Initial investigation into the factors related to employment of individuals living with a Spinal Cord Injury in a specific South African population

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Declaration

I, Lauren Anne Michell declare that this dissertation is my own work. It is being submitted for the degree of Masters of Occupational Therapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

……(signature of candidate)

……..…day of ……..…20…..

Publications and presentations arising from this study

Date	Event	Type of presentation	Title
September 2010	9th Biennial Southern African Spinal Cord Association Congress	Verbal presentation	Initial investigation into the factors that influence the employment status of individuals after a spinal cord injury in the South African context
September 2010	University of the Witwatersrand Health Sciences Research Day	Poster	Initial investigation into the factors that influence the employment status of individuals after a spinal cord injury in the South African context
April 2011	Dr Rosemary Crouch Rose's Colloquium	Verbal presentation	Initial investigation into the factors that influence the employment status of individuals after a spinal cord injury in the South African context

Abstract

BACKGROUND

Many factors have been shown to play a role in employment after a spinal cord injury. Globally the rates of employment post-injury have been disappointing with a rate of 36.8% [1].

METHODS

This mixed methods study was divided into two phases. During phase one qualitative data was gathered. This data was used to design a questionnaire which was emailed to members of the Quadpara Association of South Africa in phase two. Bivariate data analysis was performed and a logistic regression.

RESULTS

Eleven themes emerged from phase one. There was a high employment rate of 79.55% at the time of the study and 92.13% had worked for remuneration since injury. There was a statistically significant association between employment at the time of the study and six factors.

CONCLUSION

This study had a surprisingly high employment rate post-injury. Despite few results being statistically significant there were many that are of clinical importance.

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Operational definitions

Employment: Participation in an occupation which results in remuneration[2,3].

Tetraplegia: Is made up of two Greek words, “tetra” meaning four and “plegia” meaning paralysis. This has been accepted as the term used and not quadriplegia as this combines a Latin word “quadra” meaning four with the Greek word “plegia”. Tetraplegia is injury to nerves C1 to C8 in the spinal column resulting in motor and or sensory dysfunction[4].

Paraplegia: Derived for the Greek words “para” meaning two and “plegia” meaning paralysis. Injuries from T1 and below are classified as paraplegia[4].

Occupational Therapy Practice Framework II: A summary of the interrelated constructs that guide and define occupational therapy practice[5].

Sector Education and Training Authorities (SETAs): Defined by the Skills Development Act. Each SETA has its own sector and sub-sector which is related to a group of economic activities in both the private and public sectors. They are responsible for learnerships, internships, unit based skills programmes and apprenticeships within their sector[6].

CHAPTER 1: INTRODUCTION

1.1 Background to study

A spinal cord injury (SCI) is a life changing event that occurs to people in all countries in the world, affecting all ages, religions, cultures and socioeconomic levels. It usually has a devastating effect on participation in life, including the area of work or employment.

Employment is often used as a measure of overall recovery from illness or disability and successful rehabilitation[7]. Employment is a role assumed by adults which is essential for providing economic self-sufficiency, but it also has many psychological and social benefits such as improved self-esteem, interpersonal relationships and volition[8,9].

Employment is also important on a national level as taxes are derived from those that are employed. Those that are unemployed due to a disability will no longer contribute and may qualify for social assistance and require government funding therefore draining the *fiscus* rather than contributing to it.

Employment after a SCI has been well researched in developed countries. The rates of employment post-injury have been disappointing. In a review spanning from 1992 to 2005 Young et al. reported a global employment rate of 36.8%[1].

Internationally the age of onset of SCI is between 20 and 40 years of age, with less developed countries having lower mean age averages[10]. The South African studies report that the mean age at the time of injury ranges from 29.19 to 34.7 years of age[11-14]. This age is a critical stage of life for employment and career development.

According to Super's Career development theory, the career exploration stage takes place in late adolescence with Crystallization of Preference taking place between 18 and 21 years resulting in a choice of study, or a first job. This is followed by specifying a vocational preference in the early twenties as a first job is tried out as life's work. However, the implemented choice is provisional and a person may cycle back through crystallizing and specifying if it is not appropriate.

From 25 to 40 years of age the stage of Establishment takes place. This is made up of a Trial and Stabilization sub stage (25-30 years old) consisting of the process of settling down with possibly one or two job changes before the right job is found. Between 30 and 40 years the sub stage of Advancement takes place. The individuals efforts are directed at securing one's position, acquiring seniority, developing skills and demonstrating superior performance in the work place[15]. An injury therefore between the ages of 20 and 30 would affect career development and could take an individual from the advancement sub stage back to the crystallization of preference sub stage.

1.2 Statement of the problem

Documenting the employment of persons living with a SCI in developing and less industrialised countries (according to World Health Organisation and World Bank websites) is inadequate. In a review of literature from 1975 to 2006, out of 101 articles used only 4 were from developing countries[8]. A review from 1992 to 2005, reveals that only 2 out of the 48 articles used were from developing countries[1]. In a systematic review of literature from 2000 to 2006 on return to work following a SCI by Lidal, Huynh and Beiring-Soensen[9], it was found that there was a lack of reports from developing countries on employment after SCI. It was thus concluded that the under-reporting of the employment of people living with SCI presents an opportunity for further research.

South Africa is regarded as a developing country according to the World Bank[16]. There is a paucity of literature in peer reviewed journals on employment after a SCI in South Africa. Research in this area is therefore required.

The prevalence and aetiology of SCI in South Africa is largely unknown. The few studies that have been done in South Africa show that violence-related and motor vehicle accidents are the leading causes of injuries[11-14,17-20]. The size of the population of individuals living with SCI in South Africa is therefore unknown.

South Africa has no National Database to record the incidence of SCI[17,21]. The Quadpara Association of South Africa (QASA) estimates that every year approximately 500 South Africans sustain a spinal cord injury as a result of trauma. Many of these injuries occur in young people aged between 15 and 29 years old[17]

and the percentage of these individuals that return to be economically productive is largely unknown. There have been limited studies in South Africa to investigate employment after a SCI. Several studies have mentioned the employment rate as part of their results[12,13,22], but none have investigated the aspects that influence employment. Phase two of this study focuses on one section of individuals living with a SCI namely those with access to the internet. Although this sample does not represent the status of all individuals in South Africa living with a SCI, it provides some insight into employment status among the SCI population which to date, have not been investigated.

Many factors have been shown to play a role in employment after a SCI. These include demographic variables (e.g. age, gender, marital status, race); injury related factors (e.g. lesion severity and the time since injury); educational and vocational factors (e.g. vocational counseling, employers' attitudes and education); and general factors (including social support, medical problems, psychological state and the environment)[8]. The role and impact of these factors in the South African context is unknown.

Despite a dearth of information regarding the employment of people with disabilities in general, and persons with SCI specifically, there are sociopolitical factors which should contribute to their employment possibilities in South Africa. In 1996 the South African Constitution was promulgated and resulted in various Acts such as the Employment Equity Act[23], the Promotion of Equality and Prevention of Unfair Discrimination Act[24] and the Labour Relations Act[25] being adopted. These acts have the potential to prevent discrimination against people living with disabilities[26] and assist them in returning to work. This legislation should have provided a more conducive environment for returning to work. However the impact of the legislation on employment after a SCI in South Africa has not been investigated.

1.3 Research question

Based on the statement of the problem of a lack of investigation into employment after a SCI and the factors which affect employment, the following research question was asked "What are the factors that affect employment of individuals living with a Spinal Cord Injury in a specific South African population post-injury?"

1.4 Purpose of the study

Due to the under-reporting on SCI in South Africa an exploratory study was performed. The purpose of this study was to investigate the factors that affect employment after a SCI in South Africa. The employment status and the role these factors had on employment of a specific sample of the South African population were investigated.

1.5 Aims and objectives

The aim of this study was an initial exploration into the factors that influence employment after a SCI in South Africa in a select population. The study was organised into two phases. The aim for each phase with corresponding objectives follows.

1.5.1 Phase one – Questionnaire development

The aim was to develop a self report questionnaire on the employment of South African adults post SCI.

To meet this aim the following objectives were set:

- To define and clarify the variables that affect employment post SCI in SA by collecting data from focus groups and an in-depth interview.
- To format a self report questionnaire on the employment of South African adults post SCI.

1.5.2 Phase two – Implementation of the Questionnaire

The aim was to survey the prevalence of variables that impact employment after a SCI in a select population.

To meet the aim the following objectives were set:

- To describe the employment status of individuals post
- To determine the most influential factors that affect employment status.

1.6 Justification of the study

During the course of this study a questionnaire was designed which aimed to gather information on the aspects which affect employment after a SCI in SA. This is the first questionnaire in SA on employment after a SCI. It can be used as an instrument in further studies with different samples of people living with SCI.

The employment status of people living with SCI in SA and the factors that influence it will be described. Useful information to enhance clinical practice and vocational rehabilitation could emerge. The aspects that affect employment can therefore be addressed during rehabilitation. Patient outcomes might be reviewed and all this could contribute to better employment for individuals living with SCI. The results regarding the awareness and perceived effectiveness of the legislation could aid government in determining the effectiveness of the implementation of legislation and whether the public still require further education on relevant legislation.

1.7 Outline of chapters

Chapter one describes the introduction to the study and consists of the background to the study, the statement of the problem, the purpose of the study, the aims and objectives as well as the justification of the study.

Chapter two captures the literature review. Topics related to employment after a SCI are described. These include the epidemiology of SCI, the value of employment, rates of employment and the aspects that affect employment after a SCI as reported in previous studies.

Chapter three describes the research methodology of this study. The study was conducted in two phases. Phase one involved the development of the questionnaire. Phase two was the piloting and the implementation of the questionnaire with the sample population with the aim to survey to factors that affect employment of people with SCI.

Chapter four illustrates the results. The results of phase one include the themes that emerged from the focus groups and the in-depth interview with one participant, as

well as the questionnaire development. Phase two results begin with the piloting of the questionnaire. The results from the questionnaire follow. These results are presented according the domains of the Occupational Therapy Practice Framework II[5].

Chapter five captures the discussion. The results from phase one and two are discussed using the themes from phase one as a guide.

Chapter six contains the conclusion. This chapter concludes the study and presents the limitations of the study and recommendations for future research.

CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This literature review aims to provide a critical overview of the epidemiology of SCI, followed by the value of employment, the debate regarding the definition of employment and the rates of employment post SCI. The various factors reported in literature from 1992 to 2012 that affect employment post a SCI will be highlighted. These include education, injury related factors, physical and psychological health, demographics factors, the type of employment engaged in pre- and post-injury, the impact of vocational rehabilitation, the role that various environmental factors play and the mentors impact on employment post-injury.

2.2 Epidemiology

Knowledge of the incidence and prevalence of SCI is important because of the chronic nature of the disability. The effects are also felt on a personal and economic level by the individual, the community, and the country.

Information on the annual incidence of SCI is important, to ensure adequate resources are available for acute rehabilitation. With the increased rate of survival and increased longevity due to improved medical interventions, it is important to consider the prevalence of SCI. In addition, it would allow for the evaluation and amendment of prevention strategies, in an attempt to decrease the incidence. Prevalence figures are essential to ensure correct planning and budgeting as individuals continue to require ongoing medical care related to the SCI. Individuals access insurance payouts, or disability grants and there may be loss of tax revenue to the government should they no longer be employed[27]. Therefore if the incidence and prevalence of SCI are known and updated regularly, the country would be in a position to plan and manage the condition effectively.

The global incidence of SCI cannot be accurately determined due to a lack of consistency in the data reporting, or lack of reporting in certain countries[10]. Developed countries such as Western Canada, the United States of America, Portugal, Italy, Japan, Russia and Australia have successfully reported on the

incidence of SCI. Most of these countries have national databases for SCI. Information on these databases promotes effective management of the condition[10]. According to a review of literature by Ackery, Tator and Krassioukov between 1974 and 2000 the incidence of SCI in developed countries is between 14.5 and 57.8 per million people (the higher figures in the range include those who die before arriving at a hospital and the lower figures exclude deaths prior to arriving at hospitals[10]). Similar results were reported in the literature survey on 17 manuscripts from 1995 to 2005 by Wyndaele and Wyndaele. They included studies in the above-mentioned countries, as well as Turkey. The global incidence was between 10.4 and 83 per million people per year, if only the patients that survived to hospital admission are included. They reported prevalence averages for North America of 755 per million inhabitants, Europe 252 and Australia 681. No African studies were found. In fact, Wyndaele and Wyndaele reported that there is very little data for the rest of the world and called for further studies into the prevalence of SCI[28].

South Africa is one of many countries that have no reports on the incidence and prevalence of SCI, nor a have a national database to determine the prevalence of SCI[17,21]. This despite a great need for recording and publishing of this data throughout the world[10,28]. Based on the South African population of 51 770 560 people[29,30] and averages from the global data from Wyndaele and Wyndaele[28], South Africa can be estimated to have a incidence rate of between 538 and 4297 SCI per year. This is higher than the QASA estimate of approximately 500 per year[17]. When considering prevalence in South Africa , according to statistics from the South African Census 2011, 2.3% of the population, that is 1 190 723 individuals make use of a wheelchair[30.] Individuals with tetraplegia and paraplegia would be included in this large category which would include other diagnoses such as strokes and amputations. The aetiology of SCI has been reported far wider than the prevalence and incidence.

It is important to report on the aetiology as the cause and the type of injury can impact on the individual's long term participation in their chosen occupations after a SCI[31]. This information can be used to develop prevention strategies such as road safely campaigns or sports injury awareness to reduce the incidence of SCI in South Africa.

Global trends with regard to causes of SCI are (from most common to least common): motor vehicle accidents, falls, sports or aquatic related injury, violence

related and self induced injuries[10]. These reflect trends in first world countries. Third world countries or countries with an upper-middle income classification according to the World Bank show a slightly different picture. Causes of SCI in countries, including China, Thailand, Russia, Brazil, Iran and Turkey, are falls followed by motor vehicle accidents. Only in Brazil and Turkey is violence the third major cause of SCI[32]. In South Africa however results show that violence-related and motor vehicle accidents are the leading causes of injuries[11-14,17-20]. This is reflective of the socio-economic climate in South Africa and illustrates the high levels of violence and crime in the country, which are different to other countries in this category.

The South African gender distribution of SCI is more reflective of the international trends. Globally, data indicated that there are three to four males injured for each female, but in lower income countries this ratio rises to 8.1 to 1.[10,28] In South African studies the difference ranged from 11:1 at a rehabilitation centre to 1:1 in an acute unit, both in the Western Cape[11,13] and the average of three to four males for each female for studies in Gauteng[12,20], which is reflective of the international literature. The severity of the injury reported in South African studies is slightly different to international trends.

Internationally Ackery et al. reported a higher incidence of cervical injuries (tetraplegics) [10], but Wyndaele and Wyndaele found they accounted for only a third of all injuries[28]. Their reports however agreed that complete and incomplete injuries have almost equal incidence. The South African studies reported more paraplegics than tetraplegics[13,14,20]. It appears that the number of complete and incomplete injuries in South Africa[13] are similar to those in the international literature. Age at injury is also similar in South Africa to the rest of the world.

The age of onset of SCI is reported internationally to be between 20 to 40 years of age, with less developed countries having a lower mean age averages[10]. Wyndaele and Wyndaele reported a global mean age of 33 years[28]. The South African studies report a mean age at the time of injury to range from 29.19 to 34.7 years of age[11-14]. This age band is a critical stage of life for employment, because this is the economically active phase of life.

Literature on all aspects of epidemiology discussed above in SA is extremely limited with regards to all types of SCI which creates scope for further investigation and a need to report on this [28].

Employment is one of the main roles of adulthood which makes the occurrence of most SCI in the economically active phase of life significant. The injury and subsequent hospitalisation and rehabilitation result in a disruption to the person's worker role. Often the resultant deficits require an adaption to the work, or in some cases can even necessitate a job or career change or adversely, complete loss of employment.

If employment is not achieved post-injury there is a loss of earnings to the individual, the family and the country as there is a loss of tax contributions and a reliance on the state for disability benefits[33]. This should be of importance to governments as SCI is reportedly the most expensive condition to treat in the USA[10]. Employment should therefore be an important goal post SCI. However, employment post SCI is affected by many variables and each country should be cognisant of the factors that impact on employment post SCI as these factors may vary from country to country. These factors are reported in the literature and will be discussed in detail later.

2.3 Participation in employment after a spinal cord injury

2.3.1 The value of employment

Employment is often used as a measure of overall recovery from illness or disability and successful rehabilitation[7], as successful employment impacts so many aspects of an individual's life and is the major life role of adulthood[2].

Employment is essential to living an independent adult life, as it allows financial independence and therefore an ability to procure items and services that are needed to support the individual, family or community[34]. Importantly, it is reported that current employment status is a strong predictor of employment status the year following the SCI[35].

There is a significant association between employment and independent living (especially for tetraplegics[36]) and income[8]. When the SCI occurred at 18 years or younger[36] employment was associated with marriage and the ability to drive a car independently.

From a socioeconomic perspective, work prevents poverty and the tangible rewards of generating an income are seen as the biggest motivator to work. As a result, individuals continue to work even if there is very little job satisfaction [2]. Despite this, the positive effect employment has on health[37] and psychological factors are also vital to consider.

The importance of employment from a psychological perspective has received much attention. Employment is perceived to be a source of personal growth and self affirmation [2,8]. It affords an opportunity for social interaction and facilitates a sense of belonging[2,8] and wellbeing, improved self esteem and volition[2]. A positive relationship has been found between employment and longevity, health status, personal satisfaction and positive life adjustment following a SCI[8,9,38]. Those who were employed had an optimistic attitude to life, were more goal-directed and had an improved self concept compared to those who were unemployed. This may be influenced by an individual's pre-existing personality and disposition[39]. In studies where groups of employed individuals were compared with unemployed individuals, the employed groups reported fewer health related problems, secondary complications and hosiptalisations[40-42]. This finding is important, as these aspects influence quality of life, thus those in paid employment have a better quality of life than the unemployed[43,44].

Not surprisingly, employment has been significantly associated with quality of life[44,45] and life satisfaction[36]. Work has been identified as an important aspect of quality of life, with opportunities for employment being one of the three most important domains and significant predictors of quality of life after a SCI. Being employed was also found to enhance many areas of life adjustment after a SCI[46]. In a South African study employment post-injury was a significant predictor of participation post-injury[12]. Employment is therefore a key factor to a meaningful life after a SCI.

Employment after a SCI is influenced by many different factors, from personal to environmental aspects. The first aspect that affects the reported employment rates post SCI is the definition of employment itself.

2.3.2 Employment Defined

Within the body of literature on employment post SCI, two definitions of employment are used[1], i.e. a narrow and a broad definition. Most studies make use of the narrow definition in which work related tasks or services are rendered for pay, whether it is for an employer or in self-employment. The broad definition includes other productive activities such as students, homemakers or volunteers[9]. Furthermore, the terms employment and work appear to be used interchangeably in the literature. There have been calls to standardise the definition of employment used[1].

In order to attempt to standardise terminology, a distinction has to be made between work and employment. Ross's classification of work is helpful in clarifying this distinction.

According to Ross, work can be classified into paid, unpaid, hidden and substitute work[2]. Paid work, according to Ross, refers to work in return for a material reward, usually financial in nature. Unpaid work is that of a volunteer, caregiver or an individual undergoing education or training. Hidden work is done in the informal sector, usually by unregistered organisations that do not declare tax. Substitute work refers to that work historically done by people with disabilities, which is contrived or especially created by sympathetic employers such as family members and constitutes token-jobs instead of real productive work. Substitute work undermines the many efforts by governments to include people with disabilities in the open labour market[2].

From Ross's classification it is evident that only paid work can be considered employment, which coincides with the narrow definition of employment mentioned above. Work on the other hand, includes all manner of productive activities, such as remunerated employment, homemaking and volunteering that are not considered leisure time pursuits or activities of daily living[5], i.e. the broad definition of employment. This seems to resonate with the International Labour Organization, which states that employment involves work that is productive and delivers a fair income [3].

In addition to the inconsistent use of terminology and inconsistent definitions, concepts such as the number of hours worked, full time and part time employment are also not used uniformly in reports. In most studies any time spent in employment, no matter how little, was considered employment. From the researcher's perspective employment is participation in a productive activity that is remunerated in some way.

With the definitions and terminology clarified, the rates of employment after a SCI can now be examined.

2.3.3 Rates of employment

The inconsistent use of terminology alone is not the only factor to affect the reported employment rates. In addition, methodological factors such as the geographical area, the study sample and research methods used also play a role in how employment rates were reported. Other variables include the time since the injury and the inclusion of adults only in the working phase of life[1] in the study.

In order to understand the employment rate as reported in various studies, it should be noted that rate of employment is reported on in two ways. Some studies examine employment rate at the time of the study (referred to as currently employed)[1,9,47] while others report employment at any time since the injury[1].

The reported rates for employment at the time of the study range from 13% to 48% for the narrow definition of employment to 13% to 69% for the broad definition in a review of international literature from 1995-2001 by Yasuda, Wehman, Targett, Cifu and West.[47] This is a smaller range than the more recent review by Lidal et al. from 2000-2006 which reported an employment rate ranging from 11.5% to 75%[1] for all types of employment. In a review spanning both the above-mentioned periods (1992–2005) Young and Murphy reported a global employment rate of 36.8% for individuals of working age at 12 or more months post SCI[1]. This would appear to be the average if Yasuda et al. and Lidal et al.'s studies are considered. Young and Murphy found more individuals employed in Europe than in Australia, the USA and Asia[1]. Reasons for this require further investigation.

Rates of employment any time since injury are generally higher than employment rates at the time of a specific study, but do not address the issue of job retention.

Young and Murphy reported 68% of individuals were employed at any time post-injury in a review of international literature from 1992 to 2005[1]. There is a paucity of information in the African setting, but four studies could be found for countries in the upper-middle income economies[16].

Two Taiwanese studies have been reported, with employment rates of 47%[48] and 21.8%[49] at the time of study. In a Turkish study, 36% of participants that were employed at the time of the SCI returned to employment, although they do not report on their entire samples employment rate[50]. These three studies were done prior to 2005. A more promising result was found in a Malaysian study, where 57.7% were employed at the time of the study and 76.2% at any time since SCI[51]. This is a surprising result as it is one of the few studies post the 2008 economic downturn. The South African information is limited with no published studies with employment post-injury as the main focus.

In the South African context there have been a number of studies that mention employment post-injury as part of the descriptive information. In these studies employment rates vary from 4.1% at six months post discharge(2008-2009)[13], 11% (no mention of the time since spinal cord injury, the time frame in which data was collected is not reported and makes it difficult to compare to other studies)[12] and 56.6% at least 3 months post discharge for a study in a private rehabilitation setting(2009-2010)[22]. These rates fit broadly within the international rates, but were small, convenient samples. These employment rates must be considered against the backdrop of the South African employment rate of 54,6% according the Quarterly Labour force survey, Fourth Quarter 2012[52] and 56,5%.according to Census 2011 results[29], which is much lower than many of the first world countries where studies on employment post-injury have been performed. A further consideration would be the economic down turn in 2008. All but one of these studies were conducted post 2008 in a stained economic environment which may have impacted on work opportunities for all individuals.

Employment after a SCI in South Africa has not been comprehensively investigated. The wide range in employment rates is indicative of the many other factors which influence employment after SCI. The factors that have been shown to have the greatest influence on employment status after SCI will be reviewed. There is variability across studies on the variables that are associated with employment post-

injury. The relationships between factors in studies are often weak, as there are so many variables involved[8].

2.3.4 Education

The level of education is one of the most influential factors in employment post SCI[53]. Numerous studies have found it significantly related to employment status[36,44,48,50,54-58] and it is widely considered a predictor of employment status[35,56,59-62]. Sixteen or more years of education were shown to have the most optimal outcomes, as it resulted in an improved employment rate at the time of a study, increased the participants' employment status at any time since injury, resulted in more hours worked per week and influenced the number of years worked since injury[37,46,63]. The odds of employment increased 1.32 times with each increment of education achieved[64]. A higher level of education resulted in more stable employment over time[46]. A South African study found that people with higher levels of education often are in management or senior positions which are better remunerated, thus making it more attractive to work[12].

While education as a whole is important, the impact pre- and post-injury education have on employment differs. Many studies do not differentiate between pre- and post-injury education. However where the distinction has been made, a higher level of pre-injury education reduced the time it took for them to secure their first job after being injured[65].

Post-injury education has been found to be even more important, as it resulted in greater odds of employment than pre-injury education when statistically controlling for biographic and injury factors historically related to employment status[66,67]. In fact, individuals injured during childhood who completed more than 12 years of education after their injury, had higher rates of employment than those with 12 years of education or less after injury[68]. This illustrates the importance of education after injury in a field that is viable for working post-injury. Even for highly educated individuals at the time of injury, post-injury education improves the chances of employment[67] .

Education can also limit the effect that the level of injury has on employment, as some studies found that post-injury employment status improved as years of

education increased, especially at master's and doctoral levels of education, regardless of the level of injury[35,53]. This is important, as the physical limitations of the injury in the work environment can be lessened by improving one's education.

In a Dutch study retraining post-injury necessarily delayed return to work. Importantly, however, these individuals were happier and required fewer adaptations than those who had not been retrained[57].

Notably, the level of education is therefore a more influential variable than the severity of the injury, contrary to what would be expected.

2.3.5 The injury related factors

The impact that the severity of the injury has on employment post-injury has been reported inconsistently. Krause et al. has found it be to a predictor of labour force participation in three of his studies[61,66,69] with similar samples. A higher Motor Index Score was a significant predicator of return to work[64]. In contrast, the majority of studies have found no relation between employment post-injury and the injury severity[43,56,70]. What has been agreed is that the more severe the injury, the longer it takes to become employed, with individuals living with complete tetraplegia taking the longest and individuals living with incomplete paraplegia the shortest time to secure employment after being injured[10,61,71].

The cause of the injury has not been shown to be an important factor in employment, but it has been found that persons who suffer injuries caused by violence have a lower employment rate than other aetiologies[36,53].

The severity of the injury also influences the type of job one can return to, where cervical injuries require sedentary work for which further education may be required. Pflam, McCollister, Strauss, Shavelle and Devivo reported that individuals living with tetraplegia with a poor educational level have very low employment rates[35].

Apart from the level of education, the impact the severity of an injury has on employment may also be mitigated by rehabilitation.

Rehabilitation post SCI has been largely influenced by Sir Ludwig Guttman, who started specialised units to care for injured soldiers during World War II. Since then many developments have taken place, reducing the mortality rate, improving long term survival and treatment aimed at improving independence and quality of life. SCI rehabilitation begins in the acute phase, then the sub acute phase, discharge and follow-up in the community. The sub acute phase is usually an intensive programme with a multidisciplinary approach, including nursing, physiotherapy, occupational therapy, respiratory management, medical management, psychology, vocational counselling, driver training, nutritional services, speech pathology, social work intervention, sexual health counselling and pharmaceutical services[72].

South Africa has several private hospitals which have SCI rehabilitation units. These are costly and often can only be afforded by those with a medical aid with rehabilitation benefits or when the individual has some form of insurance payout (Workman's Compensation or private insurance). There are several government facilities in urban areas, but large parts of the country do not have easy access to a unit with a specialised rehabilitation team[21]. Without access to rehabilitation many of the factors mentioned above, including independence, health, vocational rehabilitation and the ability to move within the community would not be addressed and may therefore hamper the individual's ability to work.

