of London

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **HRA Approval**. This has been issued on the basis that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).

### **Participation of NHS Organisations in England**

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with [HRA Approval Processes](#). It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate [Statement of Activities and HRA Schedule of Events](#). The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study. If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA..

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from [www.hra.nhs.uk/hra-approval](http://www.hra.nhs.uk/hra-approval).

#### **After HRA Approval**

In addition to the document, “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to [hra.amendments@nhs.net](mailto:hra.amendments@nhs.net).
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

### **Scope**

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

### **User Feedback**

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at [hra.approval@nhs.net](mailto:hra.approval@nhs.net). Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

### **HRA Training**

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the [HRA website](#).

Your IRAS project ID is 178895. Please quote this on all correspondence.

Yours sincerely

HRA Approval Team

Email: [hra.approval@nhs.net](mailto:hra.approval@nhs.net)

Copy to: *Dr Sarah Lee  
Denise Watson, Research and Development, Stoke Mandeville Hospital*

IRAS project ID	178895
-----------------	--------



Wafa Turkistani <wturki01@mail.bbk.ac.uk>

**RE: - IRAS 178895; REC ref no: 16/LO/0852 - Request for Non-Substantial AMENDMENT - Category B amendment**

1 message

amendments hra (HEALTH RESEARCH AUTHORITY) <hra.amendments@nhs.net> 29 September 2016 at 12:31  
To: Wafa Turkistani <wturki01@mail.bbk.ac.uk>  
Cc: Jonathan A Smith <Ja.smith@bbk.ac.uk>, "Jones Kevin (BUCKINGHAMSHIRE HEALTHCARE NHS TRUST)" <Kevin.Jones@buckshealthcare.nhs.uk>, "Garmon-Jones Lydia (Bucks Healthcare)" <Lydia.garmon-jones@buckshealthcare.nhs.uk>, "Lambert Sharon (Bucks Healthcare)" <Sharon.Lambert@buckshealthcare.nhs.uk>, Sarah Lee <sarah.lee@bbk.ac.uk>, "k.boock@bbk.ac.uk" <k.boock@bbk.ac.uk>

Dear Miss Wafa Turkistani,

<b>IRAS Project ID:</b>	178895
<b>Short Study Title:</b>	The Experience of Unemployment in Spinal Cord Injury (Version no. 1.1)
<b>Date complete amendment submission received:</b>	26/09/2016
<b>Amendment No./ Sponsor Ref:</b>	16/LO/0852/AM01 – Change in PI to Dr Kevin Jones
<b>Amendment Date:</b>	26/09/2016
<b>Amendment Type:</b>	<b>Non-substantial</b>

Thank you for submitting the above referenced amendment. In line with the UK Process for Handling UK Study Amendments I can confirm that this amendment has been categorised as:

- **Category B** - An amendment that has implications for, or affects, SPECIFIC participating NHS organisations

You should now provide this email, together with the amended documentation, to the research management support offices and local research teams at your participating NHS organisations in England that are affected by this amendment.

If you have participating NHS organisations in Northern Ireland, Scotland and/or Wales that are affected by this amendment, you should communicate directly with the relevant research teams to prepare them for implementing the amendment, as per the instructions below. You do not need to provide this email or your amended documentation to their research management support offices, as we will pass these to the relevant national coordinating functions who will do this on your behalf.

IRAS: 178895, Confirmati... x (83 unread) - waturkistan... x book\_476\_0.pdf x

https://mail.google.com/mail/u/0/#sent/1569834153e742ed

**Birkbeck** UNIVERSITY OF LONDON

in: sent

Mail

3 of 108

COMPOSE

Inbox (679)

Starred

Important

Sent Mail

Drafts (1)

More

Sent: 17 August 2016 12:13  
To: 'Wafa Turkistani'; Sarah Lee  
Cc: Kennedy Paul (Bucks Healthcare) Psychology NSIC  
Subject: IRAS: 178895, Confirmation of Capacity and Capability at Buckinghamshire Healthcare NHS Trust.  
Importance: High

People (8)

Lambert Sharon (Bucks H...  
sharon.lambert@buckshealthcare...

Show details

Dear Miss Wafa Turkistani,

**RE: Confirmation of Capacity and Capability at Buckinghamshire Healthcare NHS Trust.**

**Full Study Title:** Exploring the Personal Experience of Transitioning from Employment to Unemployment following Spinal Cord Injury.