Rehabilitation could delay return to work. This is important, as the length of time since the injury has been significantly associated to employment post SCI[69]. It has been found to be a predictor of ever having worked[61], or studied since injury as well as the nature of the person's post-injury occupation[59]. Furthermore, there is a positive correlation to the total years employed since injury[46]. However, Tommassen,Post and Asbeck in a Dutch study did not find that time since injury was related to employment. The Netherlands has a well developed social security system and only 37% of the sample were employed at the time of the study. It is not financially viable for many individuals to work, despite many of the unemployed expressing that they thought they were capable of working[56]. This is a different situation to many of the other countries where studies have been done and may account for time since injury not being related to employment post-injury.

The time taken to become employed varies, from an average of 12 months[57] to a range of 4.1[65] and 4.8 years[55]. Interestingly, securing full time employment took longer: from 4.3[65] to 6.3 years[55].

A study in the USA found the probability of working increased as time since injury neared 5 years and plateaued thereafter[35]. Young and Murphy, in their review of literature, found that employment rates increase as time since injury increases, peaking at 10 to 12 years post-injury[1] which is a longer period than the USA study.

As time since injury increases, the individual's independence may increase, especially for those who attended rehabilitation[36,56]. A quantitative study found that individuals only thought about return to work one to two years post-injury[73]. This illustrates how important it is to have continued vocational rehabilitation or vocational support long after initial rehabilitation has been completed. In longitudinal studies the adjustment after a SCI continued beyond the rehabilitation period and did not appear to have an end point[31,74].

Independence has been shown to affect employment status[36,43,48,49,54,56]and has been measured using two scales in the literature, The Functional Independence Measure (FIM) and the Barthel Index.

Higher scores on the FIM, both self report and those completed by a professional, indicating greater independence, have been found in individuals that are employed[36,43,49,54]. This was especially true for the subscale of sphincter control[36]. However, others have argued that the FIM is not a useful predictor of employment and has limited explanatory value[62,70]. It may be useful in determining the time taken to return to work rather than just the outcome of employment[70].

Higher Barthel Index scores are related to higher employment rates[48,56]. Better functional mobility has been associated with employment post-injury[22]. Individuals who are unemployed cite, amongst other reasons, the lack of consistent attendant care to ensure they are able to get to work on time, as a reason for not being able to work[7]. Greater independence would reduce this reason for not working.

Independence post-injury appears to impact employment[8]. The state of one's health also affects employment post SCI, which is highlighted in the next section.

2.3.6 Physical and psychological health

Physical health is an important factor in the process of deciding to return to work and sustaining employment. It may also be the cause of terminating employment. Poor physical health has been reported as a reason for not working[36,43,75]. It has also been found to be an important consideration in the decision making process of deciding whether to return to work or not, post-injury[76]. Individuals that were employed full time post-injury had significantly better physical and mental health. The presence of fewer complications was a predictor of employment[36].

The most common and significant secondary conditions post SCI are chronic pain, respiratory complications, urinary tract infections and pressure sores[71]. Pressure ulcers, serious urinary tract infections (requiring antibiotics or hospitalisation), spasticity, respiratory problems and hospitalisations for aspects other than urinary tract infections were related to employment post-injury. In fact, the first three were significantly associated with employment post-injury[36] in that the incidence of urinary tract infections specifically was found to be a predictor of employment three years post-injury and increased hospitalisations resulted in unemployment[42]. In a study on pressure sore development, there were fewer hospitalisations among those that were employed[41]. This is one instance where the severity of the injury influenced employment, as more tetraplegics were unemployed due to complications than paraplegics[36].

Psychological health, while under reported, also influences employment post SCI. Work participation was reportedly less if a somatic or mental disorder was present[43]. Many factors affect psychological health, such as locus of control (LOC) and attitude to work. Locus of control can be measured using the rehabilitation LOC (RLOC), scale. This scale generates three sub-scores: Internal RLOC (measures the extent to which one believes that internal factors are responsible for rehabilitation outcome), Powerful Others RLOC (relates to the belief that the rehabilitation outcome is determined by powerful others) and Chance RLOC (the extent to which one believes that the rehabilitation outcome is due to fate, luck or chance)[62].

Rehabilitation locus of control and work attitude were found to play an influential role in predicting labour force status post-injury[62]. In a later study, work attitude was shown to be important, but labour force status (i.e. being employed or unemployed at

the time of the study) was significantly related to chance locus of control (LOC), with those individuals with high chance LOC scores less likely to be employed. Similarly, favourable employment outcomes were found for individuals who had higher scores in activity (personality) and an internal locus of control. Lower rates of employment were found for those with neuroticism (anxiety) and chance and powerful others locus of control[69].

In a qualitative study where employed individuals were matched with unemployed individuals, the unemployed had an external locus of control and were pessimistic, whereas the converse was true of employed persons. It was speculated that pessimism and external locus of control probably was a long standing personality trait and not linked to the injury *per se*. The employed had greater motivation and considered work important as it gave them independence to maintain their pre-injury lifestyle, a sense of purpose, in addition to providing mental stimulation and social contact. They also had a better self concept than the unemployed[39].

When facilitators and barriers to employment were assessed, motivation was found to be a predictor of employment post-injury. Motivation consists of the value placed on work (also referred to as the meaning of work) and confidence in one's ability to do the work[61].

Crewe et al. describes how the meaning of work occurs: the individual has to decide that work is important, that they want to be self sufficient, do not want to rely on their disability payout and have a desire to work[77].

Psychological well-being and a desire to work are therefore important aspects in process of returning to work. Various demographic variables, such as marital status also play a role in employment post-injury. These demographic factors will now be discussed.

2.3.7 Demographic factors

For the purpose of this report, four demographic factors will be discussed, i.e. marital status, age at the time of injury, gender and racial or ethnic demographic.

Being married has been reported to increase the likelihood of finding work[35]. Marriage was a highly significant predictor of employment in year one and a significant predictor in year two after the injury. This was especially true for men. In year three, it did not influence employment status[48,64]. Therefore in the first years after injury being married assisted in being employed post-injury, the reasons for this are not yet established, but may be due to the support marriage provides. It has been reported that social support makes it easier to return to work and a spouse may be that support[8].

The majority of studies, however, have found no association between employment and marital status[9]. Although social support has not been described as one of the major aspects that influence employment, social support from significant others was predictive of employment in a sample of men living with SCI [78]. A strong social network is associated with an easier return to employment post-injury[8]. There has been more conclusive evidence with respect to the age of the individual relative to their employment status, rather than marital status and employment.

Regarding age, two aspects need to be considered, i.e. the age at which the injury occurred and the individual's current age.

The younger the individuals were at the time of the injury the more likely they were to be employed[8,53,59,64,79]. Younger ages at injury have been significantly associated with higher rates of current employment, of ever having worked since injury and increased hours worked per week[69,80]. Age at injury has been found to be a predictor of ever having been employed post-injury and currently being employed[59]. This was found to only be true for men in a more recent study[43].

The ability to maintain employment over a three year period was best if the injury occurred at 18 years of age or younger, with employment decreasing with every 10 years over 18 years of age at the time of injury[64].

Krause found that unemployed individuals who were young (below 27 years) at the time of the injury, found it easier to find employment than unemployed individuals who were older at the time of injury (above 33 years)[38]. An injury at a younger age may therefore allow the individual the opportunity to study post-injury and ensure they choose a career that is suited to their abilities. They still have a long period

where they can become employed and therefore may be more motivated to work post-injury.

Older ages at injury are negatively associated with return to work, with an individual least likely to return to work if the injury occurs between the ages of 46 to 61 years of age[81]. Individuals that are unable to return to their pre-injury job, were less willing to study or make major changes so that they could work and many retire at a younger age.

Age at injury was negatively correlated to the number of years it took to become employed in the first job post-injury and first full-time job after injury[55]. Thus individuals who were injured at an older age found employment in a shorter space of time than their younger counterparts. This may be due to older individuals having work experience and not requiring further education to be able to return to work, provided they are able to perform their pre-injury job.

A younger age at injury is therefore an important factor, as it is associated with working at any point post-injury, currently working, being able to maintain employment over time and working more hours per week. Current age affects employment opportunities similarly to that of the general population.

Employment post SCI increases as age increases until the age of 30, it then stabilises until the middle 40s and then declines with many studies showing an earlier than usual retirement age[36,56,59]. Pflam et al. found the peak employment rate to be at 27 years of age[35] and Krause found employment to peak in the range from 31 to 50 years of age[80]. Age therefore plays a similar role as it would in the career development of non disabled individuals. The role of gender is also similar to the non disabled.

Gender has been found to influence the type of work performed post-injury. Men were twice as likely to be in paid employment, whereas women were involved in unpaid, productive activities[54,81].

Male gender was a predictor of employment[27,56], however some studies reported women to be more likely to be employed at any time post-injury[36,38]. There were significantly more females that became employed in the first year post-injury in a three year analysis in the USA[64]. Gender was significantly associated with the

number of hours worked, with men working full time and women part time[36,53]. It important to note that the samples in most studies are primarily men and this could affect these results. It has further been suggested that the differences may be due to the financial resources available and the type of work obtained by men and women[75]. Women are more likely than men to occupy non-manual jobs and therefore return to work may be easier[8]. Finally these gender differences are highly dependent on the cultural and social norms of the participants[56]. Other studies have found that different factors affect the different genders with regard to employment[8]. One would expect that in South Africa with its diversity of cultures, gender issues would impact employment post SCI, but no studies could be found.

A surprising finding from the literature, is the effect of race and ethnicity on employment. Race or ethnicity has been reported as a factor influencing employment post SCI for studies done in the USA. It has consistently been found in American studies that Caucasians are more likely to be employed than minority groups[35,46,54,64]. Anderson and Vogel reported that minorities had greater barriers to employment post-injury[36]. In a study determining reasons for unemployment, minorities reported employer bias and lack of transport, where as Caucasian males reported physical barriers and women reported family reasons for not working[75].

There are no South African studies reporting on the racial distribution of the employment of persons with SCI. South Africa has many policies and legislation, such as the Employment Equity Act 55 of 1998 to promote the employment of not only people with disabilities, but also people from previously disadvantaged communities. Further research needs to be conducted to establish whether these policies and legislation have succeeded in eradicating the barriers reported in the American studies such as that of Anderson and Vogel[36].

2.3.8 Type of employment

The type of employment an individual had prior to the injury and the processes of becoming employed post-injury both affect the employment status post-injury[35,53,55,56,59].

2.3.8.1 Pre-injury employment

Employment prior to injury is significantly related to labour force status post-injury, with those employed prior to injury more likely to be employed post-injury[63]. Being employed prior to injury has further advantages, particularly if an individual is able to return to their pre-injury job. These advantages include a quicker return to work: up to 5 years earlier than if one had to find new employement[8,55,65,70]. Returning to work may be easier as the employer already knows the employee and may therefore be more willing to make accommodations[8]. However, existing employers can also be a barrier, especially where they are biased or do not have adequate knowledge of appropriate alternative jobs[61] and may be unsupportive or afraid of employing someone with a SCI[82].

A pre-injury job with lower work intensity was a predictor of employment post-injury. People who held a low-intensity job prior to injury, were three times more likely to be employed than those who held jobs with intense physical requirements. Those with a higher work intensity job, would most probably have to change to a different lower-intensity job, which is likely to require additional education or training and may not be something they enjoy doing, which could lead to a person opting for early retirement[7].

2.3.8.2 Post-injury employment

Once employed the probability of staying employed was greater than that of an unemployed individual becoming employed[35]. This may be because it has been found that in order to find work post SCI, one either needs to return to one's previous employer or have a personal contact for a possible job[8,39]. Despite this somewhat limited ability to find work, Ysauda et al. reports that more individuals in their study found new jobs post-injury, than those that returned to their pre-injury jobs[81]. The results of this study may indicate that if individuals make an effort to become employed, with the support from vocational rehabilitation professionals, finding work is not necessarily an insurmountable task.

2.3.9 Vocational Rehabilitation

Vocational counselling and rehabilitation are part of the rehabilitation process to return to work or become employed. Various other terms are given to this process depending on the country in which the services are rendered. Other terms include work rehabilitation, occupational rehabilitation, injury management, vocational practice and disability management[2]. In South Africa vocational rehabilitation is largely the preferred term[83-88] and occupational therapists are trained on an undergraduate and post graduate level in this process[89].

In a review of literature from 1975 to 2006 Anderson et al. found that vocational counselling increased the likelihood of return to work, especially if a change in profession was required. They also found that the content of the program was important, with 37% of participants reporting that the content was insufficient and half reporting that the support they received during vocational rehabilitation was inadequate in preparation for work[8].

For vocational development to take place the following aspects should be present in the program: opportunities to find funding for further education, assistance to achieve independent driving, assistance to ensure that the individual has the correct disability-related equipment, access to counselling services and allowing the individual to stay in an independent living centre for a period of time[77]. Assistance in being able to further one's education is very important in the light of a South African study. It was found that 96% of the sample of people living with a SCI in the Western Cape experienced a complete barrier in accessing education and training services[13].

It is important that individuals have access to formal and informal advocacy and support in the process of finding a job and maintaining it[76]. Job retention requires long term support and follow up[90].

If the individual was injured as a child, the role of vocational rehabilitation may not be as important as it is for adults who are injured. Anderson and Vogel report a study in which vocational rehabilitation did not affect the employment outcome in a sample of adults that were injured as children[36]. This is to be expected, as they had to return to school after the injury where assistance may have been required, but this would have been different to returning to employment. The correct educational career choice

guidance and having lived with the SCI for a period of time, should enable these individuals to have adapted substantially to living with a SCI by the time they start to seek employment.

Vocational rehabilitation is important and the content of the program should be carefully considered, so as to assist individuals in the process of becoming employed. Consideration should also be given to the employee's ability to get to and from work, as well as physical access in the work environment.

2.3.10 Environmental factors

2.3.10.1 Physical environment

Transportation to work is very important as it affects punctuality and daily attendance. Independent driving has been associated with employment post-injury[36,39,48], making driving training and hand controls an important part of rehabilitation[77]. Transport is often the main reason given by unemployed persons with SCI for not working[36,61,91] and the ability to drive independently removes the reliance on a third party to get to work.

Transport was found to be a predictor of employment[59] as it impacted on an individual's decision to return to work or not[76] and was important in enabling the individual to retain work[90]. Transportation has been found to be specifically problematic for people from lower income ranges were individuals cannot afford to purchase their own (adapted) vehicle[59].

Transport for individuals living with a SCI is problematic in South Africa, especially public transportation and minibus taxis. Individuals describe how transport is inaccessible, because minibus taxis often do not stop for people in wheelchairs and alternatives to minibus taxis are expensive[12,82]. In a study in the Western Cape, participation according to the World Health Organisation in the following domains was studied: mobility, self care; domestic life; interpersonal interactions and relations; major life roles; community aspects, social and civic life. Thirty-seven percent of the sample of individuals with a SCI reported transport as a complete barrier to participation[13].

Driving independently was found to be beneficial to employment. Similarly, being able to move independently in the environment enhanced employment. Community mobility and environmental access was found to be a predictor of employment[36].

Environmental access includes getting to work from where the car or taxi stops, as well as accessing all the areas in the work environment that are necessary to perform the job and meet the individuals personal needs, such as bathrooms and the cafeteria. Inaccessibility of the environment is a common reason cited for being unemployed[36,61].

In South Africa The Promotion of Equality and Prevention of Unfair Discrimination Act 4 of 2000[24] (Equality Act) prohibits individuals and the state from discriminating based on race, gender and disability. This Act includes environmental barriers in the scope of unfair discrimination. The impact it has had however has not been reported with regards to individuals with SCI.

An Australian study, however, found that experiencing environmental barriers was positively associated with employment post-injury. Thus, while experiencing environmental barriers may make working more difficult, it does not prevent people from becoming employed[59]. Therefore it appears that other factors, such as motivation to work, can reduce the impact of environmental barriers.

2.3.10.2 Labour Market

A further consideration to the environment is that of the labour market in which an individual is employed or seeking employment.

Globally labour markets, both in advanced and developing economies, have struggled since the global financial crisis in 2008. The International Labour Organisation estimates that 197 million people were without a job in 2012[92] . It is within this context that individuals with SCI are attempting to secure, or maintain employment. South Africa is a part of this global context.

The South African labour market is an interesting and divided one. It has one of the highest unemployment rates in the world[30] and jobs are in short supply. Individuals of

a working age are in one of three categories, employed in the formal sector, employed in the informal sector or unemployed. The formal sector is made up of firms that are formally registered and have to comply with employment laws and regulations. The informal sector is outside the labour regulation system and has the characteristics of a poor, less developed country. Employees in this sector generally receive a lower income than those employed in the formal sector and are open to exploitation[30]. To enter the informal sector one requires capital and some entrepreneurial skills[30]. The formal sector, in contrast, has the characterises of a middle income country, the advantage of a mineral economy and involvement in resource-intensive, capital-intensive, or skills intensive manufacturing[30].

Statistics South Africa reports in the Quarterly Labour Force Survey, Quarter 4, 2012 that the unemployment rate for the 4th quarter of 2012 was 24.9% of the labour force[52]. This is concerning, as people with disabilities face increased barriers to employment[17] and the rate of unemployment for individuals living with disabilities in South Africa is likely to be much higher than this[26]. There are, however several Acts in the South African context that promote employment of those living with disabilities. People living with disabilities, including those with a spinal cord injury, are considered employment equity (affirmative action) candidates in terms of the Employment Equity Act 55 of 1998.

2.3.10.3 Social Security

Internationally, developed countries have well-established social security systems. Many of these systems are means-based and therefore becoming employed post-injury may decrease the benefits received. Therefore loss of benefits and financial disincentives have been cited as reasons for not seeking employment post SCI[8,35,59,61,75]. The social security system in South Africa is very different and comprises social grants as well as compensation from the Road Accident Fund following motor vehicle accidents and the Compensation Commissioner in the case of an injury on duty. Importantly, Dube found that the legislation that deals with compensation post-injury has been implemented better than the other disability equity legislation.[85]

The Social Assistance Act (No 13 of 2004) makes provision for a disability grant for individuals who are unable to “provide for his or her maintenance” due to a physical

or mental disability and meet the requirements of a means test[93]. In January 2014 the grant was R 1 270 per month[94].

The Road Accident Fund (RAF) is governed by the Road Accident Fund Act (No 56 of 1996) (as amended) and came into operation on 1 May 1997. This fund is a fault-based system paying compensation for personal loss or damage wrongfully caused by driving a vehicle. The compensation includes past and future loss of earning, which is capped [95] at R160 000 per annum. It is likely that individuals with a high earning potential will elect to continue working, as this amount may not be sufficient to meet their financial responsibilities and needs.

The other source of compensation is the compensation for injury on duty. This is regulated by the Compensation for Occupational Injuries and Diseases Act (No 130 of 1993) (as amended). The Act provides for compensation when employees sustain injuries or contract occupation-related diseases such as Asbestosis, in the course of their employment[96].

A disability grant is a less than a living wage and among low income earners, may replace their pre-injury income. This compensation is not as comprehensive as social security systems in first world countries such as the Netherlands, Denmark, UK and the USA. In these countries compensation equals about 70% of their last earned salary[56]. For South Africans that earned more than a disability grant prior to their injury, this government compensation may not serve as such a strong disincentive to return to work. In South Africa, only a few individuals (usually those with extensive personally funded personal insurance) are able to maintain their pre-injury standard of living without generating some kind of additional income.

2.3.10.4 Policy and Legislative environment

Post-Apartheid South Africa has come a long way in terms of dealing with discrimination on a policy level. In 1996 the Constitution recognised equal rights for all, and asserted that discrimination based on disability was not permissible. In 1997 the Government adopted the Integrated National Disability Strategy (INDS) White Paper, the vision being to ingrate disability issues in government strategies, planning and programs and to provide a framework for policy development[97]. Legislation has been adopted as enactments of the South African Constitution in 1996 and according

to the framework of the INDS. Legislation that affects individuals with a SCI will briefly be discussed.

The Labour Relations Act (LRA) (No 66 of 1995) created the Commission of Conciliation, Mediation and Arbitration (CCMA). This is of importance for employees who may be dismissed on unfair grounds after their injury and wish to resolve the dispute before going to Labour Court. The LRA also contains the Code of Good Practice: Dismissal in Schedule 8 which deals with dismissal of employees due to, amongst other reasons, disability. This Act is important for individuals that were employed prior to their injury, as it stipulates the fair process an employer should follow to accommodate the individual within the organisation before considering dismissal[25].

The Employment Equity Act (EEA) (No 55 of 1998) provides individuals with disabilities the right to reasonable accommodations, something that is often essential in employment after a SCI. There are several codes that guide and are used to interpret and apply the EEA. They are the Code of Good Practice on Key Aspects of Disability in the Workplace (2001)[98], the Code of Good Practice on Employment of People with disabilities (2002) [99], and the Technical Assistance Guide to the Employment of Persons with Disabilities (2004)[100].

Reasonable accommodations as provided for by the EEA, can apply to the job application process, adjustments to the job, the work environment and the method in which the job is performed. In terms of item 6.1 of the Code of Good Practice on the Employment of People with Disabilities, the aim of a reasonable accommodation is to mitigate the impact of the disability on the individual's ability to perform the essential functions of the job[99]. This, therefore, affects the job application process and once an individual is employed. The EEA also requires designated employers to have an Employment Equity plan and to implement affirmative action measures[98]. This should benefit individuals with SCI, as they are affirmative action candidates.

In a USA study individuals with SCI that were working, or had worked in the last 5 years, reported that 80% of their assistive devices were important for the work they did[32]. In studies in the Netherlands, 74% of those that were working post-injury, either had accommodations made for them in the form of physical, environmental changes, assistance with transport, a change in the work tempo, or the number of hours that they worked, or they worked from home[57]. A prior study to this in the

Netherlands reported that individuals preferred more personal time management and the opportunity to work from home[60].

The Skills Development Act (No 97 of 1998) created a fund to which all designated employers have to contribute. The fund is used to promote skills development though learnerships run by the Sector Education and Training Authorities(SETAs). Learnerships are programmes which consist of skills development while employed with attendance of courses which result in a National Qualification Framework qualification[6]. Despite the comprehensiveness of this legislation the implementation has lacked the desired effect[101].

According to a study by Dube on the efficacy of disability equity legislation in March 2005, the Skills Development Act has been poorly implemented with regard to people with disabilities. Dube found no available data on the implementation of the Promotion of Equality and Prevention of Unfair Discrimination Act, or the Labour Relations Act. The impact of the Employment Equity Act has been minimal according to Dube[101]. However, Dube found that the disability equity legislation has succeeded in achieving a sense of awareness of the needs of disabled people.

According to the 12th Commission for Employment Equity Annual Report (2011-2012) people with disabilities made up approximately 0.8% of the total reported workforce. Government set a target of 2% for the public service by 2005 and has extended it twice to 2010 and now to 2015, as the target has not been achieved to date[102].

The change this legislation has had on the employment of individuals living with a SCI within the South African labour market has not been reported.

2.3.11 Mentors

Individuals with SCI who are employed often have positive role models[39] and they are more likely to be employed if they observe someone in a similar situation to themselves achieving[76]. A study assessing the impact of a mentoring programme after a SCI, found that while it did not affect the employment rate of individuals, mentored individuals did have a higher quality of life than those that were not in the programme[103]. In a qualitative study, employed individuals had positive role models regarding work and the unemployed had more negative role models[39].

2.4 Conclusion

Employment rates post SCI have been disappointing worldwide where studies have been done, with a global employment rate of 36.8%[1].

There are numerous factors that affect the outcome of employment post SCI. Some of them have been shown to be very influential, such as the level of education, while the impact of others, such as the severity of the injury are easily mitigated, by improving one's level of education. Some factors can negate the influence of others, such as motivation to work making it possible to overcome environmental barriers to secure employment.

Human resources can assist the person with SCI in the process of becoming employed, be it in the form of a spouse, a member of the rehabilitation or vocational rehabilitation team or a mentor. The more support the individual has the more promising the outcome.

In addition to support, the economic, legislative and physical environments also contribute to the employment outcome post SCI.

There is very little information on SCI in South Africa, including the prevalence, incidence and aetiology. Employment after a SCI in South African has not been reported. The factors that affect employment are therefore largely unknown. When this information is not available, it affects the quality of service delivery on multiple levels for example budgeting, human resources, programme planning, measuring outcomes of service delivery and client satisfaction of services. There is thus a dire need to collect this type of information within the South African context. This study was focused on the employment of individuals after a SCI in South Africa using the methods described below.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 Introduction

This chapter describes the methods and procedures undertaken to meet the aim of this study. The aim was to explore the employment status and factors that affect employment of South African adults who have sustained a SCI.

3.2 Research design for the study

In order to design and implement an instrument or questionnaire in this case, a mixed method, exploratory design was the design of choice. This design allows for exploration in one phase and then these findings are applied to a next phase. A mixed methods design is used to confirm findings from different sources in each phase of a study. The qualitative phase made use of the philosophical assumption of constructivism. This involves inductive processes, in an attempt to gain an understanding of multiple realities. The qualitative design was a collective case study as more than one data collection point was used. The quantitative phase was deductive and used the philosophical assumption of post-positivism as this type of scientific enquiry focuses on the reduction of large qualitative data into quantitative categories which can be tested. The data collected in phase two would either support or refute the data collected in phase one [104,105].

The study was divided into two phases. The qualitative study was to explore the factors that affect employment in South Africa after a SCI as no such study had been done to date. This was the constructive phase with inductive processes. The outcome of phase one was the construction of a questionnaire. Phase two with its post-positivist nature comprised quantitative data collection with the newly constructed questionnaire from phase one. It was applied to a specific population of individuals living with a SCI in SA. The qualitative and qualitative data together would provide a better understanding of individuals living with a SCI than only one type of data collection [105].

The study was sequential as phase two required the data from phase one. The sequential process is illustrated in Figure 3.1.

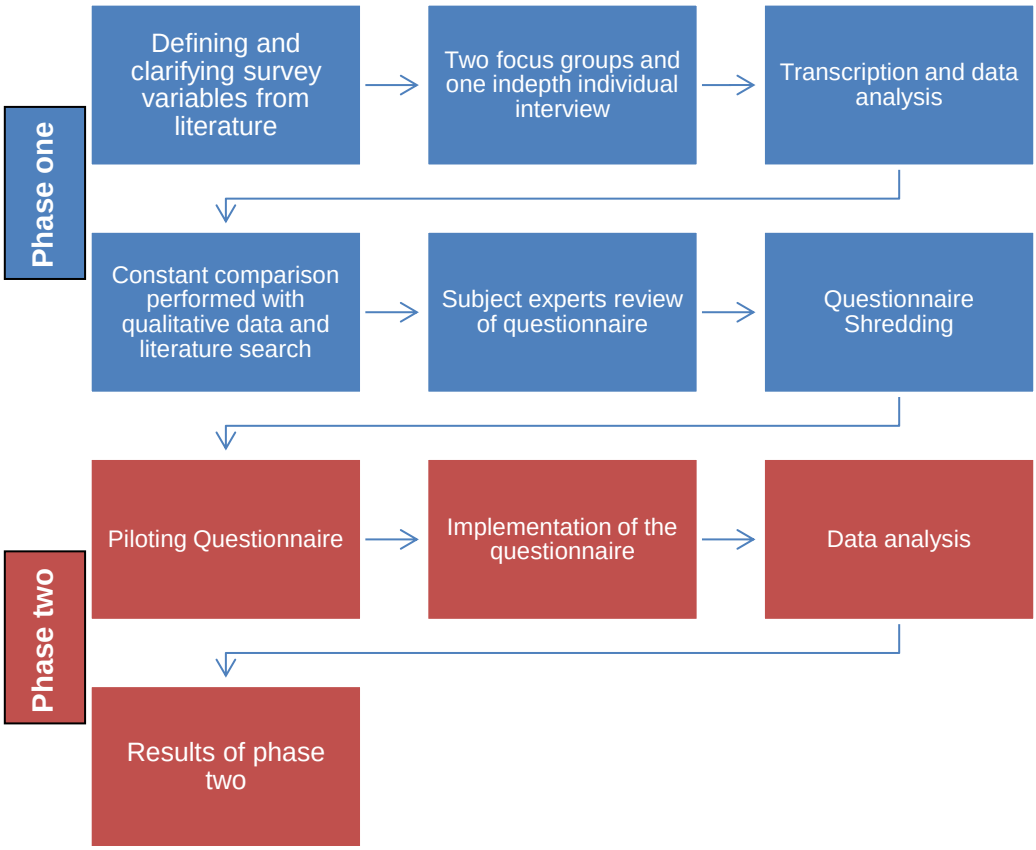


Figure 3.1: The sequential, exploratory design of the study

The methodology for each phase will now be described. Each phase included the aims and objectives, research design, participant selection, measurement techniques, data gathering and analysis as well as ethical considerations.

3.3 PHASE ONE: Questionnaire development

The steps followed in phase one are presented below. The details of each step will be discussed.

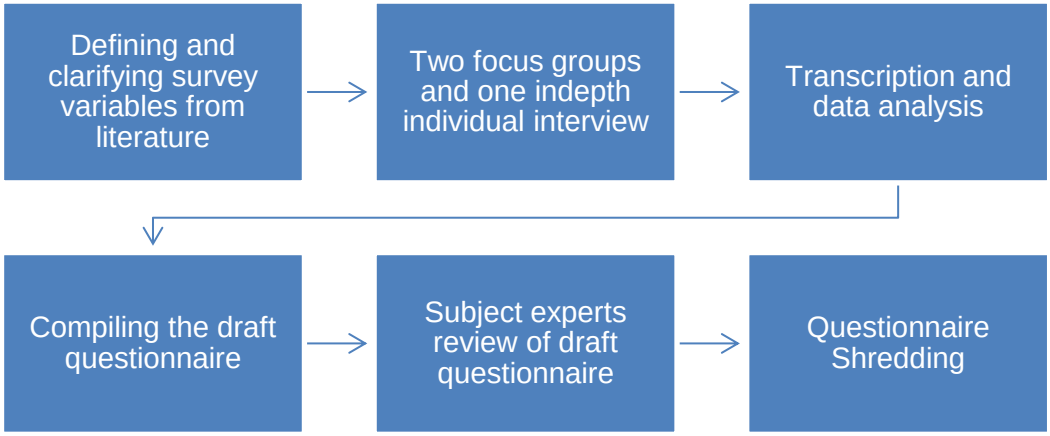


Figure 3.2: Summary of the methodology of phase one

3.3.1 Defining and clarifying survey variables from literature

According to Forsyth and Kviz the first step in questionnaire design is to identify and clarify the variables to be measured[106].

A literature search was conducted to identify and clarify the variables to be included in the questionnaire. The search included databases namely Pubmed, MEDLINE and CINAHL in 2009. The following key words were used: spinal cord injury, work, employment and return to work. Articles from 1998 were included and reviewed for variables.

These variables had to be confirmed to be relevant in the South African setting and therefore focus groups and an in-depth interview were conducted.

3.3.2 Focus groups and in-depth individual interview.

3.3.2.1 Research design

A qualitative collective case study design was used to explore employment of a person after a SCI in South Africa in order to determine the factors that should be included in the questionnaire. Multiple cases were chosen to gain valuable information. The cases were occupational therapists who had experience in employment of individuals after a SCI and individuals who were living with an SCI and had been employed since their injury. Focus groups and an in-depth interview were chosen as the means to collect data. This allowed comparisons to be made between the cases and concepts. The aspects that influence employment after a SCI could therefore be extended and validated and used in the questionnaire[107].

3.3.2.2 Participant selection

A purposive sample of subject matter experts in the employment of individuals after a SCI, were selected to assist in the development of the questionnaire. The subject matter experts had a vast collective knowledge and experience in a variety of vocational rehabilitation aspects as well as first-hand experience in the employment of individuals after a SCI. They were able to contribute their perceptions of the factors in the SA context. Their clinical expertise was of great assistance to start with the process of identifying factors and issues to be covered in a questionnaire.

The data that emerged from these focus groups were used to inform the questionnaire for phase two of the study.

To confirm the data gathered from the qualitative phase, triangulation was used by including one individual living with SCI in the focus groups and conducting an individual in-depth interview [108].

Invitations for the first focus group were sent to experts from the following fields:

- an occupational therapist with experience in vocational rehabilitation in a private practice setting,
- an occupational therapist with experience in teaching of the vocational rehabilitation process,
- an occupational therapist with experience in vocational rehabilitation in a spinal unit,
- a member of the Quadpara association who had been employed since injury.

In order to ensure that rich data was collected a second focus group which adhered to the same inclusion criteria as the first group was held. This increased the representation of opinions of the occupational therapists and thus improved credibility of the data collected [108].

Triangulation of data is important in collective case study design. In this study two focus groups with different participants gave the researcher the opportunity to collect data from different individuals and different settings. A final data collection point was built in the design to increase the rigor of data and to improve the transferability and dependability of the data. An in-depth individual interview was held with an individual living with a SCI in South Africa who relied on government service provision and had been employed post SCI . His authentic experience with government services and being employed post SCI could be used to confirm the data that emerged from the two focus groups. Should new issues have to come forth, this would have been incorporated and further explored. This last data collection point was thus used to test data saturation.

3.3.2.3 Measurement techniques

The two focus groups were conducted using a questionnaire guide designed from the relevant literature. It is attached as Appendix A. It consisted of open ended questions used to facilitate the group.

The individual interview was conducted according to the designed interview guide. The questions addressed injury details, rehabilitation after the injury, educational history and training post-injury, employment pre- and post-injury and aspects that affected employment post-injury. The researcher probed for information by posing

questions such as “could you provide examples” or “could you expand” to the individual. Where necessary clarification was also sort by asking “just to confirm” or “have I understood correctly” and rephrasing the participants answers. The full guide is attached as Appendix B.

3.3.3 Transcription and analysis

The focus groups and individual interview were audio recorded and the researcher made field notes during the groups and interview. The recordings were transcribed by the researcher into Microsoft Word.

The data from the focus groups and the in-depth interview was analysed using inductive content analysis. This is recommended when there is inadequate knowledge on the topic. While there is international information on employment after a SCI, there is limited South African information. During inductive content analysis categories were derived from the data and therefore move from specific concepts to general themes[109].

The transcripts and field notes for the two focus groups were read several times to submerse the researcher in the data[108]. Concepts within each of the two focus groups were noted and listed. The concepts were then coded. The individual interview was summarised and concepts identified and coded. Inductive content analysis was then performed to determine categories and themes using thematic content analysis[109,110]. Cross case analysis was then performed between the focus groups and in-depth interview to create one set of results.

The analysis was performed in such a way as to capture the themes in the depth that was required to perform a constant comparison with the identified variables after the initial literature search. The rich data had to be reduced so that it could be used for the concrete questionnaire. Themes and categories that were not captured by any of the variables in the review of literature would be included as additional variables.

To ensure the credibility of the qualitative data analysis the transcripts were reviewed and analysed by an expert in qualitative data analysis. The results were compared with the researcher’s results to prevent misinterpretation of the data. A consensus of at least 90% between results was deemed as sufficient confirmability.

3.3.4 Compiling the draft questionnaire

The second step in developing the questionnaire according to Forsyth and Kviz was formulating the questions[106]. This involved formulating questions to obtain information for each variable using the data from the focus groups, in-depth interview and the literature search. The questionnaire was then formatted by arranging the questions in a logical sequence. The "funnel" principle[106] was applied where one starts with general questions followed by questions that become more specific.

The questionnaire was designed in Microsoft Word 2007. Legacy tools in the developers tab of Microsoft Word were used. The text form field option was used where the participants would need to enter text. The drop-down form field option was used for questions with one answer from a number of category options and the check box form field was used for questions requiring a box to be ticked.

Once the questionnaire was finalised, the document was protected by enforcing the editing restriction of "filling in forms" and was password protected. This prevented the participants editing the questionnaire and only allowed it to be completed.

3.3.5 Subject experts review of the draft questionnaire

A reference group of two South African experts in vocational rehabilitation in occupational therapy was made to perform a content validity check. This was done to increase the credibility of the data contained in the questionnaire [108]. They were independent participants who had not taken part in the focus groups.

The questionnaire, aims and objectives for phase two of the study were sent to them via email and they were asked to check the questionnaire for inclusion of the most important factors affecting employment after a SCI as well as editing errors. Feedback was received via email.

The questionnaire was not tested for reliability as the content of the questionnaire was pure recall of facts from the participants. It was not aimed at measuring or predicating outcomes, but capturing the information and perceptions of the participants.

3.3.6 Shredding of questionnaire

Following all the above mentioned steps the questionnaire had become too lengthy. The questionnaire was shredded by systematically examining each question to check its appropriateness to the study aims and objectives to refine the questionnaire to its key variables. Shredding also involves the checking of punctuation, grammar, ordering and clarity of questions.

A convenience sample of two participants working in the academic environment who had participated in the focus groups was selected. Their participation in the focus groups increased their awareness of the variables to be included in a questionnaire. They had experience in developing questionnaires in the past and knew how to judge a questionnaire for clarity, relevance and ambiguity.

The participants were provided with the aims and objectives of the study and the draft questionnaire. They were asked to comment on the clarity, relevance and ambiguity of each question in relation to the aims and objectives. Any other comments were also welcomed. The discussion was audio recorded for later reference and field notes were made.

3.3.7 Ethical considerations

Ethical clearance was obtained from the University of the Witwatersrand Committee for Research on Human Subjects (Ethical Clearance Number: M090528). A copy of the Ethical clearance certificate is included in Appendix C. The protocol for this study was approved by the University of the Witwatersrand.

All participants were provided with an information sheet (individual interview-Appendix D, focus groups-Appendix E). The process of data collection was explained, the method of storage of data was made apparent and confidentiality ensured. Participants were free to withdraw from the study at any time during the focus groups and individual interview. Completed informed consent forms (Appendix F) were received from all participants in the focus groups and individual interview.

To ensure confidentiality of participants the audio recordings of the focus groups and individual interview were stored under a password protected file in the researcher's

electronic documents. During the transcription phase no names were transcribed, participants were given pseudo names. The signed informed consent forms from the focus groups and individual interview were kept separate to the transcripts and recordings, in a locked draw.

3.3.8 Conclusion

The questionnaire design had been completed. Content validity had been addressed and the questionnaire was ready to be piloted.

3.4 PHASE TWO: Implementation of questionnaire

Phase two consisted of the piloting and implementation of the questionnaire as shown below.

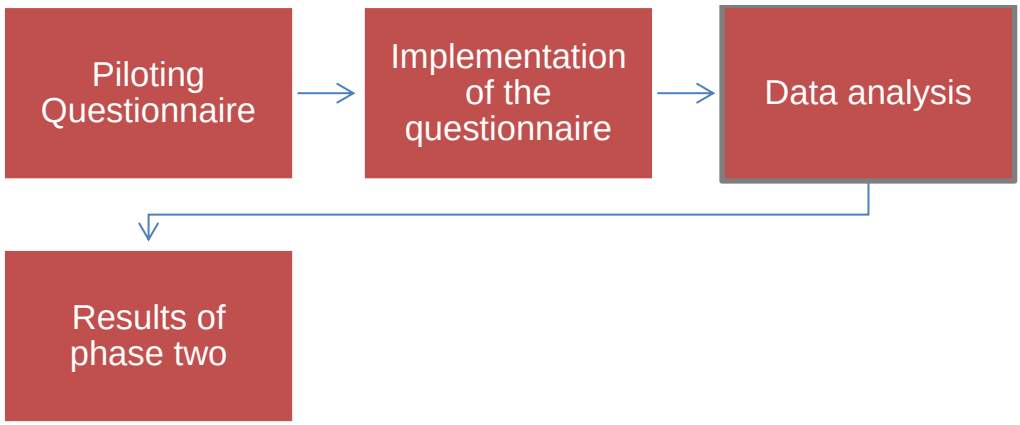


Figure 3.3: Summary of the methodology of phase two

3.4.1 Questionnaire piloting

Once the variables and the formulation of the questions had been finalised, the questionnaire was tested.

3.4.1.1 Sampling

The sample for the testing or piloting of the questionnaire consisted of ten individuals who met the inclusion criteria for phase two. The inclusion criteria stipulated individuals who:

- had sustained a SCI resulting in them having a complete or incomplete tetrapelgia (quadriplegia) or paraplegia, with motor and sensory deficits[91]:
- were at least one year post-injury,
- were 18-65 years old,
- were literate and able to understand English,
- had access to email and
- reside in SA.

Ten individuals were conveniently selected from individuals participating in the Supersport wheelchair basketball series who were willing to participate in the piloting. They were approached at a wheelchair basketball game and asked if they would be willing to participate. Their email addresses were obtained.

3.4.1.2 Data gathering

Participants were emailed the information sheet (Appendix G) and the questionnaire (Appendix H) and asked to complete it. They were given two weeks to complete the questionnaire after which a reminder email was sent. At the end of the questionnaire various piloting questions were asked. These questions can be seen in Appendix H.

A telephonic interview was conducted with those participants who had provided feedback that required further investigation. The purpose was to ensure that all the feedback was collected and understood.
These questions and telephonic interview were to ensure there was no ambiguity in the questions and to detect any problems in the administration of the questionnaire.

3.4.1.3 Data analysis

All the piloted questionnaires were reviewed to determine if all the relevant questions were answered. Comments and answers to the piloting section of the questionnaire, and information gained during the telephonic follow up were used to correct and improve the quality of the questionnaire.

3.4.1.4 Ethical considerations

During the piloting of the questionnaire the participants were free to withdraw prior to sending their completed piloted questionnaire. The completed questionnaire was returned to the researcher via email. This implied informed consent. No identifying information was placed on pilot questionnaire. Once the email had been received, the feedback was reviewed and a telephonic interview was conducted if necessary. To ensure confidentiality the questionnaire and feedback from the telephonic interview contained no identifying information and were saved without reference to the participant in an electronic folder. Once the telephonic interview had been conducted, the email was permanently deleted.

The questionnaire could now be implemented with the study population.

3.4.2 The Research Design

Phase two was a quantitative, non-experimental, cross sectional, descriptive survey, implementing the questionnaire designed in phase one. This was done so that a large number of participants could be reached and the data collected within a reasonable time period with the purpose of describing factors affecting employment after a SCI. This also supported the explorative nature of the study where as many individuals could be reached to explore employment factors after a SCI.

3.4.3 The study population

3.4.3.1 Inclusion criteria:

Individuals who had sustained a SCI resulting in a complete or incomplete tetrapelgia (quadriplegia) or paraplegia, with motor and sensory deficits[91] who:

- were at least one year post-injury,
- were 18-65 years old,
- were literate and able to understand English,
- had access to email and
- reside in SA.

3.4.3.2 Exclusion criteria:

Individuals with sensory and motor deficits not due to a SCI (such as tumours[56]) as the pathology is different and the prognosis differs from a SCI.

3.4.3.3 Sampling method:

A convenience sample of the members of the Quad-Para Association of South Africa (QASA) on the email database was used (330 members) to commence with the distribution of questionnaires. Membership to QASA is voluntary and therefore not necessarily representative of the majority of individuals living with a SCI in South Africa. Snowball sampling was performed by asking the sampled population to forward the email to anyone that would be eligible for the study. Snowball sampling is often used in surveys to increase the response rate, especially of hard-to-find individuals. Individuals living with a SCI not belonging to QASA with access to email could be considered hard-to-find[107].

3.4.4 Measurement Techniques

The final questionnaire (Appendix I) designed in phase one was used as the measurement instrument in phase two. Details of the questionnaire are provided in the results section 4.2.4 to 4.2.7.

3.4.5 Data collection

A letter was written to QASA seeking their permission to send the email to members. An email with the questionnaire and information sheet (Appendix J) attached was sent to QASA. They forwarded the email to their email data base.

The QASA members had three weeks to complete the questionnaire. During the third week the questionnaire was resent to the sample with a thank you to those who had completed it and a request for those that had not, to consider completing it. They were given a further two weeks to complete the questionnaire. A second reminder was sent at the end of the two weeks and a further two weeks given for the completion of the questionnaire. An interview was done on SAFM's Disability Report regarding the study during which a request was made for individuals to complete the questionnaire, or to request a copy of the questionnaire if they had not received it. A further two weeks were given for responses.

The questionnaires were returned via email to the secretary of the Occupational Therapy Department at University of the Witwatersrand. This was to ensure that the researcher was blind to the source of the questionnaire and therefore could not have been biased by this knowledge. It also ensured the confidentiality of the participants.

The secretary saved the returned questionnaires as a Word document as "Questionnaire and participant number" in a folder in her documents. She then permanently deleted the email from her Outlook express. The returned questionnaires were sent to the researcher, via email as an attachment. Once the questionnaire was sent to the researcher the secretary permanently deleted the document from her computer. The researcher printed the questionnaires and saved a copy to a password protected folder.

Data collection was complete 9 weeks after the first questionnaires were sent out. The questionnaire questions responses were coded and recorded on an Excel spreadsheet.

3.4.6 Data Analysis

The demographic, injury and work information was obtained from the self-report questionnaire. This information was analysed descriptively in terms of frequencies and percentages for categorical (nominal) data, and means and standard deviations for continuous (ordinal) data. Nominal and ordinal data was listed in a table. Due to the vast amount of data due to the explorative nature of the study, a structure was compiled to arrange the data into a logical structure.

The Occupational Therapy Practice Framework 2nd edition[5] was used to guide this structure as it provides "a summary of interrelated constructs that define and guide occupational therapy practice" (p625)[5]. The framework is divided into two major sections, the domain and the process of occupational therapy. Only the domain section was utilised. The domain involves all aspects that "support health and participation in life through engagement in occupation" (p626). The domain consists of activity demands, performance skills, client factors, performance patterns, context and environment and areas of occupation[5]. The sections of the domain that were used in this study are described in Table 3.1.

Table 3.1: Occupational Therapy Practice Framework II: Domain[5]

Aspects used	**Description of the aspect**	**Examples**
Client factors (all those factors that reside within the client and may affect performance in areas of occupation)	• body functions (as categorised in ICF) • body structures (as categorised in ICF) • values • spirituality,	• Cause of the injury • Level of paralysis • Pain • Endurance • Presence of pressure sores
Performance patterns (patterns of behavior related to an individual's or significant other's daily life activities that are habitual or routine)	• routines • roles • habits	• Bowel and bladder routines • Pressure relief routine
Contexts and environments (a variety of interrelated conditions within and surrounding the client that influence performance)	• cultural • personal • temporal • virtual • physical • social	• Age at injury • Level of education • Awareness of legislation • Transportation • Marital status
Areas of occupation (various kinds of life activities in which people, populations, or organisations engage)	• activities of daily living, instrumental activities of daily living • rest and sleep • work • play / leisure and • social participation	• Perceived independence in personal management, • Social interaction, • Sector of employment • Retraining post-injury

The pre-injury and post-injury work variable means were compared using the Mann-Whitney U-Test to determine a significant difference between the employed and unemployed rank totals.

The post-injury employment status was made into an artificial dichotomy, employed (full time, part-time, or self employed) and unemployed (full time student, volunteer or unemployed). This was viewed as the outcome. The variables were viewed as risk factors for not returning to work. Bivariate analysis was performed, outcome verses individual risk factors. This was done by using the Fisher's exact test for the categorical variables and the t test or Mann-Whitney test for continuous data.

The risk factors significant at the 0.2 level of significance were then included into a logistic regression for further analysis. This level is not as strict as the 0.1 suggested in literature. The level of 0.2 was a decision made by the researcher and statistician because the variables have an unpredictable nature and one has to allow for the vast variation in individuals with SCI. The numerous factors that influence employment post-injury also justify this relaxed level of significance.

3.4.7 Ethical considerations

Ethical clearance was obtained from the University of the Witwatersrand Committee for Research on Human Subjects (Ethical Clearance Number: M090528). A copy of the Ethical clearance certificate is included in Appendix D.

The information sheet (Appendix J) explained that participation was voluntary, that participants were free to withdraw from the study by not completing or submitting the questionnaire. It provided a brief description of the research including how confidentiality would be ensured, the researcher's contact numbers and that participants may request the results of the study by contacting the researcher. The returning of the questionnaire was considered informed consent.

To ensure confidentiality the questionnaires were returned via email to the secretary of the Occupational Therapy Department at University of the Witwatersrand. This was to ensure that the researcher was blind to the source of the questionnaire and therefore could not have been biased towards certain questionnaires. The secretary saved the returned questionnaires as a Word document as "Questionnaire and participant number" in a folder in her documents. She then permanently deleted the email. The returned questionnaires were sent to the researcher, via email as an attachment. Once the questionnaire was sent to the researcher the secretary

permanently deleted the document from her computer. The researcher printed the questionnaires and saved a copy to a password protected folder.

3.5 Conclusion

This study consisted of two phases. The first phase involved developing a questionnaire to assess the factors that affect employment after a spinal cord injury in South Africa. This included a review of the international literature, the use of two focus groups and an individual interview to identify and clarify the variables to be included. The researcher had to solely rely on rehabilitation professionals as well as people living with a SCI to generate information for the questionnaire as no South African literature could be found. Content validity was ensured through a reviewing of the questionnaire by subject matter experts. This method is a well-used and well-reported strategy to validate the questions in a questionnaire. Piloting was conducted at the end of phase one to strengthen the utility of the questionnaire. Phase two involved quantitative data collection implementing the questionnaire designed in phase one. The questionnaire was sent to the QASA email data base and snowball sampling was used.

CHAPTER 4: RESULTS

4.1 Introduction

The results of the two phases are presented in this chapter. The findings from phase one were the qualitative data from the focus groups and individual interview that were used to design the questionnaire for phase two. Phase two results were the quantitative results from the implementation of the questionnaire.

4.2 Phase one results

The qualitative data collected during the two focus groups with subject experts and the individual in-depth interview were analysed with inductive content analysis[110]. Cross case analysis was performed between the focus groups and the in-depth interview which resulted in the one set of findings presented below.

4.2.1 Demographic information of focus groups

The first focus group was attended by five occupational therapists and one member of QASA. Unfortunately the member from the QASA, due to attend focus group two, was unable to do so at the last minute due to illness. This focus group consisted of four occupational therapists.

Table 4.1: Demographics of the occupational therapists that attended the focus groups

	Focus Group one (n=5)			Focus Group two (n=4)		
Age	**20-35**	**36-50**	**>50**	**20-35**	**36-50**	**>50**
	1	4	0	1	2	1
Years of experience	**<10yre**	**>10yrs**		**<10yrs**	**>10yrs**	
	1	4		1	3	
Practice setting	**Private**	**Public**	**Academic**	**Private**	**Public**	**Academic**
	2	1	2	2	1	1
Field of practice	**Acute Spinal rehab**	**Voc rehab**	**Lecturing SCI and Voc rehab**	**Acute Spinal rehab**	**Voc rehab**	**Lecturing SCI and Voc rehab**
	1	2	2	1	2	1

The member of QASA who attended focus group one lives with incomplete C5/6 tetraplegia and sustained her injury in 1979. She has completed post graduate studies and been employed since her injury.

4.2.2 Demographic information of the in-depth interview

The participant was a 50 year old male who was injured in 1994 resulting in T4 complete paraplegia. At the time of his injury he resided in a large township in the Johannesburg area, had a Grade 10 (Standard 8) level of education and was unemployed. Since his injury he completed his matric and a clerical course though Access College. This course covered office administration, computer literacy and business studies. At the end if his studies in 1998 he was placed as an administration clerk in a government health department. In 2001 he transferred to work at a hospital as a senior administration clerk until 2003 when the Gauteng Shared Services Centre opened. He then worked in this centre as a finance practitioner. At the time of the interview in 2010 he was in the process of being boarded as his spine was collapsing below T4 resulting in pain, spasms and scoliosis. He has made use of government health services and has been reliant on public transport.

4.2.3 Results of focus groups and individual in-depth interview

The first focus group took place in February 2010, followed by the second focus group and in-depth interview in March 2010. Focus group one was one hour and thirty-one minutes, the second focus group an hour and fourteen minutes and the in-depth interview was an hour and twenty-seven minutes long. The participants were vocal and minimal input was required from the researcher other than to ensure participants kept to the topics under discussion. The individual living with a SCI from QASA who attended focus group one was very interactive in the group.

After the thematic content analysis various themes and categories emerged which are presented in Figure 4.1. Selected quotations are extracted from the data to support the themes and categories. Occupational therapists are denoted with a “T” and the participant number and individuals living with a SCI with a “P” and the participant number.

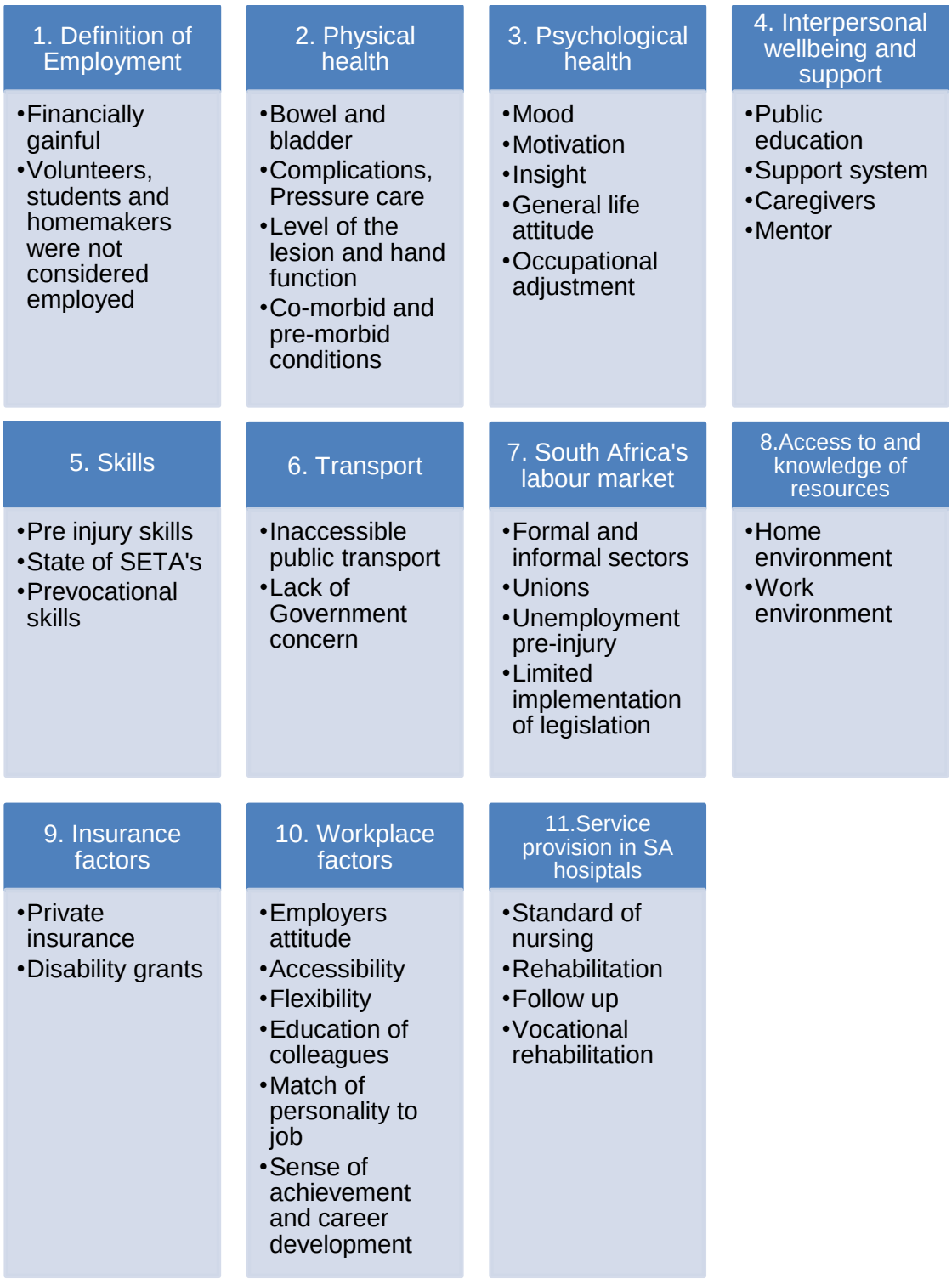


Figure 4.1 Summary of the themes and categories that emerged after phase one data collection

Theme one: Definition of employment

The first theme that emerged was the definition of employment. Participants debated this definition and from this discussion valuable information was gained. Their conclusion was that employment must be financially gainful, therefore volunteers, students and homemakers were not considered employed.