This email confirms that Buckinghamshire Healthcare NHS Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation. Based on HRA approval letter dated 10th August 2016.

Date site selected 15/08/2016 (date of provision of local information package by CI including HRA approval letter)  
We agree to start this study on 17/08/2016.  
Target of Patients to recruit to this study is 12.  
First Patient to be recruited by 24/10/2016 as per metrics set by Department of Health.  
Study end date is 14/06/2019.

You will find attached a version control form for your site file. Should any amendments be necessary could you please let the Research office know as soon as possible.

If any changes are made to the team could you also let us know so our records can be amended.

You will be asked to provide recruitment numbers on a monthly basis. Could this please be done in a timely manner to ensure that all recruitment reports (reported at National Level), reflecting our performance, are accurate.

I have also enclosed a copy of an auditing form used by the trust when auditing a study, this gives good guidance on the expectations of your study file and recording patient data, if you have any queries relating to this then please contact Jacqui Carr (07825 281910).

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

Sharon

Sharon Lambert  
Research Information Officer  
R&I  
Stoke Mandeville Hospital  
Tel. 01296 316200  
[Sharon.lambert@buckshealthcare.nhs.uk](mailto:Sharon.lambert@buckshealthcare.nhs.uk)

CLINICAL RESEARCH IMPACT  
2015

11:14  
18/08/2016



**Appendix (2): Invitation letter for participants in the first study**



**Research Project Invitation**

<b>Study Title</b>	<i>Exploring the personal experience of individuals transitioning from employment to unemployment following spinal cord injury</i>
--------------------	--

Dear (name of participant)

I am writing to invite you to take part in a research project under the title '***Exploring the personal experience of individuals transitioning from employment to unemployment following spinal cord injury***'. As you will see from the **information sheet** enclosed, this would involve participating in a one-to-one interview to explore personal views and perspectives on the experience of leaving work following spinal cord injury.

Please read the information sheet enclosed which will explain more about the project. I will be available to answer any questions you may have before you decide whether you would like to take part in the project or not. Please note that your participation is entirely voluntary, and there will be no further consequences if you decide not to take part.

Thank you for taking the time to read this material.

Yours sincerely,

**Wafa Turkistani**

**Appendix (3): Participant information sheet in the first study**



**Participant Information sheet - to be handed to potential interviewees**

<b>Study Title</b>	<i>Exploring the personal experience of individuals transitioning from employment to unemployment following spinal cord injury</i>
--------------------	--

Wafa Turkistani

Professor Jonathan Smith

Dr Kevin Jones

Researcher

Academic supervisor

Research key contributor

Birkbeck, University of London

Birkbeck, University of London

Stoke Mandeville Hospital

[Wturki01@mail.bbk.ac.uk](mailto:Wturki01@mail.bbk.ac.uk)

[Ja.Smith@bbk.ac.uk](mailto:Ja.Smith@bbk.ac.uk)

[Kevin.Jones@buckshealthcare.nhs.uk](mailto:Kevin.Jones@buckshealthcare.nhs.uk)

Dear (name of participant)

We would like to invite you to take part in a study that aims to understand the meaning of leaving work after acquiring spinal cord injury and the perceived views on work and work return.

The study is being done as part of a *Doctorate in Philosophy (PhD)* degree in the **Department of Psychological Sciences, Birkbeck University of London** in collaboration with the **Clinical Psychology Department at the National Spinal Injuries Centre – Stoke Mandeville Hospital**. The study has received NHS ethical approval.

Before you make a decision, you need to understand why this study is being done and what it would involve for you. Please take time to read the following information. Talk to other people about being involved if you wish.

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

Research into employment following spinal cord injury is inconclusive, but little research has looked at the experience of work absence following spinal cord injury. We need to know what it means to leave work due to spinal cord injury and what it means to return to work and the factors that can help the individual take this decision.

The researcher of this study aims to recruit approximately 12 male participants with spinal cord injury between the age of 20 and 55 in order to explore their experiences of being previously employed, but currently unemployed due to spinal cord injury.

The findings of this study will help inform health specialists working in the field of rehabilitation about the experience of work absence in spinal cord injury and develop programmes that meet the needs of unemployed spinal cord injury individuals.

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

No, it will be up to you if you would like to take part. We will describe the study to you and leave this information sheet for you to consider taking part. If you would like to take part, we will ask you to sign a consent form to show you have agreed to be interviewed by the researcher of this study, and to the terms and conditions of participating in this study.