Theme two: Physical health

The second theme identified was physical health. Bladder and bowel management played a role in employment, not only physically managing the routines, but also the emotive aspect of the fear of a bowel or bladder accident and the subsequent embarrassment at work. This was the first category.

> *"I think that's a huge* (issue)*, bladder and bowel are mentally huge."* (T1)

> *"Then it* (urine bag) *sometime overflow eish, that's another part of this. Your colleague, the one who sees you, will be afraid to tell you, he will go tell another colleague."* (P11)

Complications secondary to the SCI was a category. The most mentioned ones were pressure sores and urinary tract infections.

> *"Medical complications were a big problem and he* (a client) *was senior, senior management, and it was a big problem for him. He was often in hospital with medical related issues."* (T7)

> *"…we looking firstly for the absence of pressure sores, because in my experience people who don't get back to work or who get back to work and then collapse, it's because of pressure sores. Nearly always…"* (T2)

> *"I've seen people go back to work and then still die later from pressure sores, even in situations where there were occupational health nurses available."* (T1)

The next category was the level of the lesion, including the mechanism of injury, endurance and the amount of hand function present as these all affect overall functional ability.

"The higher the lesion the less realistic (return to work)*."* (T3)

"I recently had a C4 who was an incomplete quad, he was mobile…he could manage till about 12 (pm) *and then he just was exhausted and his productivity just didn't meet the demands of the job. He could do the work, but he just couldn't sustain it for the whole day."* (T7)

The final category of physical health was co-morbid and pre-morbid diagnoses as these would also influence functional ability.

Theme three: Psychological health

The third theme was psychological health. This was made up of five categories. The first of these was an individual's mood, which can play a major role in being able to become employed.

"I think it's general health, physical health is very important, but I think mental health, the psychological preparation, rehabilitation for some to be ready to go back to work. You may have someone who has severe depression after a traumatic incident who just doesn't want to go back to work." (T6)

The individual's motivation to work was found to be essential to ensure successful employment and was the second category.

"I strongly believe, that (a will to work) *is the strongest, strongest indicator of whether your return to work will be successful or not."* (T8)

The third category was insight after an SCI. This was important as the individual is taught many things during rehabilitation, but insight is required to make sure they are integrated in his or her life once discharged.

"The insight penny never dropped properly in the rehab process and somehow he could not teach his own caregivers to look after him properly." (T2)

"It takes a long time for insight and they can't stay that long (in a government rehabilitation unit)*."* (T3)

The individual's general life attitude was also a category to consider. It was felt that this was something that was present prior to the injury and affected their outlook on life.

> *"That is what I have seen, that 50% of the rehab is the attitude of the person from the beginning. Like you were saying here, I've got the support, I've got to get back to work, I've got to make a plan, and they rehab quickly and they are gone. And they do make a success of it. Whereas others, they lie and say I'm sick now*" (T8)

Occupational adjustment to the SCI, including the adaption after a SCI and the dependence on others one has to deal with was the final category of psychological health.

> *"Call it an occupational adjustment; you have to change your whole identity to that. It's that whole acceptance thing. To realise that this will always be something that will limit what I can do."* (T9)

<u>Theme four: Interpersonal wellbeing and support</u>

Interpersonal wellbeing and support was the fourth theme. The four categories of this theme covered the greater social context and that of the family.

In the greater social context, public education of SCI to diminish stigmatisation was considered something that was still required in South Africa and was the first category. The stigma is illustrated in this quote:

> *"In fact in all, when you are disabled like us people, you are not regarded as a person. You are not. You are half, you are not counted."* (P11)

On a personal level an adequate support system was the second category and is important when considering employment. This involved education of family members and their support, as seen in the quotes,

> *"You know when you don't have somebody next to you who will assist you, it's a sad life, you won't reach where you want to reach."* (P11)

> *"*(His wife played) *a major, major role* (in being able to work). *Because she's the one who could advise me, you know eish.. She is really helped, even now, I say thank you to her that she was around. If it wasn't for her I think my life is going to be messed up."* (P11)

The role of caregivers was important. This was the third category. The management of the relationship between the person living with a SCI and the caregiver and reliance that the individual living with a SCI has on the caregiver were discussed. The following quotation illustrates this,

> *"It's that relationship* (with caregivers) *as well. How do you manage that? It's a very, very precarious area and position."* (P5)

The role of a mentor was advantageous to assist in learning to live life despite the SCI. This was the fourth category and included support from others living with a SCI, these were usually contacts made during rehabilitation.

> *"She* (a mentor) *brightened my life really."* (P11)

Theme five: Skills level of the individual

The skills level of the individual was the fifth theme. It included the individual's vocational skills which formed the first category, but also problems in acquiring the skills. It was felt that pre-injury skills, knowledge and experience determined which jobs one would be able to do. It also determined the extent to which an employer would go to ensure one returned to work post-injury. The following quotes highlight the need for education and a good work history.

> *"I encourage people who are disabled to really, really they must go to school, so to open the doors, if you are not educated and you are disabled really how are you going to make your future. Education comes first."* (P11)

> *"How good your work history was and if you are worth getting back. You have some unique skill."* (T7)

The state of SETA's and learnerships in South Africa emerged as a problem and was the second category. In South Africa at present, individuals skills levels may be affected by this as illustrated by this quote,

"Skills development …is becoming like a job so to speak, where the person may do a learnership a year….when they are finished with that learnership, get their qualification, not find gainful employment, ..go on to another learnership…learnership hopping". (P5)

Prevocational skills were the third category and were highlighted as important. Prevocational skills included amongst others the ability to perform personal management tasks independently, or within a reasonable time period and move around independently.

"I really used to tell people that if you can be clean, as you are disabled, when you are dirty, no one will come next to you. Because there is that smell which makes people to stare at you, but if you are clean you will see, people will love you, they will come and talk to you, that's the start of everything." (P11)

Aspects which needed to be assessed are captured in the following quotation,

"Are they prompt, on their own, do they need help, can they handle their own chair?" (T8)

Theme six: Transportation

The sixth theme was transportation. This theme had two categories, the first was the inaccessible public transport system. Where transport was available one often requires assistance to access the transport. This was either in the form of physical assistance or access to information before one knew where and how to access the transport. The following quotes capture the essence of the theme.

"Transport has wasted lots of people's opportunities to return to work." (T2)

"I think transport is a big issue, you know even if you were doing a sedentary job before and you took the taxi to work, now that's not easy anymore." (T7)

"I think transport is a big limitation, a variable really, people who could go back in every other way, the company is willing to take them, they want to work, but they can't get to work." (T4)

The frustration that transport can cause is captured in the following quote:

> *"It's because of this wheelchair* (that taxi's will not stop)*, then comes the time that you will curse being like that- on a wheelchair."* (P11)

The second category of transport was the perceived lack of concern by government or intervention to provide transport for those in wheelchairs.

> *"We got stuck with transport* (when trying to place someone at work)*. And I don't think anybody's making little plans. …, but I can't understand how they can have taxi's for the Confederations Cup. Why can't they say ok fine, there are five taxis in the province to drive up and down. Whatever just try something, even if it doesn't work… whatever at this stage I will take anything, but nobody is trying."* (T6)

Theme seven: The South African labour market

The South African labour market was the next theme. The category of the role of the formal and informal sectors included several aspects. Employment within the informal sector was essential as many SCI individuals in SA are manual labourers or were unemployed prior to injury.

It was felt that some companies are employing individuals living with a SCI in the formal sector due to Black Economic Empowerment targets and not due to a strategic decision to employ those that are disabled.

> *"They* (companies) *are compliance driven, to meet BEE targets."* (P5)

The role that unions play in helping their members return to work was the second category. Participants reported that the role they play was generally one of supporting their members' wishes, but they were not knowledgeable about how to accommodate someone post-injury.

> *"If their member does not want to* (return to work) *and wants a pension that is what they will try for. So basically they fight for their member. Whatever their member wants so… it does vary, but they are not very informed."* (T2)

The high levels of unemployment in South Africa was the third category, as this quote captures:

> *"Most of the patients don't even have a job before the injury."* (T9)

The limited implementation of legislation was found as the final category of the South African Labour market. South Africa has excellent legislation. However, it is seldom implemented.

> *"The frustrating thing currently in our country, there is so much lip service to disability…but when it comes to implementation and action everyone just stands back...in most instances it's because people are clueless".* (P5)

Another reason for the lack of implementation is highlighted by this quote,

> *"Disabled people are not taking their employers to court. It is extremely expensive".* (T6)

Theme eight: Knowledge of and access to resources

Theme eight was knowledge of and access to resources. The first category was the knowledge and access to resources within the home environment and the effect this would have on being able to become employed. Participants felt that access to resources was largely affected by the socioeconomic status of the individual.

> *"They've got lots of ideas, but nothing gets enacted because it's just so limited, there's no resources and there's no money."* (T8)

> *"If you think as a young person sitting at home, with nothing to do. I wonder about the social effects of that – drugs, alcohol, even suicide, you know, major depression."* (T7)

The knowledge of resources and access to them in the work environment was also important and was the second category. All the information that is required when working, such as transportation details and health assistance available at work played a role.

"If they don't have that information, about general support resources, which are going to enable, facilitate your return to work, then even the guys who are motivated to go back to work, they get quite despondent." (P5)

Theme nine: Insurance factors

Insurance factors formed theme nine. There were two categories in this theme, the first being privately insured individuals. This was largely seen as a positive factor in being able to become employed as disability insurance benefits usually provided vocational rehabilitation, case management, funded work trials and reasonable accommodations to individuals. However participants felt that the client's best interest was not always considered. What was provided was affected by:

"How badly do they (the insurer) *want someone to get back to work…and are they actually prepared to put their money where their mouth is."* (T8)

"The commitment is tied in directly with how big the fund is. If it's big and this is going to save the (insurance) *company millions, let's pay out a quarter* (to get the person back to work)*."* (T3)

The paradox of government disability grants was the second category. This was as a result of the disability grant being viewed as an advantage post-injury if one was unemployed prior to the injury, despite it not being a large amount of money each month. The disability grant served as a disincentive to the older individuals to seek employment following their injuries and it was reported that some of the younger unemployed individuals used their disability grant to provide capital to start their own business within the informal labour market.

"Most are happy because they weren't working before, so a DG (disability grant) *is alright."* (T9)

Theme ten: Work place factors

Theme ten was the work place factors. The six categories related to the workplace aspects that need to be considered. The employer's attitude and their commitment towards employing someone with a SCI was the first category.

> *"You have to make an effort to accommodate and employ disabled people. It doesn't just happen."* (P5)

The accessibility of every aspect of the workplace was also essential and the second category.

> *"One thing you really have to look at is with regards to spinal cord injuries is actual accessibility. Toilets, parking, canteens, elevators. It can fail at that point because what does that cost? It costs money. "* (T3)

Flexibility within the job due to decreased endurance levels was the third category. This may involve reduced work hours, or being able to work from home.

> *"One of the main accommodations we ask for is reduced work hours."* (T7)

If this was not available individuals considered other employment options.

> *"Most of them have gone and done self employment things."* (T9)

Education of colleagues with regards to the disability and destigmatisation is required. Category four is illustrated by these quotations,

> *"They* (colleagues) *are saying the disabled they stay at home, why do you want to be better? Just go home man."* (P11)

> *"You think you are smart, all the disabled people are at home. What you want here?"* (P11)

Category five was the match of the individual's personality to the work. It was important as it was beneficial to have an interest in the field of work one can do post-injury.

> *"One of the problems* (with the work they can do post-injury)… *it's just not the right fit, personality wise."* (T7)

A sense of achievement and career development was the final category. Individuals had to have the capacity to do the work. They would want to prove that they were

able to do the work and employers must know that the work the individual living with a SCI is employed to do and paid to do, will be done. The individual must be accepted on a professional and social level within the workplace and they must experience career development as a non-disabled person would.

> *"To be employed they have to be at a competitive level. They must be able to compete with their colleagues, otherwise it is not going to work."* (T2)

> *"One does not understand what some of these guys have to go though to be accepted amongst their colleagues, as one of the boys."* (T7)

Theme 11: Service provision in South African Hospitals

Theme eleven was the state of service provision in South African hospitals. This was supported by four categories. The first was the standard of nursing care in acute hospitals. The discussion focused on the development of pressure sores and the role of nursing care.

> *"It* (a pressure sore) *happened when I was sick here at* (private hospital).*"*(P11)

> *"People get their pressure sore before they get to rehab in the initial stage of nursing."* (T5)

> *"People are dying, basically people with SCI in our country are dying from pressure sores because the nursing care is so terrible."* (T2)

The scope of rehabilitation in private and public hospitals was highlighted and was the second category. The focus was primarily on independence in personal management.

> *"It was the focus* (of rehabilitation) *was going back home. You must just master your wheelchair and only that. They would tell us that now your life has changed, you must really try to know your wheelchair so that at home you can do things for yourself. The working part.. ay, they not did not talk about it."* (P11)

Often groups of individuals were seen at the same time in rehabilitation which is beneficial as it served as a peer support group in the initial coping stages, but may lead to limited client-centered intervention, which is problematic as

> *"people can only listen when they are ready to hear"* (T8)

> *"In a rehab hospital you've got 12 patients and two of them are not ready, but you've got to move, because there are 12 more coming. And nobody goes back to those two who aren't ready. Or they fall through the cracks."* (T2)

The private setting may have the advantage of a case manager to prevent individuals not receiving the rehabilitation they require at the time it is required.

> *"I think in a medical sense we seeing people fall though major gaps because there is not a case manager. It's a luxury of the rich, the insured."* (P5)

Follow-up was the third category. Within government hospitals this was largely absent and was limited within the private setting, illustrated by the following quote:

> *"Discharge - closed the chapter. Go home."* (P11)

Vocational rehabilitation was the final category. It was largely absent if one was in the government health system or uninsured.

> *"At the acute stage they are not always ready to deal with work, then we send them home and there's nothing… we don't have any work intervention at all."* (T3)

> *"The voc rehab process has died in* (certain province) *health services."* (T4)

An expert in qualitative data analysis read through the transcripts from the two focus groups and the interview. She then analysed the data and it was found that her themes and categories corresponded with the researcher's.

These themes and categories guided the development of the content of the actual questionnaire.

4.2.4 Questionnaire content

The first part of designing the questionnaire was to define the variables that needed to be included in the questionnaire.

4.2.4.1 Defining and clarifying the survey variables

The list of variables that influence employment after a SCI was identified following the initial literature search. This list is presented in Appendix K. The most important variables in the South African context were determined using deductive analysis between the qualitative data in Figure 4.1 and the variables found in the literature.

The variables were listed from the literature and the qualitative data were then matched to this. The variables were grouped into six sections: demographic information, injury details, pre-injury work information, post-injury work information, unemployment post-injury and legislation. These became the six sections of the questionnaire. The method in which this was done is illustrated in Table 4.2 for the section on injury details. The other sections of the questionnaire were done in the same manner.

Table 4.2: Matching of literature variables to the themes and categories from focus groups and interview.

Variables from literature	Theme in which the variable was found in phase one	Section in questionnaire
Time since injury	Psychological health (adjustment)	Injury details
Cause of injury	Physical health	
Level of impairment	Physical health	
Initial perception of functional abilities	Physical health	
Perceived disability	Physical health	
Social support	Social/Interpersonal well being	
Pain	Physical health	
Independence at home	Physical health	
Length of hospital rehabilitation	Service provision in hospitals	
Rehabilitation hospital	Service provision in hospitals	
Medical complications	Physical health	
Involvement of OT in the return to work process	Service provision in hospitals	
Services received which aided employment	Service provision in hospitals	
Other professions involved in the return to work process	Service provision in hospitals	

All the themes and categories could be related to a variable from the literature, therefore no new variables were created.

4.2.4.2 Formulating the questions for the questionnaire

The questions were compiled using various types of questions. Closed questions with some response choices and the option of “other (please specify)” were provided. Scaled questions according to de Vos were used when more subjective, non-exact information was required such as question 9 in Section B (Table 4.3) and question 12 in Section D (Table 4.4)[107].

Table 4.3 Example of a scaled question as used in section B

B9	How functional are you at home	Independent
		Partially dependent
		Dependent

Table 4.4: Example of a scaled question as used in section D

D12	How you would you describe the majority of your colleagues' attitude to your return to work, or employment post-injury?	Dismissive
		Neutral
		Favourable and understanding

An open ended question was asked at the end of the questionnaire to gain any further information. The questionnaire then required formatting.

4.2.5 Formatting of the questionnaire

The questions were arranged in a logical sequence. The funnel principle where general questions are followed by ones that become progressively more spceific[106] was applied. This is seen in Table 4.5 used in Section B question 10.

Table 4.5: Example of a question making use of the funnel principle

10 a	Do you have a caregiver?
10 b	Is he/she a family member?
10 c	Has it placed strain on your relationship?

The full questionnaire was then checked for content validity.

4.2.6 Ensuring content validity of the questionnaire

The two subject matter experts selected to check the content validity of the questionnaire were both between the ages of 36 and 50 years, had more than 15 years experience as occupational therapists and worked in private practice in vocational rehabilitation.

The two subject matter experts made comments on the questionnaire.

These comments included spelling errors, response categories that required additional options, alternative adjectives in the Likert scale question options and additional questions on certain aspects were suggested. Examples of some changes are presented in the table below.

Table 4.6: Feedback and changes made to questionnaire following subject matter experts' comments

Original question	**Original answer options**	**Feedback**	**Revised question**	**Revised answer options**
How many dependent children do you have (less than 18 years of age)?	0 1 2 3 or more	Rather a question to give an indication of their socio-economic status. You may want them to indicate their approximate family income range**.**	What is your family's combined monthly income?	R _____?
			Were you the bread winner of the family before your injury?	Yes
				No

Original question	Original answer options	Feedback	Revised question	Revised answer options
What was the physical intensity of your work?	Sedentary	Include some basic parameters here, otherwise you are only going to get 'sedentary' and 'heavy' as responses	What was the physical intensity of your work?	**Sedentary:** Sitting most of the time, but may involve walking or standing for short periods
	Light work			**Light work:** exerting 9 Kg of force 33% of the time and 4.5 Kg for 34-66% of the time. Or negligible amount of force constantly to move objects
	Medium			**Medium:** exerting 9 to 23 Kg of force 33% of the time, 4.6 – 11 Kg for 34-66% of the time or 4.5 Kg of force constantly to move objects.
	Heavy			**Heavy:** Exerting 23 Kg to 45 Kg of force 33% if the time, or 11Kg to 23 Kg for 34-66% of the time, or 4.5 to 9 Kg to constantly move objects
	Very Heavy			**Very Heavy:** Exerting more than 45.5 Kg of force 33% of the time, or 23 Kg for 34-66% of the time to move objects, or more than 9 Kg to constantly move objects.
Do you perceive the support you get from your family and friends as adequate?	Yes	A wider range of choices such to allow for the "in between" cases such as support from one member but not others; good physical support, but not emotional support; etc.	Do you receive adequate physical support from your family and friends?	Yes
	No			Somewhat
				No
			Do you receive adequate emotional support from your family and friends?	Yes
				Somewhat
				No

At this point the questionnaire had become too lengthily and therefore a review of the content was performed by shredding the questionnaire.

4.2.7 Shredding the questionnaire

After revisiting the aims and objectives, the questionnaire was critically reviewed by two members from the focus groups and the researcher. Each question's relevance to the study was considered. Questions which did not contribute to the aim and objectives of the study were removed from the questionnaire. Examples of the questions removed are seen in Table 4.7.

Table 4.7 Questions removed from questionnaire after shredding

Question	Reason for removal
How old were you when you were injured?	Could be determined from knowing the date of injury.
Rate your perceived impairment	Perceived functional level deemed sufficient.
Were you satisfied with your rehabilitation?	Did not relate to aims and objective of study.
Were your colleagues briefed before you started working after your injury?	Too detailed, colleagues' attitude towards person living with a SCI sufficient.

4.2.8 Concluding the Phase one results

Employment after a SCI is influenced by many factors. Thus it was not unexpected to find the number of aspects that were raised during phase one of the study. There was much debate regarding the most important issues. This was to be expected as it was an exploratory study. A summary of the results is found in figure 4.1 with the following aspects of specific concern in the South African context.

- There is a lack of follow-up post discharge from rehabilitation centers and vocational services were limited to those that can afford them

- The need for accessible public transport, as many individuals do not have the financial resources to own their own car and even this may not negate the problems with transportation.
- Despite South Africa's comprehensive legislation with regard to those with disabilities, the implementation has not been adequate and therefore the impact of the legislation has not been obvious for those with disabilities.
- As South Africa does not have the same sort of social security system as First World countries, this was not viewed as a reason to not seek employment. However, as many individuals in SA were not working prior to their injury due to high levels of unemployment among unskilled individuals, the monthly disability grant was viewed as a benefit. This despite it not being a large amount.

There were many factors that emerged from phase one. It was impossible to include all the aspects in the questionnaire and the researcher decided to take a reductionist approach to find a balance between quantity and depth of questions. Long and tedious questionnaires have been criticised in the literature and taking a reductionist approach was thought to overcome this criticism[106,107].

This concludes the results for phase one. Phase two began with the piloting of the questionnaire so that the prevalence of the variables found in phase one could be determined in a specific population.

4.3 Phase two results

Phase two results include the piloting of the questionnaire and the results from the implementation of the questionnaire.

4.3.1 Piloting the questionnaire

Of the ten people who were selected at the Supersport wheelchair basketball match day, six individuals returned the piloted questionnaire via email, thus achieving a 60% return rate. Similar concerns were highlighted in the six returned questionnaires (Appendix L) and a decision was made not to follow up on the four outstanding questionnaires.

The time it took individuals to complete the questionnaire ranged from ten to 35 minutes with an average of 18 minutes and 33 seconds.

Telephonic follow-ups took place with two of the participants as they had indicated on their questionnaire that they felt certain aspects required more detail. The follow-ups were required to ascertain exactly what they meant. Feedback from the participants was to discuss aspects that were not in the scope of the study, such as difficulties with a Road Accident Fund claim or the opportunity to expand on an answer provided. As the questionnaire was already a lengthy document these changes were not incorporated.

After adapting the questionnaire with the comments from the six individuals, it was ready for implementation. The questionnaire is attached as Appendix I.

4.3.2 Implementation of the questionnaire

The questionnaire was sent to the members of the QASA email database. There were 330 members. The individuals were asked to forward the questionnaire to any other individuals who would be eligible to complete it. This snowball sampling method was used to obtain a maximum number of participants.

Ninety questionnaires were returned, however one of the questionnaires was blank. There were therefore 89 questionnaires that met the inclusion criteria for the study. There were 71 (79.78%) males and 18 (20.22%) females. The majority of the sample were white (77.01%) and 51.14% of the sample resided in Gauteng with 26.14% in the Western Cape and the remaining 22.72% in the other seven provinces.

The quantitative results from phase two will be presented in tables, and graphs. The descriptive results will be presented first and this will be followed by the results of the comparison of employed and unemployed individuals and finally the logistic regression results.

The domain from The Occupational Therapy Practice Framework: Domain and Process II[5] (see Table 3.1) has been used as a method of categorising the results for

the descriptive results and the comparison between the employed and unemployed individuals as described in the methodology chapter.

4.3.3 Descriptive results

The descriptive results will be presented as frequencies and percentages for categorical (nominal) data, and means and standard deviations for continuous (ordinal) data

4.3.4 Context and environment

At the time of the injury, 41.18% of the sample reported they were the breadwinners in the family and were young to middle aged at the time of injury. The range of income was extreme with a large standard deviation. This was due to one outlier with R900 000 income per annum. Table 4.8 provides the personal and temporal context information.

Table 4.8: Demographic data of personal and temporal context

Variable	n	Median	Mean	Range	Standard deviation
Age	89	41	40.11	22 -61	9.26
Current Income	77	R41 377.90	R20 000	R2 000- 900 000	104036.2
Time Since injury	88	14 years	16.59	1-58	10.80
Age at injury	89	22 years	24.18	3 - 45	8.07

	Single		Married/ living with partner		Divorced/ Separated		Widowed		No response	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Current marital status	33	37.08	45	50.56	8	8.99	1	1.12	2	2.25

The sample was fairly well educated as can be seen in Table 4.9.

Table 4.9: Personal context: Education level

Variable	Grade 9 or less		Grade 10		Grade 11		Grade 12		No response	
Secondary education level	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	2	2.25	5	5.62	3	3.37	73	82.02	6	6.74

	Certificate		Trade		Diploma		Degree		Degree with honours		Masters		PhD		No response	
Tertiary education level	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	12	13.48	4	4.49	19	21.35	10	11.24	11	12.39	9	10.11	1	1.12	23	25.84

4.3.4.1 Social context

More than half the sample required a caregiver (52.81%). Of these individuals 38.30% had a family member as their caregiver. This placed strain on their relationship with the family member for 41.18% of the individuals.

4.3.4.2 Legislative

The sample was generally aware of legalisation affecting people living with disabilities. However, their perceived impact it had had on employment status was disappointing.

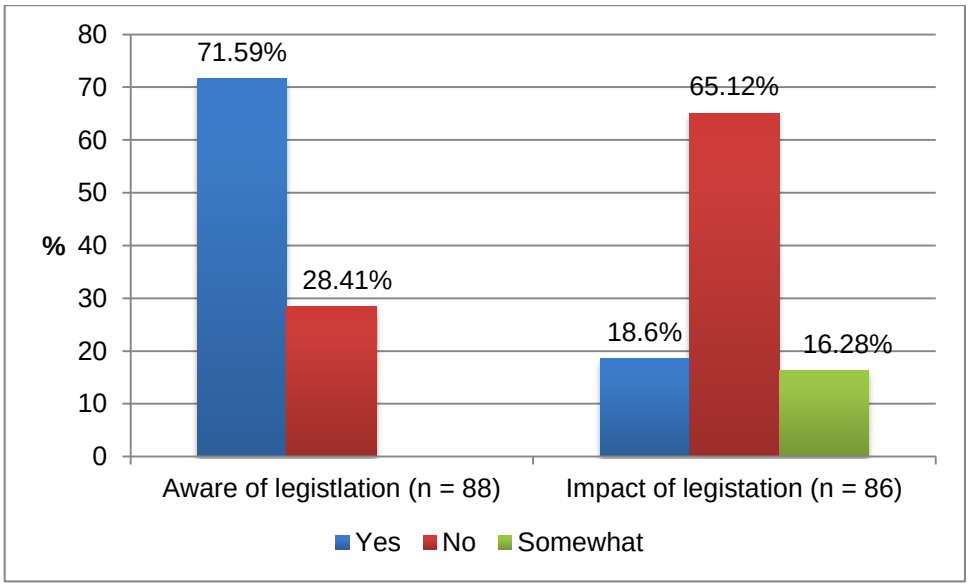


Figure 4.2: Participants' perceived awareness of legislation and perceived impact it had on employment

4.3.4.3 Economic environment

A payout was received by 47.19% of the sample post-injury. As the leading cause of injury was motor vehicle accidents, it is not surprising the highest source of payout was the Road Accident Fund as seen in Figure 4.3.

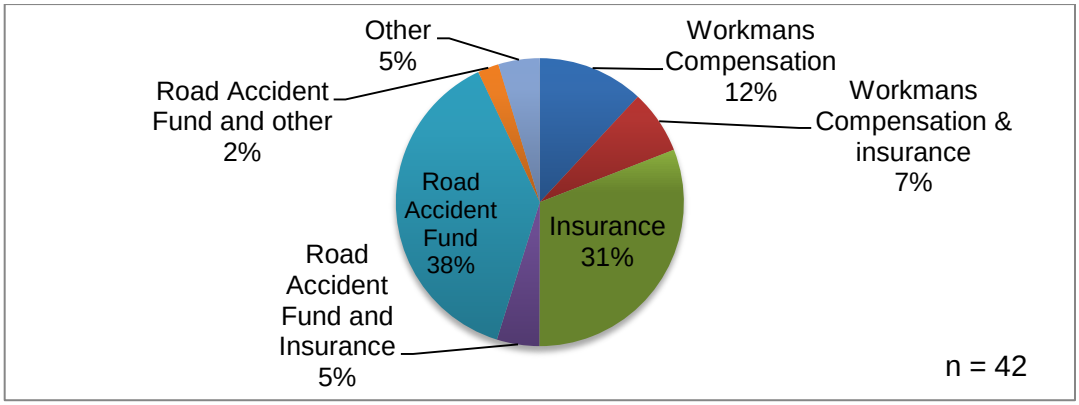


Figure 4.3: Sources of payout after injury

Only one individual of the 14 that had not been employed post-injury was living off a disability grant alone, all the other unemployed individuals had other or additional sources of income as seen in Figure 4.4.

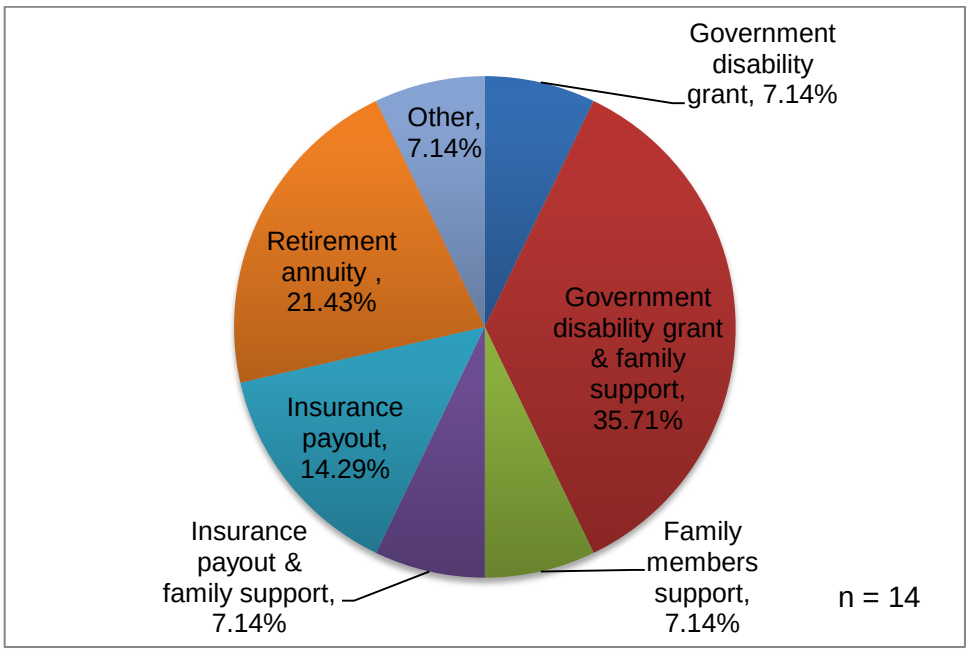


Figure 4.4: Unemployed participants' source of income

4.3.4.4 Physical Transportation

The majority of the sample had their own car (70.59%), as shown in table 4.10

Transportation was problematic for 20.22%% (18 individuals) of the sample at the time of the study. The type of transport used by these individuals is indicated in table 4.10

Table 4.10: Transportation used at the time of the study and the type of transport that was problematic

Type of transport	Used at time of study (n=85)		Problematic at the time of study (n=18)	
	n	%	n	%
Drive own car	60	70.59	10	16.67
Have a driver	20	23.53	4	20
Public transport	1	1.18	0	0
Other (lifts)	2	2.35	2	100
None	2	2.35	2	100

Transportation impacted more than half the participants to a greater or lesser degree during the process of becoming employed as seen in Table 4.11.

Table 4.11: Impact that transport played in becoming employed

	Did not play a role		Mild impact		Moderate impact		Severe impact	
	n	%	n	%	n	%	n	%
Transportation (n=82)	36	43.90	14	17.07	7	8.54	25	30.49

4.3.4.5 South African hospitals and rehabilitation

The sector in which rehabilitation was received was more or less equal, with 45.45% of the sample receiving their rehabilitation in a private and 52.27% at a government hospital. Two individuals reported that they had not received any rehabilitation and one individual did not answer the question. Sadly not all individuals and their families were provided all the information they required during rehabilitation. Only 44.94% of the sample were made aware of community resources and 73.03% of the individuals families were educated on SCI during rehabilitation.

It is disappointing that employment was only discussed with half of those of employment age (excluding students) during rehabilitation. Even more disappointing was the low percentage of employers of those who were employed at the time of injury that were contacted by rehabilitation staff. Of further concern was the poor

referral rate to someone to assist with employment post rehabilitation as seen in Figure 4.5.

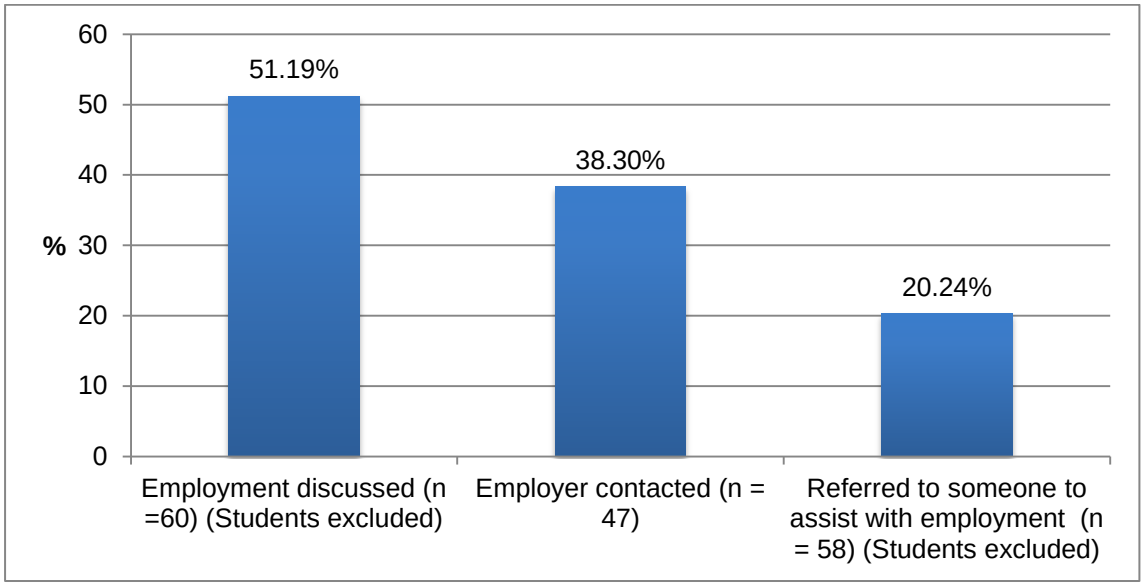


Figure 4.5: Employment aspects addressed during rehabilitation with those of employment age

Occupational therapists were the professional that contacted the employer for more than half the individuals while in rehabilitation as illustrated in Figure 4.6.

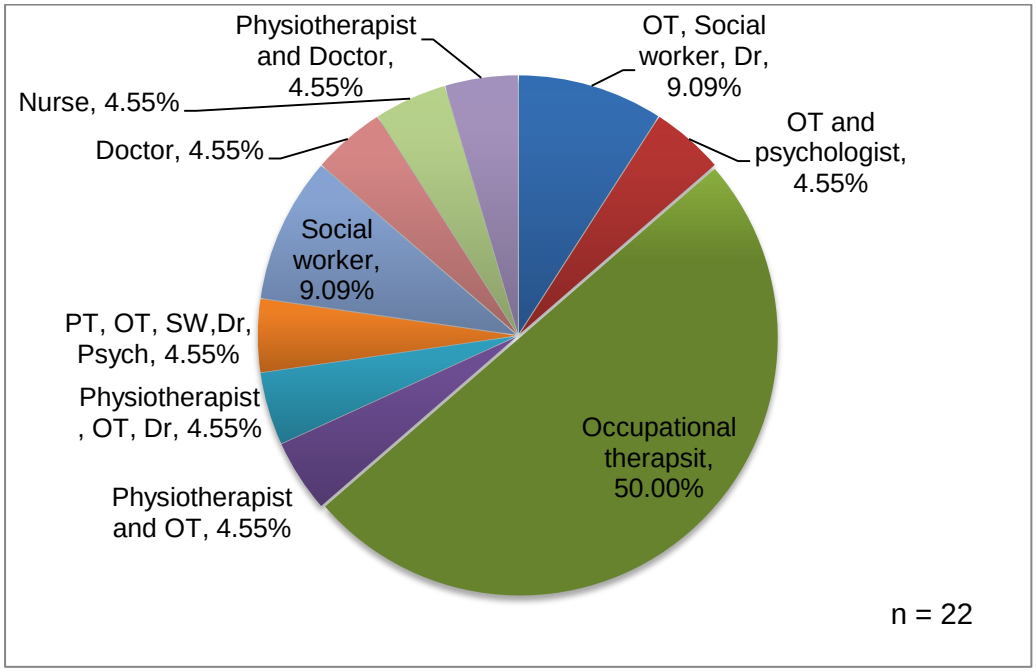


Figure 4.6: Health professionals who contacted employers during rehabilitation

It is surprising that only 41.67% of the sample had someone assist them return to work, or find employment when one considers the employment rate in Figure 4.8 of 63.64%. Family and friends were the group that helped most as seen in Figure 4.7.

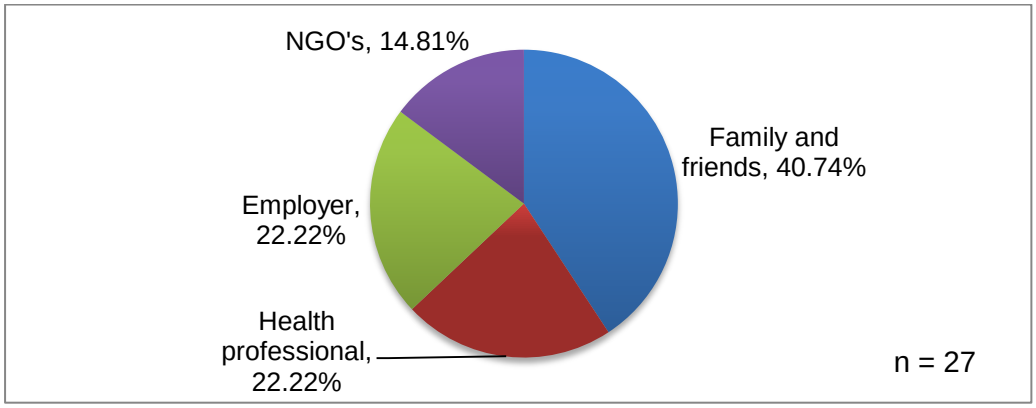


Figure 4.7: Entity who assisted participant to find employment or return to work

4.3.5 Client factors

The client factors are presented in Table 4.12. It was surprising that there were few injuries as a result of violence. Co-morbid conditions were more common than pre-morbid conditions. Co-morbid conditions included head injuries, various fractures and upper limb injuries. Urinary tract infections were the most common complications and all but one individual was motivated to work post-injury as seen in Table 4.12.

Table 4.12: Descriptive data of the participants

	Complete tetraplegia		Complete paraplegia		Incomplete tetraplegia		Incomplete paraplegia		No response	
Type of paralysis	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	25	28.09	19	21.35	31	34.83	9	10.11	5	5.62

	MVA		A Fall		Diving accident / Sports Injury		Assault/ stabbing		Gun Shot		Other		No response	
Cause of the injury	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	46	51.69	3	3.37	24	26.97	1	1.12	12	13.48	2	2.25	1	1.12

	Present		Absent		No response	
	n	**%**	**n**	**%**	**n**	**%**
Co-morbid conditions	24	26.97	65	73.03	0	0
Pre-morbid conditions	3	3.37	85	95.51	1	1.12
Depression post-injury	25	28.09	62	69.66	2	2.25
Pressure sores	42	47.19	46	51.69	1	1.12
Urinary tract infections	78	87.64	10	11.24	1	1.12
Pneumonia	14	15.73	72	80.9	3	3.37
Other complications	12	13.4	73	82.02	4	4.49
Motivated to work post-injury	86	96.63	1	1.12	2	2.25

	None		Mild		Moderate		Severe		No response	
Self perceived amount of pain experienced on a daily basis	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	35	39.33	30	33.71	18	20.22	4	4.49	2	2.25

4.3.6 Performance patterns

Individuals were generally independent in the routines associated with life after a SCI. The following were independent in the various routines: bowel 53.93%, bladder 64.04% and pressure relief 75.28%. With regards to these routines limiting the individual's ability to leave the house: 14.61% reported their bowel routine did so, 5.62% their bladder routine and 3.37% their pressure relief routine.

4.3.7 Areas of occupation

4.3.7.1 Activities of daily living (ADL) and instrumental activities of daily living (IADL)

Less than half the sample, 48.31% described themselves as functionally independent at home, with 32.25% partially dependent and 16.85% dependent. Two individuals did not complete this question.

4.3.7.2 Social participation

The sample generally reported having adequate support post-injury. Adequate physical support was reported by 84.27% of the sample, somewhat adequate and inadequate physical support was reported by 14.61% and 1.12% of the sample respectively. Emotional support was reported to be adequate by 85.39%, somewhat adequate by 10.11% and inadequate by 4.49% of the sample.

The support the sample received was not perceived to have a great impact on returning to work or becoming employed with 75.61% of the sample reporting that it played no role, 10.98% a moderate impact and 12.2% a mild impact. Seven participants did not answer this question. The majority of the sample still participated in social activities post-injury, however only 30.77% reported that they were as social as before their injury. Two thirds of the sample (67.95%) still socialized, but reported that it was less then prior to their injury and 1.28% avoided social situations. Eleven participants did not complete this question.

Forty-one percent of the sample reported they had had a mentor since their injury.

4.3.7.3 Education

Following the injury, 38.27% of those that had been employed post-injury reported requiring retraining to perform their post-injury job. It therefore comes as no surprise that almost two thirds (62.96%) of the sample reported it played no role in becoming employed post-injury. Retraining was reported to have a severe or moderate impact on becoming employed by 22.22% and a mild impact by 14.81% of the sample. Seven individuals however, did not complete this question.

4.3.7.4 Work

Since the injury 92.13% of the sample had been employed. This and the percentage of those employed (full time, part time and self employed) at the time of the study (79.55%) were high. At the time of injury a third of the sample were students as illustrated in Figure 4.8.

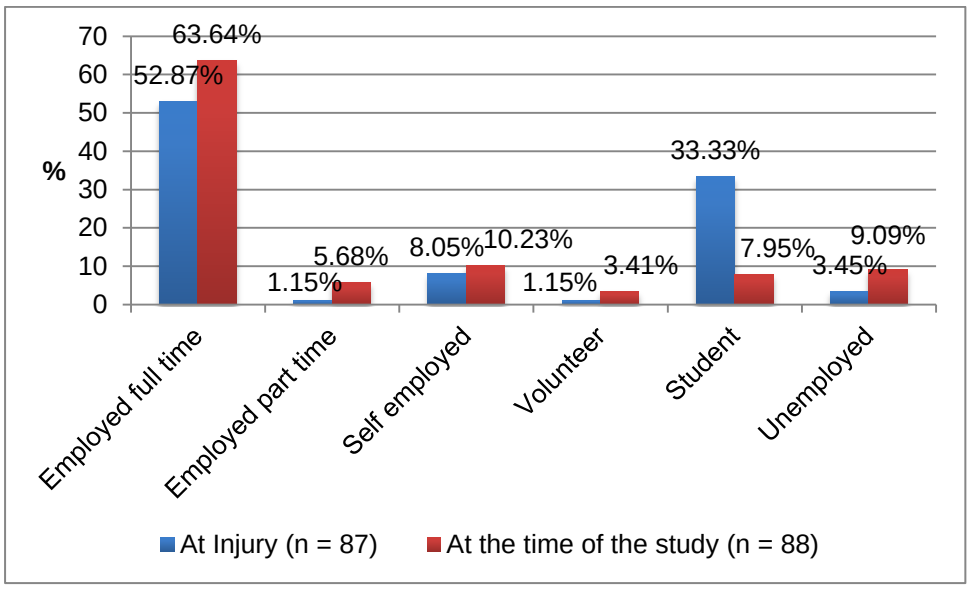


Figure 4.8: Employment status at the time of the injury and at the time of the study

Of those that were students when injured, 75.86% were employed at the time of the study.

The length of time at a job prior to injury ranged from 2 months to 25 years, with an average of 4.83 years.

Of the total sample, 44.44% returned to their previous employer post-injury and 66.67% of those that returned to their previous employer had a change in job description. The reasons given by the rest of the sample for not returning to their previous employer are presented in Figure 4.9.

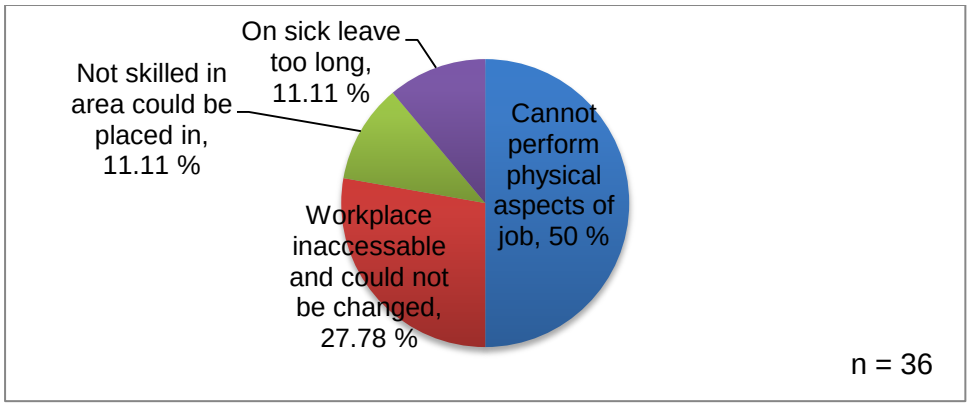


Figure 4.9: Reasons given for not returning to post-injury employer

Table 4.13 reports that the majority of the sample, 62.92% had three or less jobs since injury. Surprisingly more than half of the individuals who reported the number of hours they worked per week, worked more than 40 hours a week.

Table 4.13: Number of jobs held post-injury and hours worked per week

	1		2		3		4		5		6 or more		No response	
No of jobs post-injury n = 82	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	26	29.21	17	79.10	16	17.98	8	8.99	7	7.87	1	1.12	14	15.73

	0-30		30-40		More than 40		No response	
Hours worked per week in most current job n = 82	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
	12	13.48	28	31.46	42	47.19	7	7.87

As expected the number of individuals employed in jobs with a sedentary intensity of work increased post-injury as illustrated by Figure 4.10.

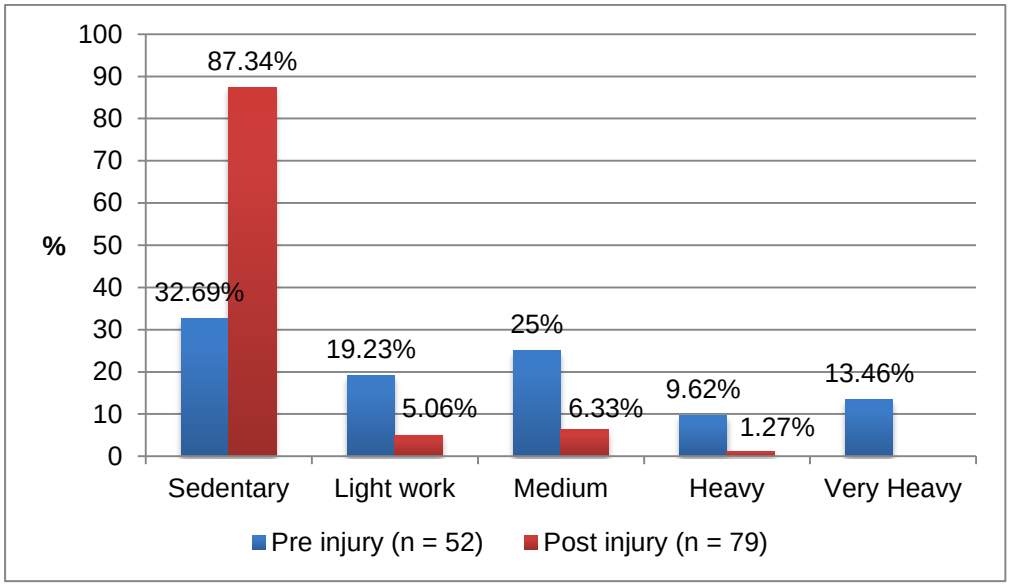


Figure 4.10: Perceived intensity of work

It is positive that there was a slight increase in the number of individuals employed in the formal sector post-injury (Figure 4.11). There was a slight decline in the number of individuals employed in the public sector post-injury as seen in Figure 4.12.

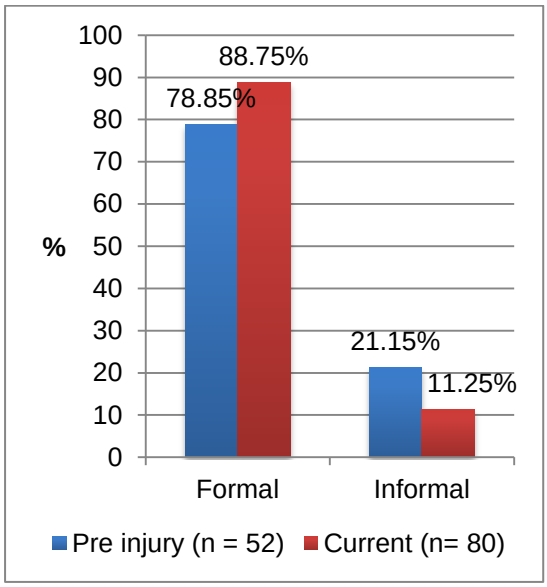


Figure 4.11: Employment in the formal and informal sector

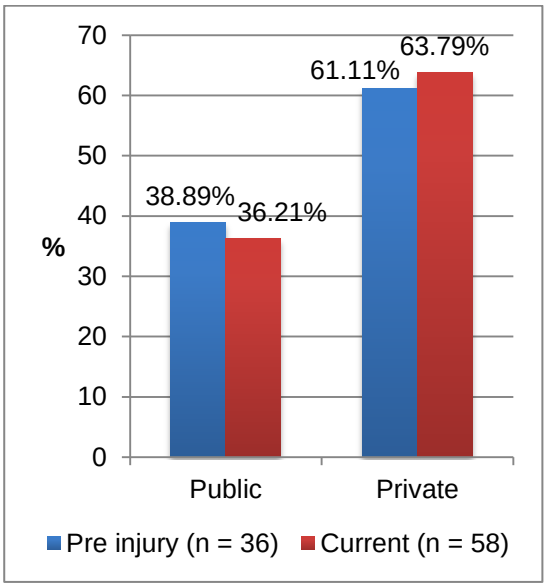


Figure 4.12: Employment in the public and private sector

Generally the work environments for those who were employed were accommodating to the individuals living with a SCI as illustrated by Figure 4.13. The participants' perceptions of their employer's and colleagues' attitudes towards them, in their most recent job are illustrated in Figure 4.14.

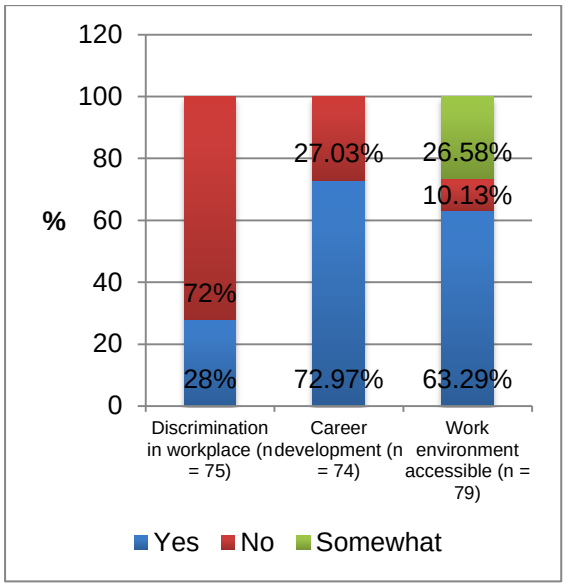


Figure 4.13: Aspects of the work environment of the participants who had been employed since injury

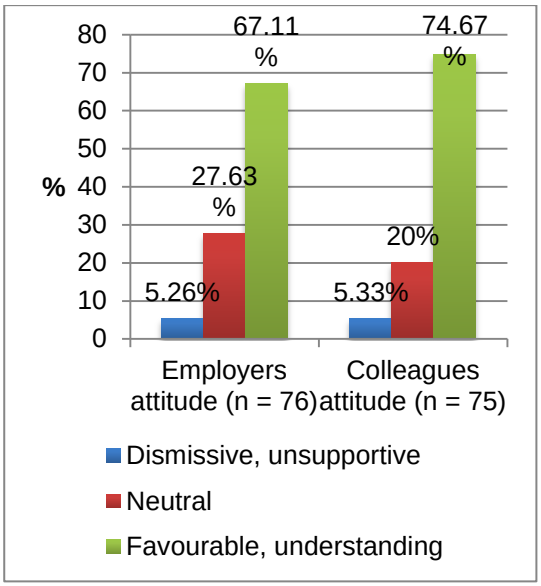


Figure 4.14: Attitude of employers and colleagues towards participants who were employed since injury

Reasonable accommodations were made for 85.90% of the sample who had been in remunerated employment post-injury. These are presented in Figure 4.15.