Participating in this study is entirely voluntary. You can withdraw from this study at any time before or during the interview. If you wish to withdraw after the interview, please email the researcher within two weeks (the researcher's email address is provided on the top of this sheet). If you withdraw from the study, your data you provided will not be used in the study and they will be destroyed. You do not have to give a reason why you want to withdraw. Withdrawal will not adversely affect you in any way neither will it affect any future treatment that you might need to receive at Stoke Mandeville Hospital.

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

If you have read and understood the information in this sheet and agreed to take part in this study, you will need to sign the attached consent form and return it by post to the ***Clinical Psychology Department at the National Spinal Injuries Centre at Stoke Mandeville Hospital*** (a stamp is included) within one week of the receipt of this information sheet.

The researcher will contact you to arrange a time that is most convenient to you. You will be invited for an interview which should last between 60 and 90 minutes and should take place at your preferred choice of either your home or Birkbeck, University of London campus.

The researcher will interview you to ask you questions about your typical day before and after the injury. The researcher will also ask questions about your work in the past and

what it means to you as well as the impact of leaving work on your daily life. Finally, the researcher will ask you about what return to work means to you and what could influence this decision. The questions will be open and allow for you to give as much detail as you feel necessary to understand your thoughts.

The interview will be audio recorded; your data will be treated confidentially and anonymously. Any identifying information, such as your name, occupation, place of residence or any other information that could lead to revealing who you are will be changed when transcribing the audio recording.

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

We cannot promise that being interviewed will help you personally, nor there will be remuneration for your participation. However, the information we obtain will be used to improve future vocational services.

### **What will happen to the information I give?**

The researcher will be interviewing you and will transcribe the audio-recorded interview to try to identify the issues you face. The researcher will use examples of what you said to illustrate the issues. All the examples will be anonymous. The transcript of your interview will also be kept anonymous.

The audio recording from the interview will be transcribed and the generated data will be saved on a password protected computer in an access controlled building. The audio recording and the generated data will only be stored for a period of three years or until the end of the study (when the researcher is granted a PhD degree) after which the audio recording will be deleted and its paper copy will be shredded. No identifying information will be stored after this period; all data used after this period will be anonymised.

The information you give during the interview will only be used for the solo purpose of understanding the experience of unemployment in spinal cord injury. Any information you give will not be shared with a third party.

However, please note that where you disclose any information that could indicate the intention of harm to others or any information that the researcher finds to require immediate attention, the researcher will have to notify the supervisors of this study who might have to report the case to legal authorities.

If you take part in the study, you can be informed of its results when they become available. Please contact the researcher (Wafa Turkistani) who can offer you with a summary of the study results.

The researcher has plans to publish the results of this study in relevant journals and present them in conferences. Anonymity of participants' identities will be guaranteed and all identifiable information about them will be changed in any papers or documents resulting from the research.

**What do I do if I need support following taking part in the study?**

If you feel that the study has raised emotional, psychological or vocational concerns and you wish to speak to someone about them, the researcher will provide you with a debrief form following your interview which will contain information on support resources that you may find helpful.

**What do I do if I want to make a complaint?**

The researcher will carry out the study ethically as a matter of course with high ethical standards in a sensitive manner. However, if you feel you need to raise any complaints, please contact the following:

*Dr Kevin Jones*

*Clinical Psychologist*

*Buckinghamshire Hospital NHS Trust*

*The National spinal Injuries Centre*

*Stoke Mandeville Hospital*

*Mandeville Rd, Aylesbury, Buckinghamshire HP21 8AL*

*E-mail address: [Kevin.Jones@buckshealthcare.nhs.uk](mailto:Kevin.Jones@buckshealthcare.nhs.uk)*

*Tel: 01296315823*

If you have any further questions, please do not hesitate to contact the research team on:

[Waturki01@mail.bbk.ac.uk](mailto:Waturki01@mail.bbk.ac.uk) or [Ja.Smith@bbk.ac.uk](mailto:Ja.Smith@bbk.ac.uk)

**\*Thank you for taking the time to read this information and considering taking part in the study.**

**Appendix (4): Informed consent form in the first study**



**Consent form**

<b>Study Title</b>	<i>Exploring the personal experience of individuals transitioning from employment to unemployment following spinal cord injury</i>
--------------------	--

Wafa Turkistani	Professor Jonathan Smith	Dr Kevin Jones
Researcher	Academic supervisor	Research key contributor
Birkbeck, University of London	Birkbeck, University of London	Stoke Mandeville Hospital
<a href="mailto:Wturki01@mail.bbk.ac.uk">Wturki01@mail.bbk.ac.uk</a>	<a href="mailto:Ja.Smith@bbk.ac.uk">Ja.Smith@bbk.ac.uk</a>	<a href="mailto:Kevin.Jones@buckshealthcare.nhs.uk">Kevin.Jones@buckshealthcare.nhs.uk</a>

**Please provide your initials next to where you agree:**

I agree to take part in the above study.