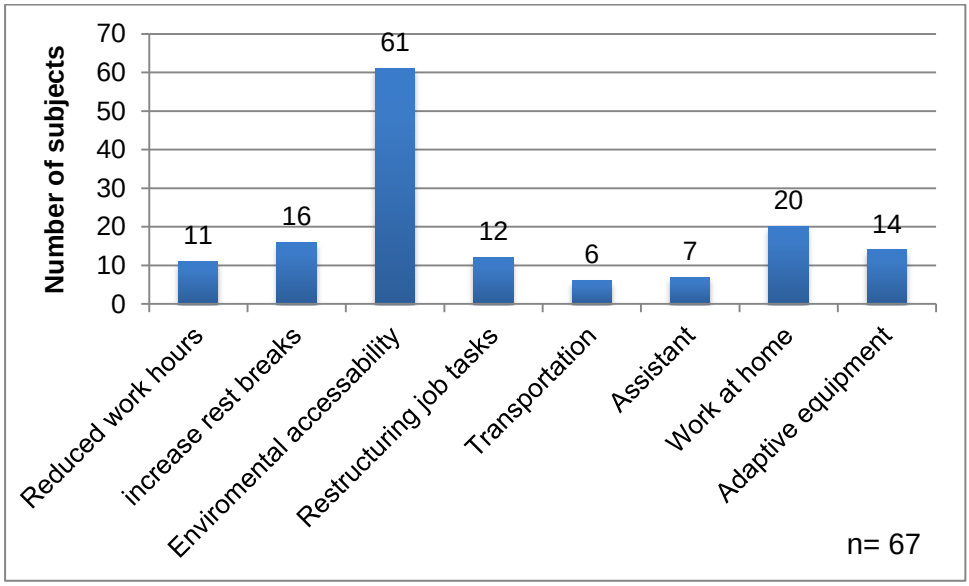
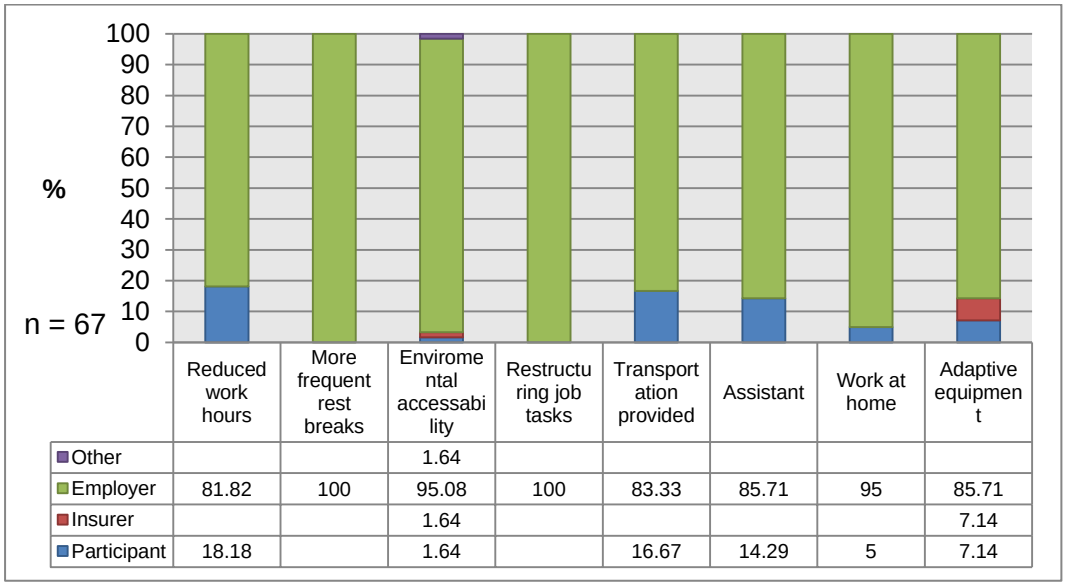


Figure 4.15: Types of reasonable accommodations provided

The financing of the above accommodations is presented in Figure 4.16. The employer financed most of these.



	Reduced work hours	More frequent rest breaks	Environmental accessability	Restructuring job tasks	Transportation provided	Assistant	Work at home	Adaptive equipment
Other			1.64					
Employer	81.82	100	95.08	100	83.33	85.71	95	85.71
Insurer			1.64					7.14
Participant	18.18		1.64		16.67	14.29	5	7.14

Figure 4.16: Financing of reasonable accommodations

Factors in the workplace that may have impacted on returning to work or becoming employed are presented in Figure 4.26. Environmental barriers were the aspect that had the greatest impact.

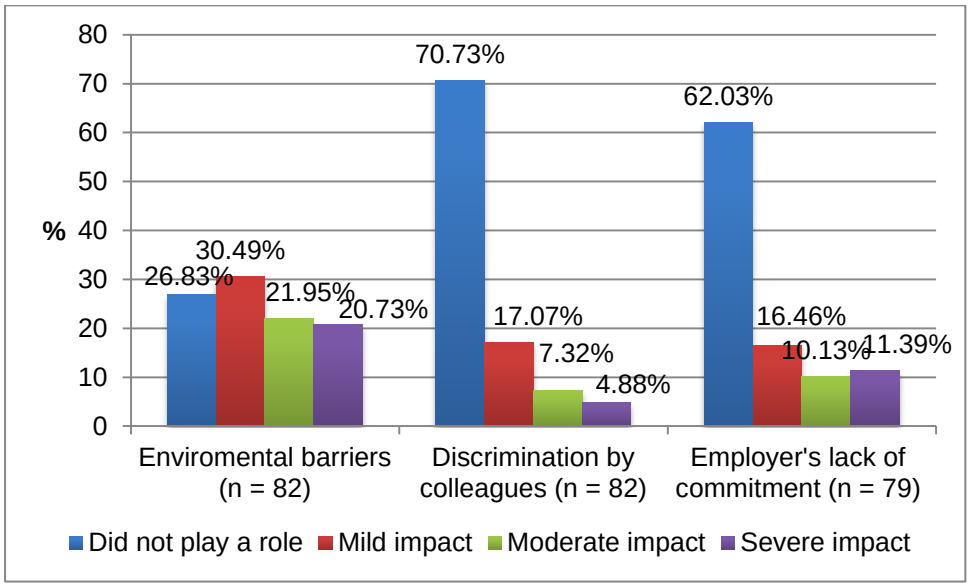


Figure 4.17: Impact of workplace factors on returning to work or becoming employed as perceived by the participants

Participants did not have much assistance with negotiations with their pre-injury employers after their injury, or they did not report it. This is illustrated in Table 4.14.

Table 4.14: Assistance with negotiations with pre-injury employers

	Union		Lawyer		None		No response	
Assistance with	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
negotiations with employer (n = 89)	2	2.25	2	2.25	49	55.06	36	40.45

4.3.8 Reasons for unemployment

Only 12 participants responded to the question on the reasons for unemployment (Table 4.15). Participants' had to rate the impact various factors had on their decision to not work. Aspects which nine or more of the individuals perceived to have no impact on their employment status were: transport, requiring assistance, work being not financially viable and inadequate social support.

Table 4.15: Impact various factors had on the decision not to work post-injury.

	No impact		Mild impact		Moderate impact		Severe impact		No response	
	n	%	n	%	n	%	n	%	n	%
Can't do pre-injury job	6	50	0	0	0	0	6	50	0	0
Working too much effort	4	33.33	5	41.67	1	8.33	2	16.67	0	0
Transport is inaccessible	9	75	1	8.33	1	8.33	1	8.33	0	0
Health issues- I am not well enough to work	6	50	3	25	1	8.33	2	16.67	0	0
Bowel and bladder routines make me unable to work	5	41.67	3	25	0	0	3	25	1	8.33
Jobs that can now be done do not suit personality	8	66.67	1	8.33	0	0	2	16.67	1	8.33
Require too much assistance to work	9	75	0	0	1	8.33	2	16.67	0	0
Cannot find job	6	50	1	8.33	1	8.33	3	25	1	8.33
Not financially viable	8	66.67	0	0	1	8.33	1	8.33	2	16.67
Retired early	7	58.33	2	16.67	1	8.33	1	8.33	1	8.33
Inadequate social support	9	75	1	8.33	0	0	4	8.33	1	8.33

The majority of the sample had worked post-injury, the sample was motivated to work and had various aspects that were required to be able to work post-injury. The result of the comparison between the employed and unemployed individuals follows.

4.3.9 Comparison of employed verses unemployed individuals

The results of the comparison of employed and unemployed individuals using the Fisher's exact test for categorical data and the t test, or Mann-Whitney test for continuous data will now be presented. Only results from the t-test and Fishers exact test with p values less than 0.35 will be presented, however only p values less than 0.05 are statistically significant. Once again the OT Practice Framework II[5] will be used as a method for categorising the results.

4.3.9.1 Context and environment

It was expected that the sample would be more or less equally split into employed and unemployed groups, however the sample was skewed towards being currently employed. There were 70 individuals employed and only 18 unemployed at the time of the study.

All the provinces except the Eastern Cape and Northern Cape had more individuals employed than unemployed (Figure 4.18). No significant difference between the two groups (p= 0.151) was found probably due to the skewed sample.

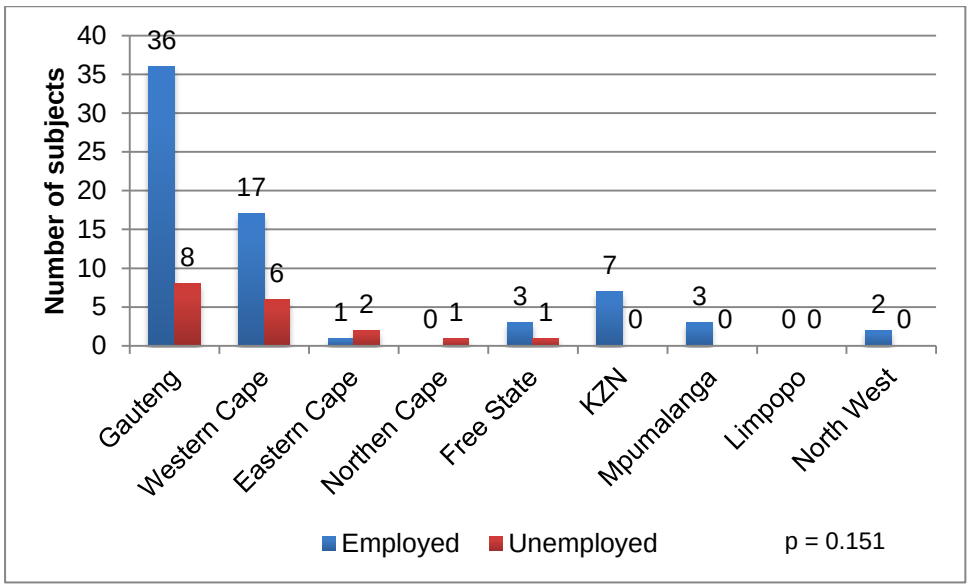


Figure 4.18: Comparison of employed to unemployed related to province (n=87)

As race was not equally represented a trend cannot be seen for the results in Figure 4.19. None of the t-test results of personal context were statistically significant in Table 4.16.

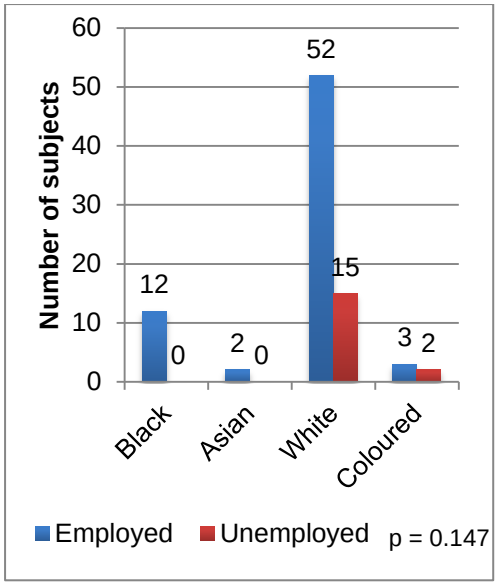


Figure 4.19: Comparison of employed to unemployed related to race (n = 86)

Table 4.16: t-test results of personal context data

Time since injury:	n = 85	p = 0.147
Age at injury	n = 86	p = 0.292
Time since injury	n = 74	p = 0.277

Neither of the social context aspects of marital status (Figure 4.20) or having a caregiver (Figure 4.21) were statically associated to employment status.

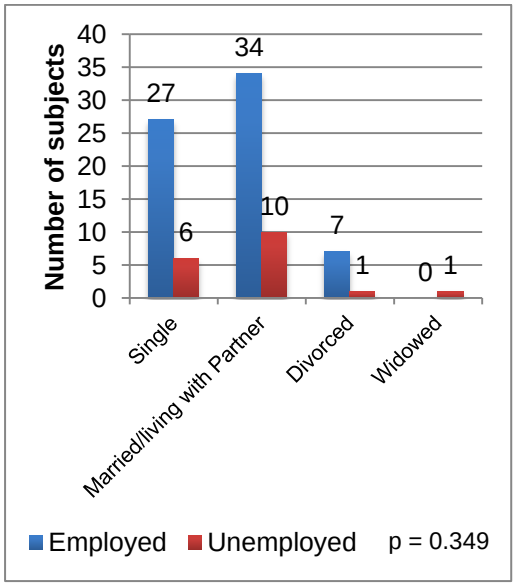


Figure 4.20: Comparison of employed to unemployed related to marital status (n = 86)

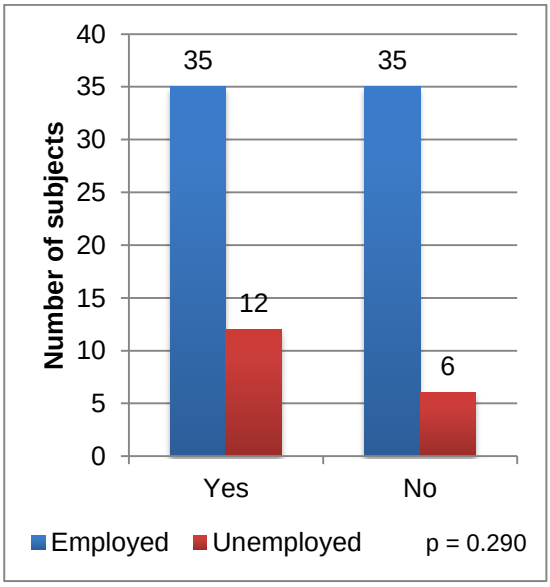


Figure 4.21: Comparison of employed to unemployed related to having a caregiver at the time of the study (n = 88)

4.3.9.1.1 Education

Education was not statistically significantly associated to employment (p= 0.195), however it is interesting that even among those with less than a Grade 12 education, 60% of them were employed (Figure 4.22). The level of tertiary education was also not statistically significantly associated to employment with p = 0.253 in Figure 4.23.

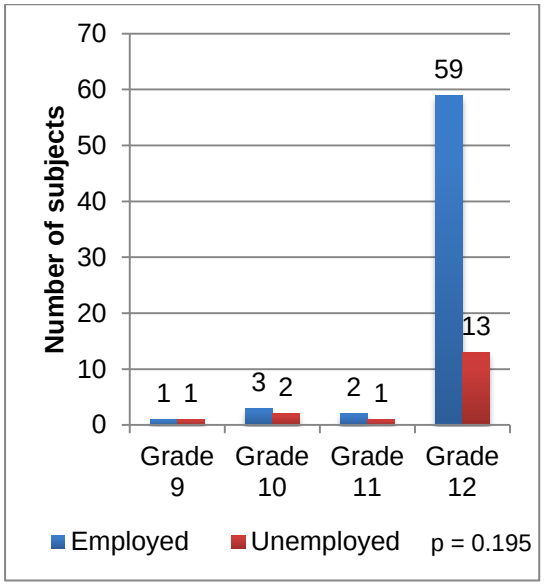


Figure 4.22: Comparison of employed to unemployed related to level of secondary education (n = 82)

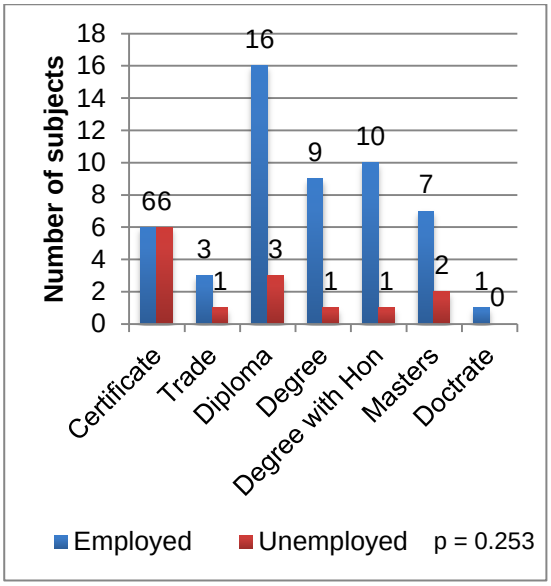


Figure 4.23: Comparison of employed to unemployed related to level of tertiary education (n = 66)

In Figure 4.23 it is of interest to note the tertiary education level of those that were unemployed. This is shown in Table 4.17. Those with a higher level of education (degree, degree with honours and masters) were either students or involved in volunteering, therefore involved in a productive activity. Four of the six individuals who were qualified with certificates and one in a trade described themselves as unemployed.

Table 4.17: Tertiary level of education of those that were unemployed at the time of the study

Level of tertiary education	Employment status at time of the study (n=14)					
	Students		Volunteer		Unemployed	
	n	%	n	%	n	%
Certificate	2	14.29	0	0	4	28.57
Trade	0	0	0	0	1	7.14
Diploma	1	7.14	1	7.14	1	7.14
Degree	1	7.14	0	0	0	0
Degree with honors	0	0	1	7.14	0	0
Masters	1	7.14	1	7.14	0	0

4.3.9.1.2 Transportation

Most of those employed at the time of the study had their own car, or a driver, but this was not significantly associated with employment status, p= 0.297 (Figure 4.24). The impact transportation had in becoming employed was statically significantly associated with current employment status with p = 0.020 in Figure 4.25.

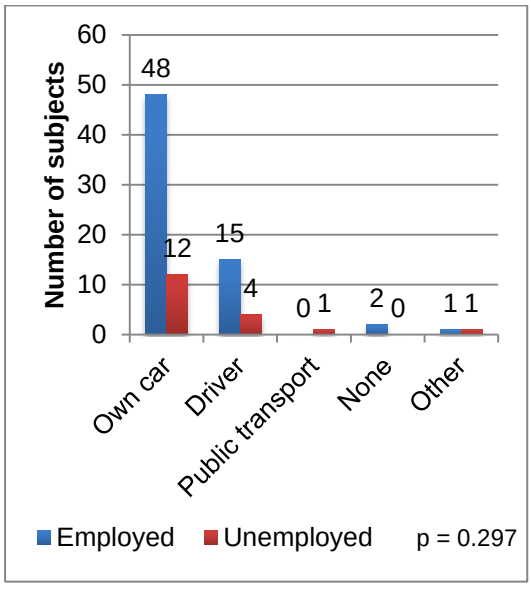


Figure 4.24: Comparison of employed to unemployed related to transport currently being used (n = 84)

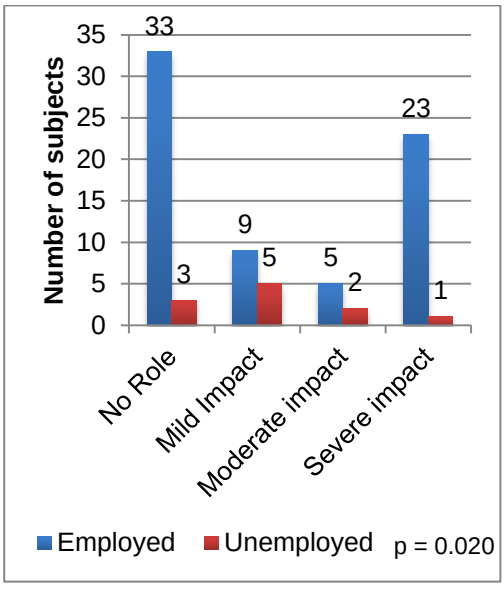


Figure 4.25: Comparison of employed to unemployed related to the role transportation played in returning to work, or securing employment (n =81)

4.3.9.1.3 Legislation

The perceived impact legislation had on employment status post-injury was not significantly associated with employment status with p = 0.096 in Figure 4.26.

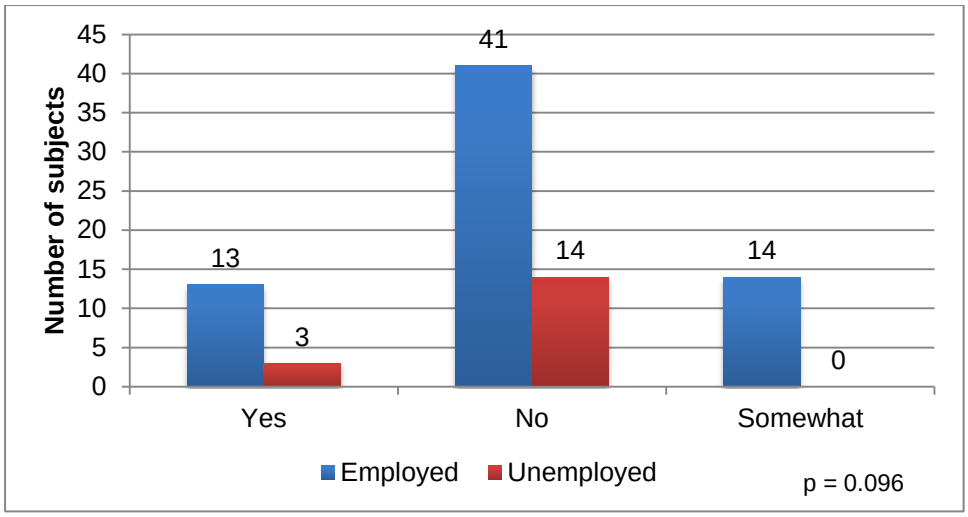


Figure 4.26: Comparison of employed to unemployed related to the perceived impact of legislation on employment status (n = 85)

4.3.9.1.4 South African hospitals and rehabilitation

The sector in which rehabilitation was received was not statistically associated with employment status (p=0.302) in Figure 4.27.

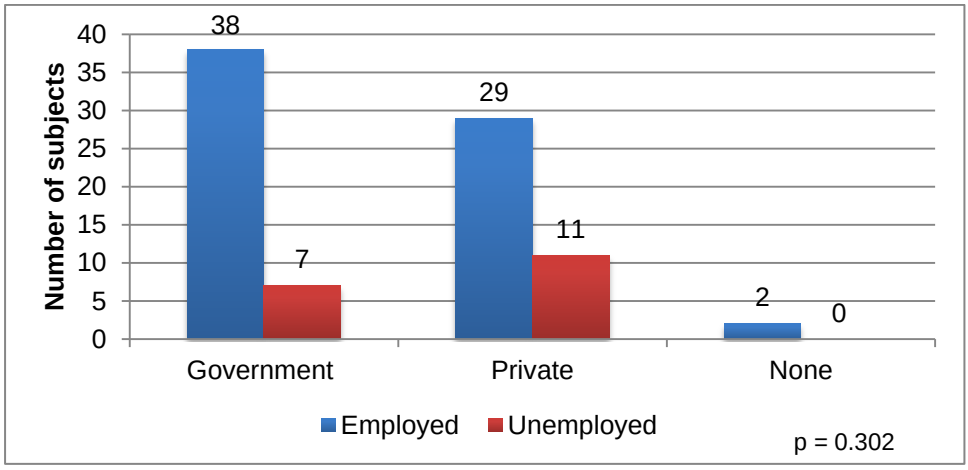


Figure 4.27: Comparison of employed to unemployed related to rehabilitation hospital (n = 87)

Family education on SCI was statistically significantly associated to employment status with p= 0.033 in Figure 4.28. Having some assistance to find work was not significantly associated with employment status with p = 0.269 in Figure 4.29.

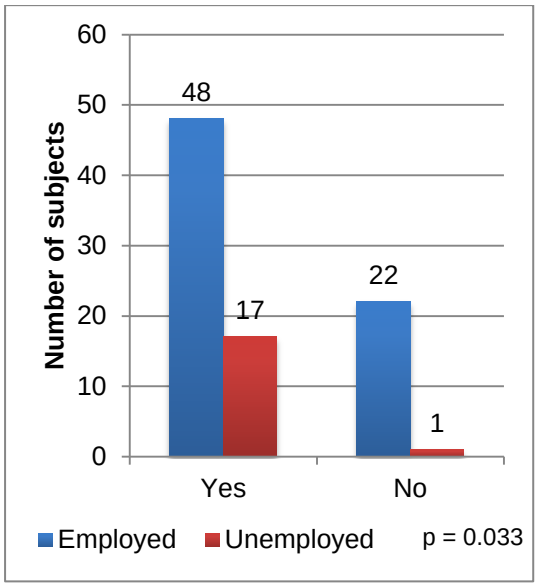


Figure 4.28: Comparison of employed to unemployed related to family education on spinal cord injury during rehabilitation (n = 88)

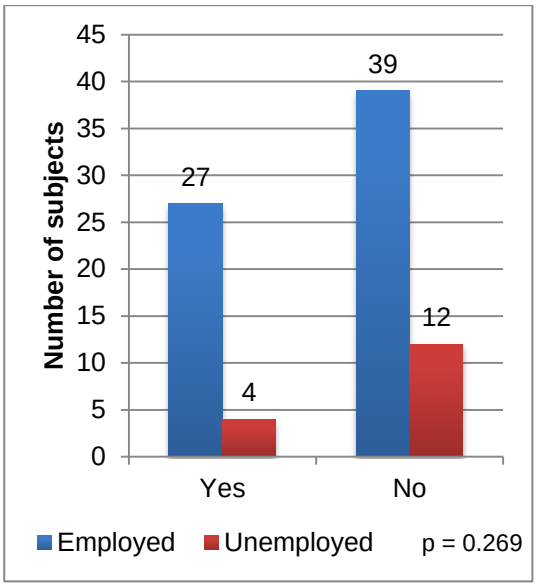


Figure 4.29: Comparison of employed to unemployed related to assistance received to find work
(n = 82)

4.3.9.2 Client factors

None of the client factors, such as cause of injury and level of injury were statistically associated with employment status. However in Figure 4.31 the ratio of individuals living with paraplegia employed to unemployed was greater than that of individuals living with tetraplegia. This was not statistically significant with p = 0.264.