.....  
 I confirm that I have read the information sheet dated 22 September 2016 (version 1.2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

.....

I agree to the interview being audio recorded.

.....

I understand that I have the right to ask for the audio recording to be turned off at any time during the interview.

.....

I understand that the interview transcript generated from the audio-recording, after changing any identifiable or personal data, will be shared with the academic supervisor of this study for the purpose of supervision.

.....

I understand the responses I give will be treated as confidential; anonymity of my identity will be guaranteed and all identifiable information about me will be changed in any papers or documents resulting from the research.

.....

I understand that information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

.....

I understand that in case of disclosing any information that could indicate the intention of harm to others or any information that the researcher finds to require immediate attention, the researcher will have to breach confidentiality by notifying the supervisors of this study who might have to report the case to legal authorities.

.....

I understand that the audio recording from the interview will be transcribed and the generated data, together with the audio recording, will be saved on a password protected computer in an access controlled building for a period of three years or until my PhD is completed before they are destroyed.

.....

I understand that participation in this study is entirely voluntary and refusal to take part involves no penalty neither any adverse impact on any future treatments I might need to receive at Stoke Mandeville Hospital or any NHS premises.

.....

I understand that I may withdraw from the study at any point before or during the interview. I also understand that I could withdraw from the study; by emailing the researcher within two weeks after the interview has been conducted, and in this case the data I have provided will not be used in the research and will be destroyed.

.....

I understand that following my interview I will be provided with information on where to seek help if I feel that the study has raised any emotional or vocational concerns

.....

I understand that there will be no remuneration for my participation in this study. However, I confirm that I acknowledge its foreseen vocational benefits to the spinal cord injury population.

.....

**By signing this form I am stating that I am over 16 years of age, and that I understand the above information and consent to participate in this study.**

Name..... Signature.....  
(Participant) Date.....

Name..... Signature.....  
(Person taking consent) Date.....

**\*There should be three signed copies, one for the participant, one for the researcher's file, and the original one will be retained by the NHS site for records**



**Appendix (5): Debrief form in the first study**



**Debrief form**

<b>Study Title</b>	<i>Exploring the personal experience of individuals transitioning from employment to unemployment following spinal cord injury</i>
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I would like to thank you for taking part in the above mentioned study, which aimed at exploring the meaning of leaving work after acquiring spinal cord injury and the perceived views on work and work return.

The findings of this study will help inform health specialists working in the field of rehabilitation about the experience of work absence in spinal cord injury and develop programmes that meet the needs of unemployed spinal cord injury individuals.

If you feel that you have been psychologically affected by taking part in the study or by the content of the interview, you may find the following sources useful in seeking support and counselling:

Source	Type of service	Contact details
NHS	Psychological counselling for distress, anxiety and depression	<a href="http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/free-therapy-or-counselling.aspx">http://www.nhs.uk/Conditions/stress-anxiety-depression/Pages/free-therapy-or-counselling.aspx</a>
Clinical Psychology Department at Stoke Mandeville Hospital	Psychological counselling	Dr Kevin Jones <a href="mailto:Kevin.Jones@buckshealthcare.nhs.uk">Kevin.Jones@buckshealthcare.nhs.uk</a> <b>Tel: 01296315823</b>

Also, you may find the following resources useful for advice on return to work

Name of source	Type of service	Website	Contact details
National Careers Service	Skills Health Check + Careers advice	<a href="https://nationalcareersservice.direct.gov.uk/tools/skillshealthcheck/Pages/default.aspx">https://nationalcareersservice.direct.gov.uk/tools/skillshealthcheck/Pages/default.aspx</a>	Tel: 0800 100 900
GOV.UK	Disability employment advisors	<a href="https://www.gov.uk/looking-for-work-if-disabled">https://www.gov.uk/looking-for-work-if-disabled</a>	-

For further advice, please contact the research team:

<b>Name</b>	<b>Job title</b>	<b>Organisation</b>	<b>Email address</b>
Dr Kevin Jones	Research key contributor	Clinical Psychology Buckinghamshire NHS Trust The National spinal Injuries Centre Stoke Mandeville Hospital	<a href="mailto:Kevin.Jones@buckshealthcare.nhs.uk">Kevin.Jones@buckshealthcare.nhs.uk</a>
Professor Jonathan Smith	Research academic supervisor	Department of Psychological Sciences, Birkbeck, University of London	<a href="mailto:Ja.smith@bbk.ac.uk">Ja.smith@bbk.ac.uk</a>
Wafa Turkistani	Researcher	Department of Psychological Sciences, Birkbeck, University of London	<a href="mailto:Waturki01@mail.bbk.ac.uk">Waturki01@mail.bbk.ac.uk</a>

**Thank you again for your participation.**

**\*Declaration**

The Research Team declares that the information provided above is in accordance to the best of our knowledge.

Appendix (6): Ethical approval letter for the second study

**Departmental Ethics Committee  
DEPARTMENT OF PSYCHOLOGICAL SCIENCES  
BIRKBECK COLLEGE UNIVERSITY OF LONDON**

**CLASSIFICATION OF RESEARCH PROPOSAL**

**Date of approval:** 11/07/2017  
**Supervisor:** Jonathan Smith  
**Investigator(s):** Wafa Turkistani  
**Reference Number:** 161772  
**Title:** Exploring the personal experience of officers who provide vocational support to individuals with spinal cord injury (SCI) in charity associations.

Dear Jonathan Smith and Wafa Turkistani,

The above application has been given ethical approval by the departmental ethics committee.

You should be aware that it is your responsibility to report any unexpected problems or events arising from the research that might have adverse consequences for you and/or your participants. In the first instance, please discuss with your supervisor who will advise you as to whether the problem causes a change to the planned research and needs further ethical approval from the committee. If so, please submit a revised application giving details of why this is necessary.

Approval for this study expires July 2020. If the study is still ongoing at this time please submit a renewal of ethical approval form that can be found on the departmental webpage.

Please retain this certificate for your records.

Good luck with the research.



Emily Jones  
Chair of the departmental ethics committee  
Date: 11/07/2017

**Appendix (7): Invitation letter for participants in the second study**



**DEPARTMENT OF PSYCHOLOGICAL SCIENCE**

**BIRKBECK UNIVERSITY OF LONDON**

**Research Project Invitation**

<b>Study Title</b>	<i>Exploring the personal experience of officers who provide vocational support to individuals with spinal cord injury in charity associations</i>
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Dear (name of participant)

I am writing to invite you to take part in a research project under the title '***Exploring the personal experience of officers who provide vocational support to individuals with spinal cord injury in charity associations***'. As you will see from the information sheet enclosed, this would involve participating in a one-to-one interview to explore personal views and perspectives on the experience of working in the domain of vocational support services with individuals with spinal cord injury.

Please read the information sheet enclosed which will explain more about the project. I will be available to answer any questions you may have before you decide whether you would like to take part in the project or not.

Thank you for taking the time to read this material.

Yours sincerely,

Wafa Turkistani

**Appendix (8): Participant information sheet in the second study**



**DEPARTMENT OF PSYCHOLOGICAL SCIENCES**

**BIRKBECK UNIVERSITY OF LONDON**

**Participant Information Sheet - To be handed to the potential interviewee**

<b>Study Title</b>	<i>Exploring the personal experience of officers who provide vocational support to individuals with spinal cord injury in charity associations</i>
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**Name of researcher:** Wafa Turkistani (Waturki01@mail.bbk.ac.uk)

Dear (name of participant)

We would like to invite you to take part in a study that aims to understand the experience of working with individuals with spinal cord injury to help them return to work or start any sort of employment following their injuries.

The study is being done as part of a PhD programme in the Department of Psychological Sciences, Birkbeck University of London. The aim of the research team is to complete the project in June 2018.

The study has received ethical approval from the Department of Psychological Sciences Research Ethics Committee of Birkbeck, University of London.

Before you make a decision, you need to understand why this study is being done and what it would involve for you. Please take time to read the following information. Talk to other people about being involved if you wish. The researcher (name and email address above) can be contacted if there is anything that is not clear or if you would like more information.