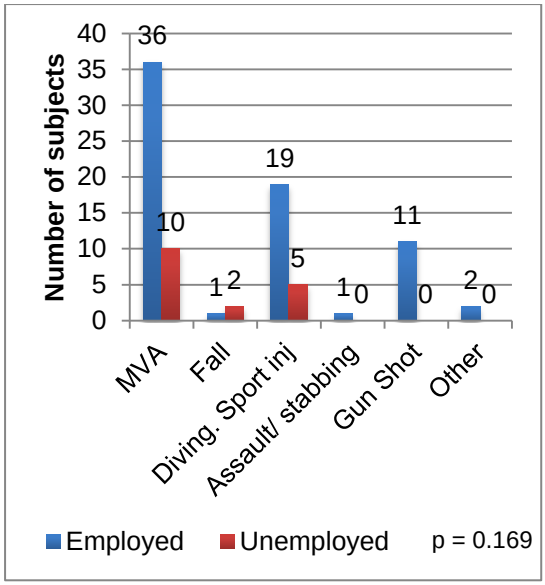


Figure 4.30: Comparison of employed to unemployed related to cause of injury (n = 87)

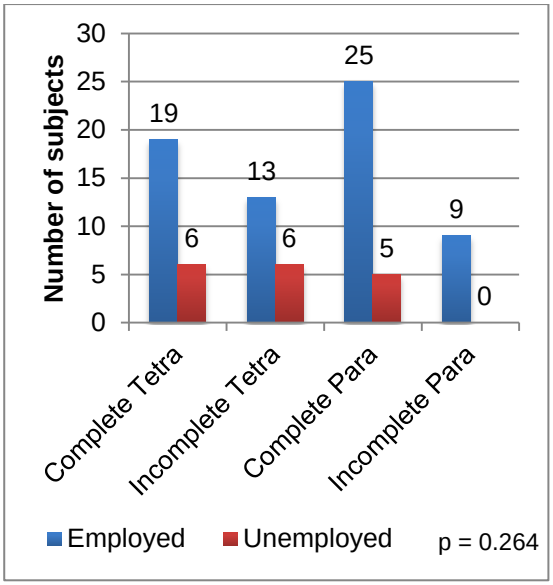


Figure 4.31: Comparison of employed to unemployed related to level of paralysis (n = 83)

The self perceived rating of pain was not statistically significantly associated with employment (p = 0.303) in Figure 4.32. The role endurance had in becoming employed post-injury was also not significantly related to employment with p = 0.097 (Figure 4.33).

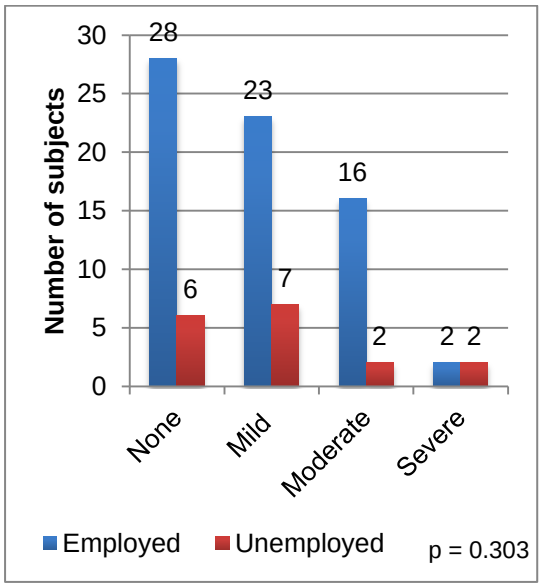


Figure 4.32: Comparison of employed to unemployed related to self perceived rating of pain experienced on a daily basis (n = 86)

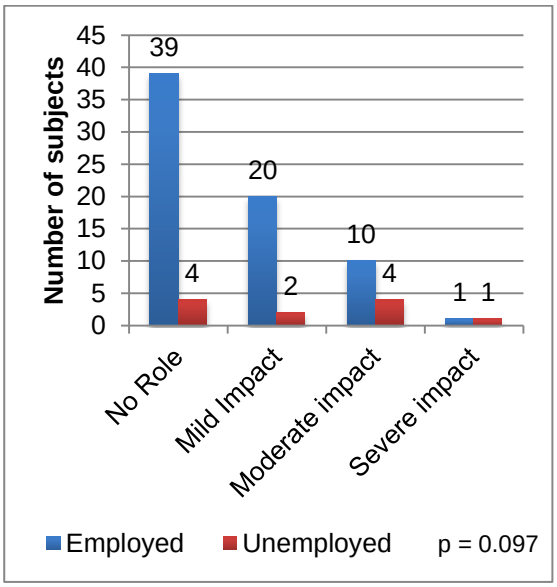


Figure 4.33: Comparison of employed to unemployed related to the role of endurance in returning to work or obtaining a job (n = 81)

4.3.9.3 Performance patterns

Independence in bowel routine was not significantly associated with employment in Figure 4.34 with p = 0.289. Independence in pressure care relief routines was statistically significantly associated with employment status at the time of the study as seen in Figure 4.35 with p = 0.044.

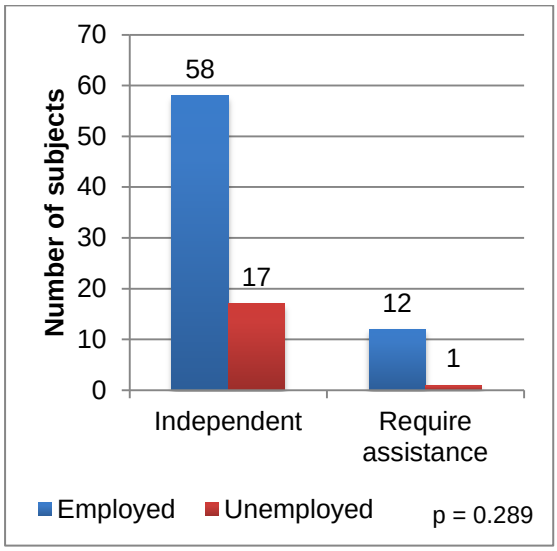


Figure 4.34: The influence of independent bowel routine on employment status (n = 88)

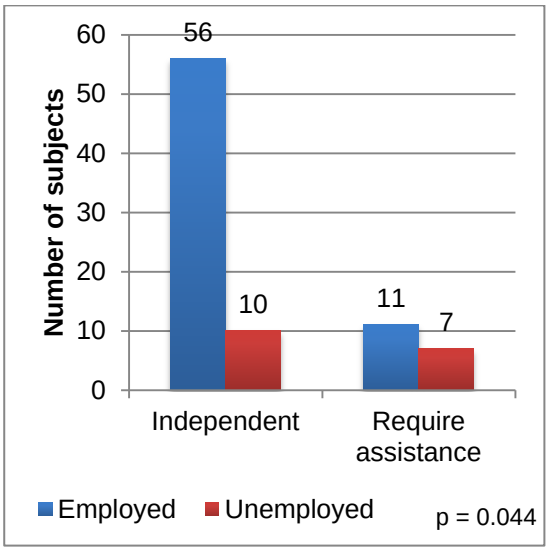


Figure 4.35: The influence of independent pressure care relief on employment status (n = 84)

4.3.9.4 Areas of occupation

4.3.9.4.1 ADL and IADL

Self-perceived independence was not statistically associated with employment status with p = 0.261. The ratio of employed to unemployed individuals decreases as participants became more dependent in Figure 4.36. Therefore clinically this may be of importance.

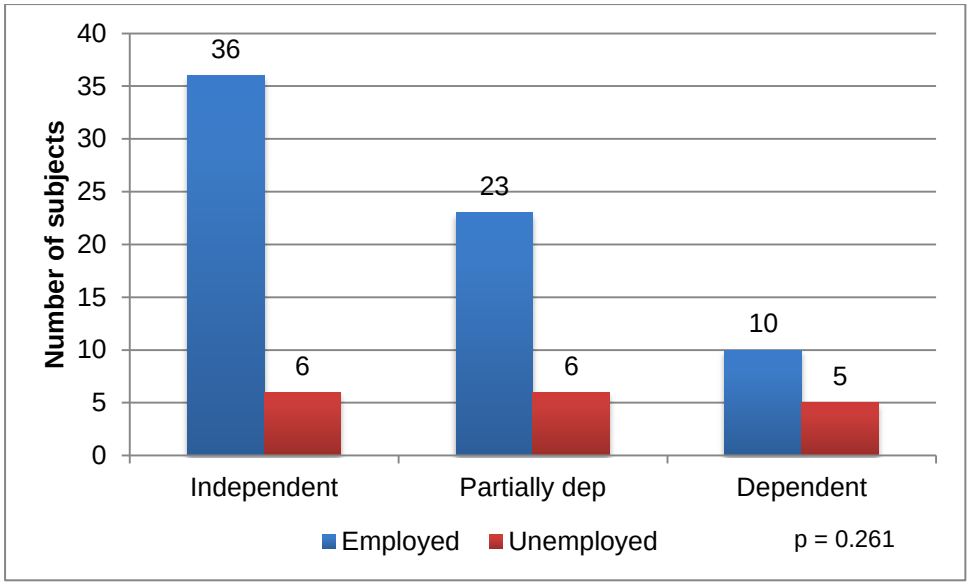


Figure 4.36: The influence of self-perceived independence on employment status (n = 86)

4.3.9.4.2 Social participation

Emotional support was not statistically associated with employment status with p = 0.291. However there seems to be a trend that as support decreases the ratio of employed to unemployed decreases. This may be of clinical importance although not statistically significant.

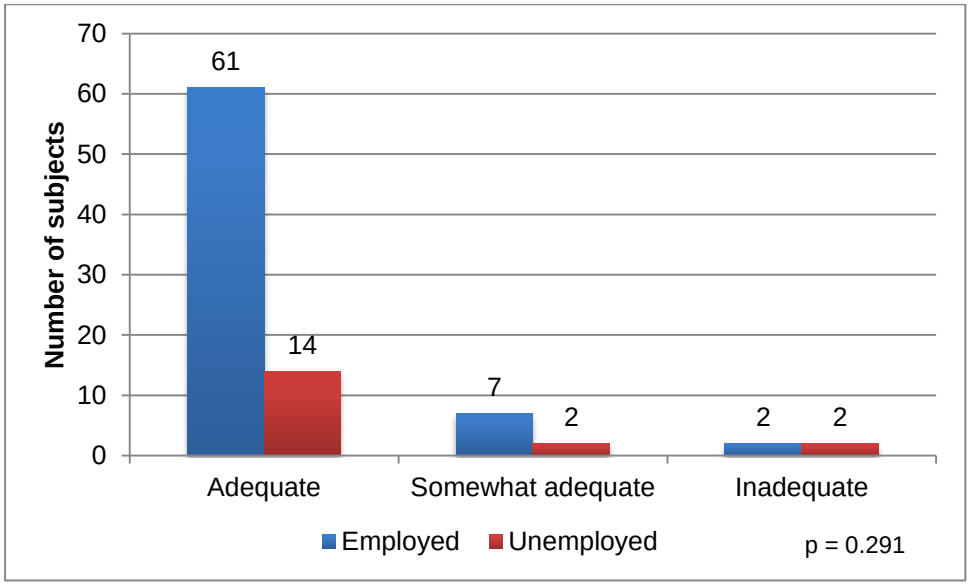


Figure 4.37: The influence of emotional support received from family and friends on employment status (n= 88)

Social interaction post-injury was highly statistically significantly (p = 0.005) associated to current employment status in Figure 4.38. In Figure 4.39 it was unexpected to see that having a mentor was not statistically significant with p = 0.283.

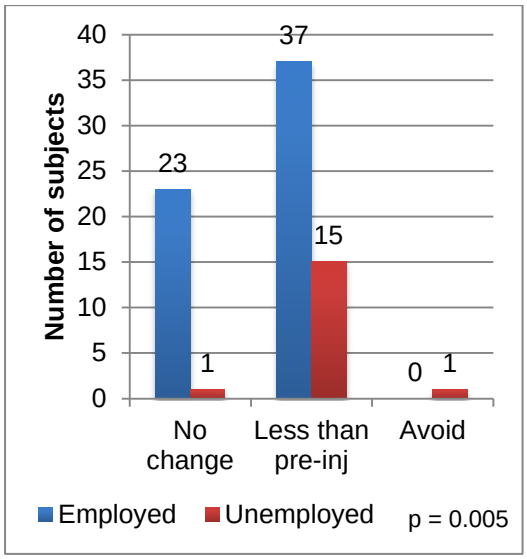


Figure 4.38: Comparison of employed to unemployed related to social interaction post-injury (n= 77)

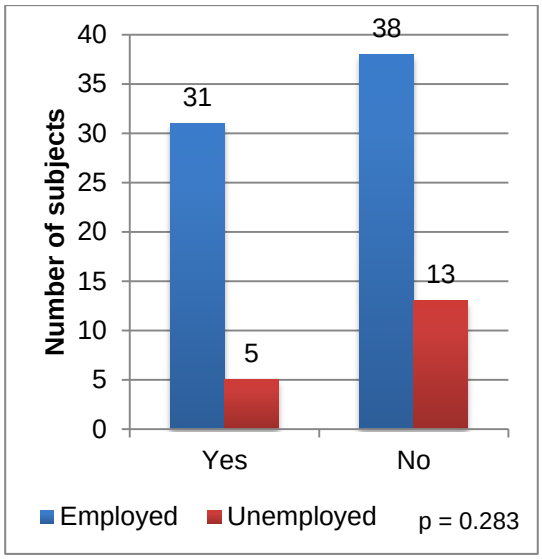


Figure 4.39: The influence having a mentor post-injury had on employment status (n = 87)

4.3.9.4.3 Education

Retraining post-injury did not appear to impact employment post-injury in Figure 4.40. These results contradict popular belief by occupational therapists that retraining is beneficial.

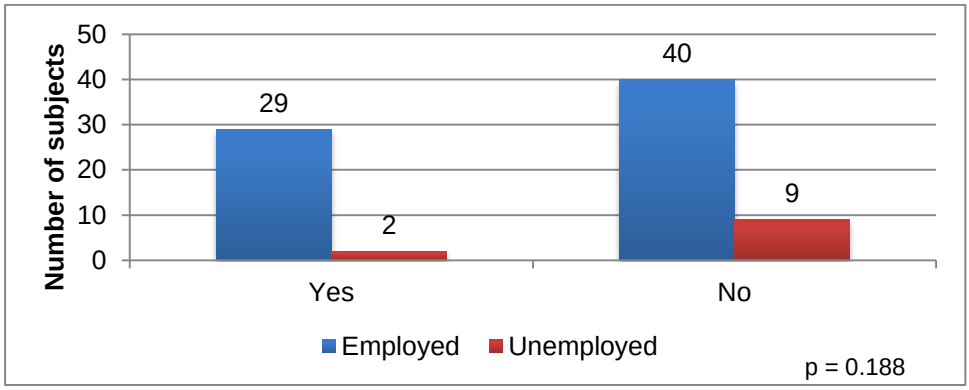


Figure 4.40: The influence of retraining post-injury on employment status (n = 80)

4.3.9.4.4 Work

It is interesting to note that all those employed in jobs that they perceived to be of a heavy intensity pre-injury were employed at the time of the study, with a p value of 0.0629 (Figure 4.41). The work intensity of post-injury jobs was not significantly related to employment status at the time of the study (p = 0.299) in Figure 4.42.

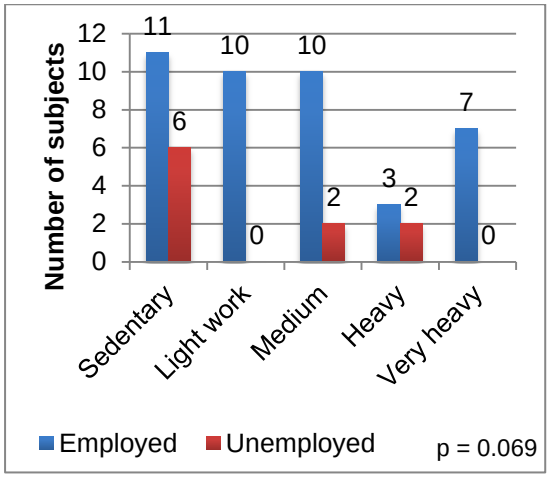


Figure 4.41: Comparison of employed to unemployed related to pre-injury work intensity (n = 51)

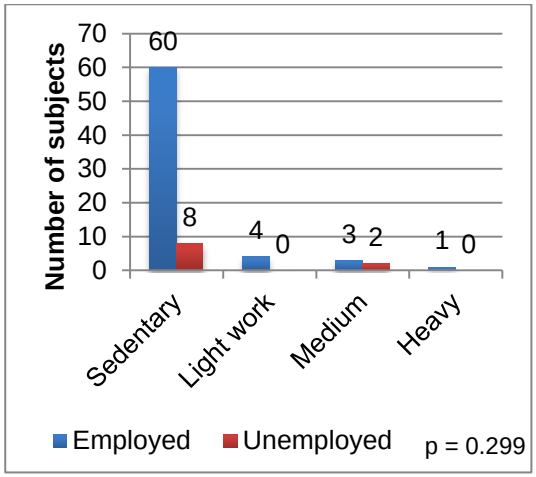


Figure 4.42: Comparison of employed to unemployed related to post-injury work intensity of most current job (n=78)

The sector of the labour market in which individuals were employed was not significant with p = 0.262 (Figure 4.43). The number of hours worked per week by those that had been employed post-injury (Figure 4.44) was significantly associated with being employed at the time of the study with p = 0.054.

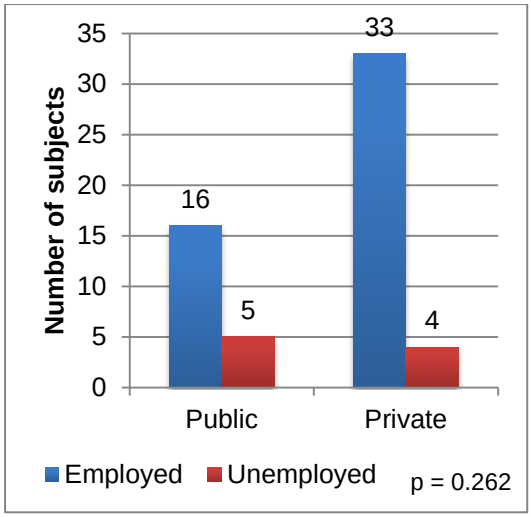


Figure 4.43: Comparison of employed to unemployed related to sector of labour market in which employed post injury (n =58)

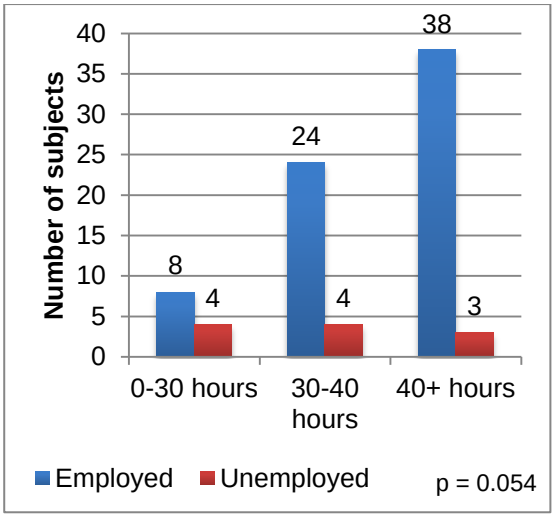


Figure 4.44: Comparison of employed to unemployed related to number of hours worked per week in most current job post injury (n = 81)

Contrary to what would have been expected, a supportive employer did not increase the odds of employment. Being employed was significantly associated with a neutral or dismissive employer with p = 0.042 in Fig 5.55. In Figure 4.46 reasonable accommodations were not significant (p = 0.341).

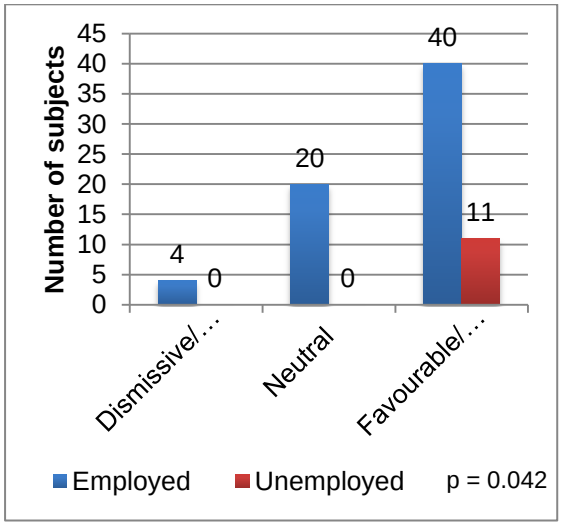


Figure 4.45: Influence of the most current employer's attitude towards the employee on employment status (n= 75)

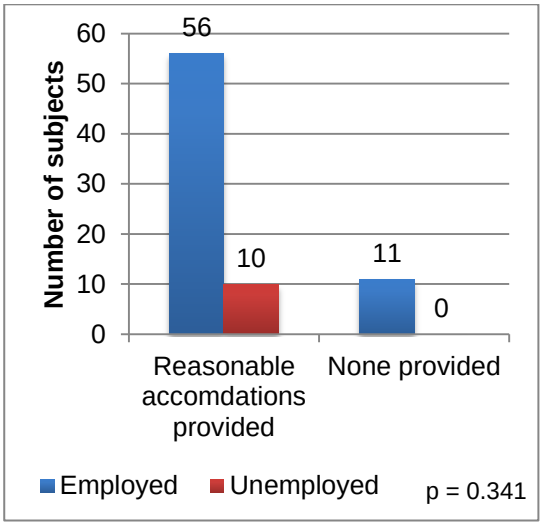


Figure 4.46: Influence of reasonable accommodations in most recent place of employment on employment status (n = 77)

4.3.9.5 Summary of the comparison between employed and unemployed individuals

This study had a great deal of data with only a few factors that were significantly associated with employment. The following factors were statistically significantly associated with employment status at the time of the study:

- The perceived role that transportation played in being able to become employed,
- the education of family members about SCI during rehabilitation,
- independence in pressure relief routines,
- social interaction post-injury,
- hours worked per week in current job and
- current employers attitude towards the individual living with an SCI.

All those variables that had a p value of 0.2 or less were further analysed with logistic regression.

4.3.10 Logistic regression results

The logistic regression was performed to predict the probability of employment post-injury based on the variables that met the inclusion criteria. The only statistically significant result in determining factors that may predict employment was the number of hours worked post-injury as illustrated in Table 4.18. As current age was a confounding variable, it was adjusted for.

Table 4.18: Logistic regression results

Current work status	**Odds ratio**	**Std Error**	**z**	**p>|z|**	**95% conf interval**	
30-40 hours a week	0.4552965	0.3939309	-0.91	0.363	0.0835255	2.481815
40+ hours a week	**0.1425343**	**0.126886**	**-2.19**	**0.029 ***	**0.0248982**	**0.8159633**
Age	1.07643	0.0442824	1.79	0.073	0.9930447	1.166817

* = 0.05 **=0.01 ***=0.001

4.3.11 Responses to open ended question

Thirty-one participants made use of the opportunity to add additional comments at the end of the questionnaire.

The comments reflected the themes and categories found in phase one of this study. These themes were the definition of employment, physical heath, psychological health, interpersonal well-being and support, skills, transportation, the South African labour market, access to and knowledge of resources, insurance factors, workplace factors and service provision in South African hospitals. The themes that were mentioned by more than two participants are described below, as there were too many to present all the responses.

1. Workplace factors:

Workplace factors featured strongly. These included physically inaccessible workplaces or discrimination by employers post-injury, this despite a large proportion of the sample currently having supportive employers. Individuals felt that they would be viewed as a burden in the workplace rather than a productive worker.

2. Transportation:

Transportation was also a common issue. The lack of a reliable accessible public transport system was mentioned often. Individuals expressed the need to prioritize independent driving during rehabilitation where possible so that reliance on public transport would be limited. This however would only be applicable to individuals who had the financial means to own and modify a vehicle post-injury.

3. General environmental factors:

General environmental access such as access to public buildings other than work and pavements being inaccessible was a common problem. The implementation of legislation that affects individuals living with a SCI was perceived to be inadequate. Individuals felt there was a need for further education of the public and potential employers on SCI.

Transportation was statistically significantly associated with current employment status in phase two of this study. The comments from the open ended questions therefore confirm these results.

4.3.12 Concluding the Phase two results

The sample in phase two was generally young at the time of their injury with a mean age of 24 years old. There were slightly more individuals with tetraplegia than paraplegia and a third of the sample had incomplete injuries. The major cause of injury was motor vehicle accidents followed by sports injuries.

The majority of the sample were highly educated and appeared to be well resourced. There was a high employment rate at the time of the study with 79.55% of the sample employed and 92.13% having worked for pay post-injury. The majority of those who were students when injured had worked since their injury. All but one participant reported being motivated to work post-injury. The majority of those that were employed at the time of the study were in sedentary jobs, in the formal and private sector. They reported that their employers and colleagues had been supportive and they received adequate physical and emotional support from their support systems.

Aspects which were concerning were that over three quarters of the sample felt that legislation had no or only somewhat of an impact on their employment post-injury. During rehabilitation employment was only discussed with half the sample of those that were of employment age and less than a quarter were referred to someone to assist with vocational rehabilitation.

There was a statistically significant association between employment at the time of the study and the following factors: being able to perform independent pressure relief, maintaining social interaction post-injury, transportation, the number of hours worked per week, the employer's attitude, and the family being educated on SCI during the individual's rehabilitation. The last two were related contrary to what was expected with unsupportive employers resulting in individuals still being employed and more individuals unemployed when compared to employed when the family was educated about SCI.

Logistic regression results revealed that the odds of being employed at the time of the study was 0.143 higher if working more than 40 hours a week compared to less than 40 hours a week in the sample of those that had been employed post-injury (when age was controlled for). This was the only significant results that emerged

from the study. Many reasons for the lack of more significant results exist and these will be discussed in the next chapter.

CHAPTER 5: DISSCUSION

5.1 Introduction

The qualitative and quantitative results of the various factors will be discussed together. First the development of the questionnaire will be discussed, then the various samples, followed by each of the factors influencing employment post-injury using the themes in the qualitative study as the headings. Finally the results of the logistic regression will be discussed.

5.2 The Questionnaire

The self report questionnaire was designed to cover all the aspects that could influence employment after a SCI. A myriad of factors emerged from the two focus groups and one interview. The inclusion of all these factors resulted in a lengthy questionnaire. As this was one of the first studies on this topic in South Africa the aim was to gain a broad understanding of all the factors that influence employment after a SCI.

Despite the input from subject matter experts, shredding and piloting some aspects were not adequately captured by the questionnaire. The psychological aspects were not adequately assessed with only one question regarding depression and one on motivation.

Formulation of questions to capture essential detail was a challenge. In hind sight some aspects may have been too detailed without having a broad initial question. This was apparent for the section on complications, where a general question regarding the number of hospitalisations since injury would have been a good indicator of overall physical health, but was not included in the questionnaire.

Some questions were not relevant to the aims and objectives of the study. These included the field of industry individuals worked in pre and post-injury as well as their job title. The questionnaire's drop down categories and tick boxes appear to have worked well.

A discussion of the various samples used in this study will follow.

5.3 The samples

This study investigated employment post SCI. The results have shown that there are many aspects that affect this.

The sample from phase one had vast experience of the issues under discussion. This resulted in transferability of data and added to the trustworthiness of the results. Their knowledge and firsthand experience of SCI resulted in a myriad of factors being identified.

The in-depth interview was conducted with an individual who was dependent on government service provision and was unemployed at the time of injury. He was in a lower socioeconomic category. Although his profile was somewhat different from the respondents in the final data collection of the study, he was able to provide meaningful insights into employment after SCI. His insights and those from the member of QASA who attended the focus group served to improve the transferability and dependability of the data collected[108].

The sample in phase two (individuals living with SCI) was limited to those that had internet access. According to the South African Census 2011 more than half of South African households (64.8%) did not have access to the internet[29]. Therefore phase two of this study only had the potential to reach 35.2% of the South African population and they were likely to be in the higher socioeconomic position as they had internet access. The results of phase two are therefore not representative of the population of individuals living with a SCI in SA, but only of those with internet access.

There was a response rate of 27% if one considers the 330 sampled QASA members. This is a below average expected response rate for email surveys, especially as snowball sampling was used. Follow-up contacts were also made which has been shown to increase response rates[111].