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

Research into employment following spinal cord injury is inconclusive, but little research has looked at the experience of supporters working with individuals with spinal cord injury to help them with work return. We need to know how the role of supporters in this regard is significant, how it affects your personality and daily living, and what the positive and negative aspects are of doing this kind of work.

### **Why have I been chosen?**

As mentioned above, this study aims at investigating the personal experience of support officers who work at charity associations and help individuals with spinal cord injury return to work. You have been chosen as a potential participant because a friend or a colleague has recommended you for the researcher and believed that your input will enrich the data of this study.

### **What does taking part in the study involve?**

The researcher will contact you to arrange a time and a place that are most convenient to you. You will be invited for an interview which should last approximately one hour.

The researcher will interview you to ask you questions about your role at the charity organization, what it means to you, how it affects your identity and daily living as well as how you perceive yourself developing in this work.

Taking part in this study is entirely voluntary. You can withdraw from this study at any time before the interview. If you wish to withdraw after the interview, please email the researcher within two weeks. You do not have to give a reason why you want to withdraw.

The interview will be audio recorded; the researcher will work to ensure that your data will be treated confidentially and anonymously. Any identifying information will be changed, such as name and workplace. They will also be either changed or omitted when transcribing the audio recording.

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

There is no remuneration designated for participants, and we cannot promise that being interviewed will help you personally, but the information we obtain from you will be beneficial to improve future services.

### **What will happen to the information I give?**

The researcher will be interviewing you and will transcribe the interview. The researcher will identify key points from your interview transcription that could help understand your role in spinal cord injury vocational support services. Examples of what you said will be used to illustrate these points. All the examples will be anonymous. The transcript of your interview will also be kept anonymous.

The audio recording from the interview will be transcribed and saved for three years on a password protected computer in an access controlled building before they are destroyed.

If you have any further questions, please do not hesitate to contact the researcher (Wafa Turkistani) on: [Waturki01@mail.bbk.ac.uk](mailto:Waturki01@mail.bbk.ac.uk)

The project supervisor is:

**Professor Jonathan A. Smith**

*Department of Psychological Sciences, Birkbeck University of London*

*Malet St, London WC1E 7HX*

*E-mail: [ja.smith@bbk.ac.uk](mailto:ja.smith@bbk.ac.uk)*

*Tel: 020 7631 6520*

**\*Thank you for taking the time to read this information and considering taking part in the study.**



**Appendix (9): Informed consent form in the second study**



**DEPARTMENT OF PSYCHOLOGICAL SCIENCES**

**BIRKBECK UNIVERSITY OF LONDON**

**Informed consent form**

<b>Study Title</b>	<i>Exploring the personal experience of officers who provide vocational support to individuals with spinal cord injury in charity associations</i>
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**Researcher's details:**

Wafa Turkistani

[Waturki01@mail.bbk.ac.uk](mailto:Waturki01@mail.bbk.ac.uk)

**Please tick below as appropriate:**

I agree to take part in the above Research project.

.....

I confirm that I have read and understood the information sheet for the above study and have had an opportunity to ask questions. I have had the details of the study explained to me and my questions have been answered to my satisfaction and I understand that I may ask further questions at any time.

.....

I agree for the interview to be audio recorded and then transcribed verbatim. I understand that the generated data from my interview will be saved for three years on a password protected computer in an access controlled building before they are destroyed.

.....

I understand that I have the right to ask for the audio recording to be turned off at any time during the interview.

.....

I understand that the non-identifiable data from the recording will be shared with the researcher's academic supervisor for the purpose of auditing.

.....

I understand that the researcher will work to ensure that the responses I give are treated as confidential, and that no information that could lead to the identification of who I am will be disclosed in any reports on the project, or to any other party. I understand that the researcher will work to ensure that I remain anonymous and that all the information given is used for this study only.

.....

I understand that participation in this study is entirely voluntary and refusal to take part involves no penalty and I may withdraw from the study at any point before or during the interview. I also understand that I could withdraw from the study, by emailing the researcher, within two weeks after the interview has been conducted.

.....

I understand that the results generated from the study I will participate in will be written up for a PhD thesis results and might be presented at conferences and written up in journals. The researcher will endeavour to ensure that any individual data presented is anonymous, without any means of identifying the individuals involved.

.....

**By signing this form I am stating that I am over 16 years of age, and that I understand the above information and consent to participate in this study**

Name..... Signature..... (Participant)

Date.....

Name..... Signature..... (Researcher)

Date.....

**\*There should be two signed copies, one for the participant and one retained by researcher for records.**