The majority of the sample was white (77%) and 77.28% resided in the provinces with major metropols namely Gauteng and the Western Cape. The logistic regression analysis that was performed in the sample of this study indicated that race did not significantly affect employment post SCI. This may be due to high representation of whites in the sample as race has been shown to be an important factor in the USA, where minorities experience greater barriers to employment than whites[36] and being less likely to be employed post-injury[35,46,54,64].

The family earnings ranged from R 2 000 to R 900 000 per month, with a median of R 41 377.90. When using the South African Revenue Service (SARS) classification of income in 2011, 38 (42.7%) of the individuals in this study had earnings in the two highest categories of earnings (more than R455 001/annum)[112]. The sample was therefore mostly in an advantaged position, with high earnings and living in an urban environment. The questionnaire did not distinguish between family earnings and participants' earnings, but it may be that for many the tangible reward of a salary was an important motivator to work as it includes benefits and affects one's socio-economic position[2].

The age range of individuals at the time of the study was within the age expected for employed individuals, 18-65 years old. A discussion of the various factors that influence employment after a SCI from phase one and the prevalence of these factors in the sample in phase two will follow. The first aspect is that of employment or work itself.

5.4 Work

The important characteristics of work were highlighted during phase one of this study. The issue of remuneration was the most important aspect that distinguished work from a productive activity performed without pay. This agrees with the narrow definition of employment[1,113].

A high percentage of the sample (92.13%) had been employed post-injury, in a part time, full time or self employed capacity. This is much higher than the global employment rate of 68% as reported by Young and Murphy [1]. At the time of the study, there were 79.55% of the sample employed (Figure 4.8). With regard to the international literature this is higher than the range of 11.5 - 75%[1,9,81]. Not only is this

high compared to the international literature, it is much higher than the somewhat limited research in South Africa which ranges from 4.1%[13] to 56.6%[22]. It is also a positive result when one considers SA has a high unemployment rate[29,52].

There are several aspects which may have contributed to the unexpectedly high employment rate. A large proportion of the sample in phase two can be classified as being from a higher socioeconomic class. Therefore aspects that require financing such as assistive devices and transportation may not be as problematic as for those in lower socioeconomic status. Many of the individuals sampled may have had access to the internet at their place of employment, therefore influencing the high percentage of those that returned the questionnaire being employed at the time of the study.

The level of education in the sample could also have contributed to the high employment rate. The results showed that at the time of the injury just over half the sample were employed and a third were students. Therefore only a sixth of the sample were unemployed and not studying. This is likely to be much lower than the figure that would be found in the total population of individuals living with a SCI in SA at the time of injury. This is confirmed by theme seven in the qualitative research which highlighted the high unemployment rates at the time of injury.

Just under half of the sample described themselves as the breadwinners of the family at the time of injury. This illustrates that the sample was largely young at the time of injury with the mean age at 24.18 years. This is lower than the international literature of 33 years[28], but falls within the mean ages reported for other South African studies[11-14].

Considering the individuals who were students at the time of their injury, 75% were employed at the time of the study and 21% were still students. Therefore only one student at the time of injury was unemployed and not participating in a productive activity at the time of the study. This supports the literature showing the importance of post-injury education and greater odds of employment[66,67], as all but one individual were either still studying or were employed. It also indicates that individuals had access to funding to complete their studies.

In this study, most individuals with jobs that they self-rated as medium, heavy and very heavy work pre-injury, were employed at the time of the study (Figure 4.42).

This was not statistically significant, but is contrary to the literature which has found a pre-injury job with a lower work intensity, was a predictor of employment post-injury[7].

The findings regarding the number of hours worked post-injury was surprising, as flexibility regarding the hours employed is often a reasonable accommodation that is requested. Half of the sample who were currently employed were working more than 40 hours per week (Table 4.13), therefore full time employed, working at least eight hours per day, five days a week. What proved to be more interesting is that the ratio of those currently employed to those currently unemployed, increased as the number of hours worked per week decreased (Figure 4.44). This was the only significant factor in the study that predicted the probability of employment status post-injury (when age was controlled for). The odds of being employed at the time of the study were higher if one worked more than 40 hours a week (Table 4.18). This contradicts what one would expect. One can speculate that those working over 40 hours a week had jobs that were in managerial or executive positions. They must have been remunerated at a level that they perceived to be sufficient, or they would have looked for another job. It may be that due to the nature of their disability they had to take more frequent breaks, perhaps longer times for toileting etc, this resulted in them working for over 40 hours a week, but they had more unproductive time than their colleagues. Those living with a SCI may have had to put in extra effort and hours to prove themselves. It may also be linked to motivation to work, which was an important factor that emerged from phase one of this study. As individuals were motivated to work, they were willing to work longer hours. The concern around working longer hours would be that the individuals must be able to manage their fatigue and not allow themselves to become burnt out, which would affect their physical and psychological health.

5.5 Physical health

Injury related factors were seen as part of the physical health of the individual in the qualitative phase of the study. This sample consisted of slightly more individuals with tetraplegia than paraplegia (Table 4.12), which is contrary to previous studies in South Africa which report that there were more paraplegics[13,14,20]. A third of the sample were incomplete injuries, which is less than other research has shown, nationally and internationally[13,28]. This could be due to the specific sampling frame used in phase two of this study.

Motor vehicle accidents were the leading cause of injury followed by diving and sports injuries and then violence related injuries. This resembled the international trends[10] more than that of other South African studies[11-14,17-20]. The reasons for this are speculative, but the sample used in phase two may account for this. The majority of the sample were advantaged and therefore may not have been as susceptible to violence that occurs in lower socio-economic groups. None of these factors were statistically significantly associated with employment status at the time of the study. This is consistent with the majority of literature on the level of injury, but violence as the mechanism of injury has been shown to impact employment in some studies[36,53], but not conclusively.

Almost 50% of this sample described their level of independence as independent. The level of independence did not significantly affect employment in this study, however the ratio of individuals employed to unemployed became smaller as individuals became more dependent (Figure 4.36). This may indicate that the level of independence may have some impact on employment status. The level of independence affects employment in studies where the Motor Index Score (MIS)[64] and the Barthel Index[48,56] have been used. The results of the Functional Independence Measure (FIM) have not been as conclusive[62,70]. In this study this item was the participants' subjective opinion of their level of independence and therefore may not have been as accurate as a score on the Barthel, MIS or FIM.

Bowel and bladder control was an important aspect in the qualitative phase of the study. The literature supports this, with sphincter control seen to be an important aspect when related to employment[36]. The risk of accidents when in the work environment was also an important issue in the qualitative data. A focus group study in Hong Kong found similar results and that the timing of bowel routines had to be changed post rehabilitation to ensure it did not clash with work hours[73]. A study involving tetraplegics in Tshwane, Pretoria reported that participants were embarrassed to seek employment because of catheters and bowel and bladder incontinence[82]. The quantitative results of this study showed that some individuals required assistance in bowel and bladder management, but this did not affect their ability to leave the house. The impact of bowel and bladder management on employment was not significant, but the interesting aspect was the employment to unemployment ratio. Those who required assistance in their bowel routine was much higher in favour of employment than those who were independent (Figure 4.34). This

could indicate that individuals had made sure the timing of their bowel routine was outside work hours when they could be assisted and they found that employment was worth the risk of embarrassment should an accident occur at work.

Another factor that emerged in this study was that 87.6% of the sample had an urinary tract infection since injury. This is of concern, as serious urinary tract infections lead to increased days of sick leave and therefore may affect employment[36]. Although the results of the sample was not statistically significant, it is of clinical importance, as fewer medical complications have been found to be a predictor of employment[36] and therefore urinary tract infections should be prevented were possible, with good urinary care and diet.

The second most common complication was pressure sores, which had affected almost 50% of the sample. Pneumonia and other complications were much lower (Table 4.12). Surprisingly a large proportion of the sample had no or only mild pain. This is contrary to the literature which reports that pain along with the afore mentioned complications are the most common and significant after a SCI[71]. In the literature with regards to employment, pressure sores, serious urinary tract infections and spasticity were related to employment[36]. Spasticity was not included in the questionnaire and none of the other complications were related to employment in this study.

However, independence in pressure care routine was significantly related to employment (Figure 4.35). The ratio of employed to unemployed was much higher in favour of employment when able to perform independent pressure relief. This emphasises the importance of pressure relief techniques taught during rehabilitation. Individuals need to be taught to perform independent pressure relief using the best methods, such as the side to side or the forward leaning technique and not traditional pressure relief by lifting up from the seat[114]. It is also essential that individuals are seated correctly in their wheelchairs, using the best cushion for their needs to avoid peak pressure areas when sitting[115]. There is a cost involved in ensuring the correct wheelchair and cushion are provided, but if it assists in the individual becoming employed, it is a worthwhile investment. It is probable that the majority of those that completed the questionnaire in phase two had access to private medical health care and therefore had the correct seating for their needs. It may also be that those who were employed had to perform their own pressure relief and made sure that the method they used could be done independently. It could be that those that did not

work, lacked this motivator to perform their own pressure relief and therefore continued to rely on others.

The level of endurance would be related to physical health: individuals with poor health would have lower endurance. The role endurance had on getting a job was not significant in relation to employment. Endurance may also have a psychological aspect to it. These factors will now be addressed.

5.6 Psychological health

The qualitative data in the theme on psychological health supports the literature that psychological factors influence employment to a great extent[43,62,69]. In phase one motivation was highlighted as essential to employment post-injury. Without motivation all the other aspects could be in place, but the individual will not succeed in maintaining employment. In phase two all but one of the participants reported being motivated to work. As motivation has been shown to be a predictor of employment[61] it may provide a reason for the high employment rate achieved in this study as discussed in section 5.4.

This confirms results from a qualitative study that found that employed individuals had greater motivation than those that were unemployed[39]. It is recognised that being employed post SCI has many challenges, as has been discussed in the literature review. Perceived high motivation is therefore essential, as these challenges are bound to arise during the work seeking process, or once employed. If one is not motivated to work, these challenges will prevent one from working, but if motivated, individuals will rise above the challenge and continue working despite the situation they face. This is why motivation (value placed on work and confidence in one's ability to do the work) has been found to be a predictor of employment post-injury[61].

The individual's mood was considered important in the focus groups. A true evaluation of mood was not achieved in the questionnaire, but since injury almost 30% of the sample had experienced depression. This was not significantly related to employment post-injury, but mental illness has been shown to negatively impact employment in the literature[43]. The sample in phase two reported they had adequate physical and emotional support, were largely employed and had financial resources. The population of individuals living with SCI in South Africa may not have all these

traits and therefore levels of depression may be much higher than in the sampled population in this study.

5.7 Interpersonal wellbeing and support

There is very little evidence in literature that social support is important for employment post-injury however, it was an important finding in both the qualitative and quantitative phase of the study.

In phase two of this study 85% the sample reported having adequate emotional support from family and friends at the time of the study. Even though not statistically significant with regards to employment status, it is encouraging to see that such a large percentage had the support they required.

A very small percentage, just over 1% of the sample selected the option in the questionnaire that they “avoided social interaction” post-injury. The majority of the sample still had social interaction, but reported that it was less than prior to the injury. This was significantly related to employment status (Figure 4.38). The ratio of employed to unemployed decreased significantly if individuals socialised less than prior to their injury, or avoided social interaction. Being employed may, however, ensure that one socialises to some extent. Further studies would be needed to further investigate this cause/effect relationship.

The qualitative data from this study highlighted that having friends or family provides emotional support and if necessary, physical support that made employment easier. It may provide the foundation from which one can become employed. The reasons for this are supported by research done with a male sample, where social support from significant others was predictive of employment[78] and social support was associated with an easier return to employment post-injury[8]. However, in phase two of the study the perceived role that social support from family and friends played in becoming employed, or returning to work was minimal, with 76% stating that it played no role. It may be that as the majority of individuals had adequate support, they did not realise the role that it played in enabling them to return to work.

As the mean age of injury was 24.18 years, with 22 individuals 18 years or younger at time of injury, being employed may have played a role in them getting married.

Employment is associated with marriage when an individual was injured prior to 18 years of age[36]. Being married could have also influenced their employment status[35]. More than half the sample were either married or living with a partner (Table 4.8). Marriage in this study was not found to be significantly related to employment. The influence marriage has on employment has not been conclusive in the literature, with some studies finding it important in the first few years post-injury[48,64]. However, the majority of studies have not found an association[9].

The category of caregivers in phase one was an important aspect as they provide physical assistance to the individual to be able to work. The dependent individual is at the caregiver's mercy for assistance with personal management and getting ready to leave for work. There is often strain on the relationship between an individual living with a SCI and a caregiver, which can be hard to manage at times. Just over 50% of the sample in phase two required the assistance of a caregiver. Of those that required a caregiver, 38% had a family member fulfilling that role and almost half of them felt that it placed strain on their relationship with each other. This is of concern as the sustainability of this arrangement may be jeopardised, as well as the individual's ability to get to work. This is illustrated by a small sample of South African individuals living with tetraplegia who reported that their caregivers neglected them and that the caregivers were not empowered or supported by rehabilitation professionals[82].

The role of a mentor emerged from the qualitative phase of this study. Someone who acts as living proof that one can still achieve post SCI and live a meaningful life, was an inspiration and a boost to motivation in general. This was also reported by Faydel and McPherson[76]. In phase two, less than half of the sample reported that they had a mentor post-injury. This, however, did not significantly affect their employment status post-injury. The role a mentor plays has not been linked to employment status in literature. A recent study reported that involvement in a mentoring programme after a SCI did not have an impact on employment rate, or return to school rate. What was found was that mentees who completed the programme had improvements in their general quality of life, but not employment per se[103]. From clinical experience a mentor may provide useful hints to improve independence in personal management issues and coping with discrimination. These aspects may not directly improve employment, but they are no longer hindrances to employment, or reasons for unemployment.

The qualitative phase of this study illustrated the need for further public education on disability, as it was evident that individuals living with a SCI are sometimes not considered or respected on the same level as the general population. The general attitude of society towards people living with a SCI was not specifically investigated in the quantitative phase of this study, but comments were made in the open ended questions. This confirms that there may still be a need for public education on SCI. This is confirmed by the study involving tetraplegics where they reported being stigmatized by society[82]. In the Western Cape study a significant number of participants reported the attitude of society was a moderate barrier to participation[13]. A study in Gauteng reported that individuals experienced negative attitudes from society and extreme pity, which was not appreciated[12]. This may affect employment participation of those individuals who do not have many of the other factors that facilitate employment. In an American study, discrimination was experienced by employed and unemployed groups, but the employed group were able to remain optimistic, whereas the unemployed group did not[39]. These attitudes can also be found in the work environment and will be discussed with workplace factors. The influence of skills and educational level will now be addressed.

5.8 Skills

Education was highlighted in the qualitative phase of the study. Without a good education employment will be limited post-injury. The quantitative data revealed that 88% of the sample had completed Matric (12 years of education). Almost 80% of the sample had done some training after school, with 37% having a degree or higher qualification (Table 4.9). It is probable that this is much higher than the general population of individuals living with a SCI in South Africa. Contrary to the strong evidence that education positively affects employment post SCI[35,56,59-62], phase two of this study did not reveal a significant relationship between employment and education. However, as school education increased, the ratio of employed to unemployed increased slightly (Figure 4.22). The categorisation of tertiary education in this study was different to that used in most literature. In the literature the number of years completed was used where as the researcher used the level of qualification. This may have affected the outcome. Over 80% of the individuals with a diploma, degree, degree with honors and a doctorate were employed at the time of the study. This is only slightly higher than the employment rate of 79.55% achieved for the

employment status at the time of study and therefore was not a significant factor according to the Fishers exact test.

It is of interest to note that those with a degree, degree with honors or masters were participating in a productive activity, either still studying, or volunteering and did not describe themselves as unemployed (Table 4.17).

Despite not being significant, these results illustrate that there are employment opportunities for skilled individuals post SCI. These employment opportunities may be as a result of the Employment Equity Act and the Labour Relations Act. The questionnaire did not differentiate between pre and post-injury education, nor did it feature specifically in the qualitative study, besides general statements that education is important. Krause et al. and Krause and Reed found that post-injury education has however been shown to be an important factor in relation to employment[66,67].

Phase two investigated retraining post-injury. More than a third of the sample had undertaken retraining post-injury, of which 93.55% were employed. This was not significant as 81.63% of those who did not receive retraining were also employed. More than half of those that received retraining also reported that it played no role in becoming employed. This is contrary to what the literature suggests. It is hard to speculate the reasons for this as the type of training they received post-injury is unknown and perhaps the individuals' pre-injury education was sufficient to find work post-injury.

The state of SETAs and learnerships in South Africa received emotive attention during the focus groups. The opinion of the participants was that the learnership programmes were not effective in the sense that once individuals successfully completed their training, they were unable to find employment. One of the factors that influence this is the labour market in South Africa, which has a high unemployment rate and a lack of jobs, even for people skilled after completing a learnership program. None of the individuals in phase two who received retaining made use of a learnership program stipulated in the Skills Development Act. This is unlikely to be the case in the total population of individuals living with SCI in South Africa. Previous literature has found that the Skills Development Act has not been effectively implemented with regards to those living with disbailities[101]. The participants in the focus groups reiterated the ineptness of the learnerships.

The qualitative results highlighted the importance of prevocational skills to ensure employment. Being able to perform all the aspects of personal management within a reasonable time period and arrive at work on time are essential. This has to be sustainable for employment to be maintained. Ensuring that the process of getting ready for work and the trip to work being as short as possible should be addressed by an occupational therapist during vocational rehabilitation.

5.9 Transport

In the quantitative phase of the study 39% of the sample reported that transport played a moderate to severe role in becoming employed. The impact this had on employment status is interesting. The role transport played in becoming employed was significant at $p<0.05$. The majority of the individuals, who reported that transport had played no role or a severe role in becoming employed, were employed at the time of the study (Figure 4.25). One would have expected that if transport had a severe impact on becoming employed that the individuals might not be employed. This may show that individuals were motivated to work and made plans to ensure that they were able to overcome the transport problems they encountered so that they could become employed. Transport was provided as a reasonable accommodation to few individuals by their employer (Figure 4.15).

The availability and reliability of South Africa's public transport system is problematic for the majority of the population. This is even worse for wheelchair bound individuals. The more recent developments in transport, such as the Gautrain and Rea Vaya (not yet fully operational) makes provision for individuals in wheelchairs, but most buses, taxis and trains are not accessible.

Transport has been associated with employment post-injury[36,39,48]. As stated in the qualitative phase, "Transport has wasted lots of people's opportunities to return to work", everything else can be in place to work, but if one cannot get to work punctually each day, employment is not possible.

It is interesting that only one individual in phase two made use of public transport (Table 4.10). This is probably due to the inaccessibility of the system. This individual who was unemployed at the time of the study did not find transport problematic. This is surprising, as research in SA has shown that public transport is problematic in

Gatueng[12,82] and the Western Cape[13]. The issue of taxis featured strongly in a Western Cape study with additional costs involved in using the service, if someone did stop for the person using a wheelchair[13]. The qualitative results of this study agreed with these studies, with very similar quotes being found in the qualitative study done by Monageng[82]. In the Western Cape study[13] individuals were either unwilling to even try and use public transport as it was inaccessible, or where they had tried to use it, they reported they would not use it again due to the difficulties they experienced. The lack of public transport was confirmed by phase two of this study. Over 90% of the sample drove their own car or made use of a driver. The population of individuals living with a SCI in SA would be much more reliant on public transport than the sample used in phase two.

At the time of the study transportation was problematic for 23.6% of the sample in phase two. Just over half of these individuals relied on a driver, with 22% driving their own car (Table 4.10). Unfortunately the study did not ask for reasons for the transport problems, so reasons are speculative.

It is interesting that such a high percentage found transport problematic even though they could drive their own car. This may relate to getting in and out of the car, which takes longer, or being able to transfer the wheelchair into the car, or onto a lift. There could be many other reasons. Making use of a driver was problematic, this may be due to the dependence one has on the driver and his or her punctuality and availability. The type of transport was not significantly related to employment status, but the ratio of those employed to unemployed was higher for those who drove independently, or had a driver.

In this study over 70% of the sample who were unemployed reported that transportation played no role in their employment status at the time of the study (Table 4.10). However, transport is a common reason cited for not working [36,61,91] in literature. Only 5% of the unemployed relied on transportation other than driving their own car or having a driver. This may be the reason it was not reported as major reason for not working. As stated before, this sample was largely economically advantaged and therefore did not rely on public transport and may account for it not being an important factor in this study.

5.10 South African labour market

The labour market was a factor affecting employment that emerged from the focus groups. The formal and informal sectors were influential in the employment of individuals living with a SCI. The formal sector was required to conform to all the legislation regarding basic conditions of employment, the Employment Equity Act, the Labour Relations Act and the Skills Development Act. In the informal sector this was not the case, but for individuals with limited education and training this may be the only employment option for them. They would need to run their own business. This confirmed the findings of Kingdom and Knight in which they investigated the causes, problems and policies related to unemployment in South Africa[30].

In the quantitative phase of the study a greater percentage of individuals were employed in the formal sector post-injury than pre-injury (Figure 4.11). This is a positive shift, as more individuals would be protected by legislation and less vulnerable to exploitation[30]. The participants who were students at the time of injury who had become employed by the time of the study could have influenced this. It may also illustrate that individuals were skilled and educated, therefore able to work in the formal sector. Once again this illustrates that the phase two sample was an advantaged one compared to population of individuals living with a SCI in SA.

When looking at the public and the private sector, both have been set targets regarding transformation. There has been limited achievement of these targets[102]. In this study the private sector fared better than the public sector. The ratio of individuals who were currently employed to those that were unemployed was higher for the private sector, in favor of employment (Figure 4.43). This was not significantly related to employment status post-injury and reasons for the difference would be speculative.

During the focus groups it emerged that unions supported their members wishes with regards to return to work post-injury. They either advocated for return to work or payment of benefits should the member not want to work. In the quantitative data, there were only two individuals who reported having a union representative assist in the negotiations for them to return to work post-injury. The percentage of the sample that belonged to unions at the time of their injury was not established.

The qualitative results reported that many individuals that have a spinal cord injury were not employed prior to their injury. Based on the high unemployment rate in South Africa and the majority of the population that is unskilled, this was not surprising. However in the quantitative phase of this study 62.07% of the sample were employed at the time of their injury and 33.33% were students at the time of their injury (Figure 4.8). Therefore very few individuals were truly unemployed at the time of injury. This may be a contributing factor to the high employment rate post-injury in this study, as pre-injury employment is significantly related to post-injury employment[63]. It also illustrates that the sample in phase two was not a representative sample of individuals living with a SCI in South Africa.

The qualitative results illustrated that South Africa has comprehensive disability legislation. However, participants felt that the implementation was not yet at an acceptable level. In the quantitative study a high percentage of the sample were aware of the legislation affecting individuals with disabilities (Figure 4.2). As positive as this may sound, it is concerning that over 10 years since most of this legislation was adopted, 27% of this sample, which can be described as a higher socioeconomic class were not aware of the legislation. Almost two thirds of the sample reported that to their knowledge the legislation had had no impact on their employment status post-injury, with the remaining third split between the legislation definitely impacting or somewhat affecting their employment status. The poor implementation of legislation was thus highlighted in the qualitative data as well as the quantitative data. The high percentage that reported that the legalisation had had no impact may have been because individuals are not aware of all the aspects of the legislation and therefore were not aware when it was applied in their favour. A higher ratio of employed to unemployed was found for those that reported that the legislation had some sort of impact on their employment status when compared to those who reported that legislation had had no effect. This was however not statistically significant.

The lack of impact that the legislation has had on employment is supported by research done by Dube who found that the impact of the Employment Equity Act has been minimal, as did the 12th Commission for Employment Equity Annual Report[102].

5.11 Knowledge and resources

A SCI affects so many aspects of an individual's life. Knowledge and resources (human, economic) are often essential to adapting and coping after the SCI. This was highlighted in the qualitative results of this study. Being aware of what services or resources are available and how to access them is important. In the lower socio economic population, they may have ideas for starting their own business post-injury, but are not aware of who to approach for funding, or where to acquire the skills they need to start the business. This could also play a role in returning to work, where individuals are not aware of their rights and the laws that protect them with regard to being able to return to work.

The rehabilitation team and those who continue to follow up on individuals post SCI should provide their clients with as much information as possible about the available resources in their community. This is a role that a mentor can perform, as they have had to adjust to living with a SCI and would have firsthand knowledge of the resources that are available and how best to access them.

This theme was not investigated thoroughly in the quantitative questionnaire, but the one question that was included showed that under half of the sample had been made aware of resources in their community by the rehabilitation team. This is concerning as individuals would have had to find these resources for themselves. This may not be problematic for those that are highly motivated, or that have a good social support system. However, for the de-motivated, or poorly supported individual knowledge of those resources could make the difference between being able to adapt post-injury and therefore be able to resume an active role in the workplace.

5.12 Insurance factors

In the qualitative phase of this study it emerged that those who were privately insured and had disability benefits should have access to vocational rehabilitation, case management, work trials and reasonable accommodations. One would therefore expect that an individual who is able to work post-injury would receive the assistance and funding required. However it was felt that the individual's best interests may not always be considered, as insurers might not fund all that is necessary to get the person back to work. Where insurers could prevent paying out a large lump sum,

they were willing to make every effort to ensure the individual was provided all they required to return to work. For smaller payouts this commitment might not be as great. Disability insurance would be a benefit in South Africa, as there are very few government vocational rehabilitation centers which offer the services mentioned above. Private vocational rehabilitation costs would have to be personally funded or paid for by an employer.

In the quantitative phase of the study almost half of the sample received some sort of payout. The main sources were the Road Accident Fund and insurance. This is to be expected as over half the sample were involved in a motor vehicle accident that resulted in the SCI. The extent of the payout was not known, but based on the fact that 92.13% of the individuals in phase two had been employed since their injury, it was not enough money to deter the majority of them from seeking employment post-injury. This is opposite to the trend seen in some of the first world countries where the loss of social security benefits, which could include exclusion from government funded equipment and medical supplies, may occur if individuals do become employed[8,35,59,61,75].

The disability grant was seen as a paradox in the qualitative phase of the study. It is not a substantial amount of money and yet for many individuals who receive it post SCI, it is more than what they had prior to the injury as they were unemployed. The disability grant is often perceived as a guaranteed monthly income. If they became employed they would more than likely fail the means test for receiving the grant and therefore forfeit the grant. The effort it takes to work may not be worth it for some individuals who earn a low wage.

Only six participants in phase two received a disability grant at the time of the study. This is in stark contrast to other studies done in SA which have reported high unemployment rates post SCI where the majority of the sample received a disability grant from the state[12,13] highlighting the differences between the sample population in phase two and the greater SCI population in SA . Only one of the six participants reported that the disability grant was their only source of income. The other five participants had additional financial support from family members. This indicates that the disability grant is inadequate to fund living costs post-injury as found in a study in Tshwane[12].

5.13 Workplace factors

There are numerous workplace factors what emerged from phase one. The first of which was the employers' attitude and commitment to employing someone with a SCI. Employing someone with an SCI requires involvement and willingness from the employer, as reasonable accommodations in some form or other are usually necessary. The knowledge that the employer, usually in the Human Resources department, has on the accommodations needed and the resources that they access or have available to them is important. This is in agreement with literature that states that the employer's ability to accommodate an individual with a SCI depends on their capacity to make accommodations and access the resources available to do this. Employers need to have the knowledge to do this, or an outside resource that can assist in this matter[8].

The phase two results indicated that almost 70% of the employed participants reported that their employers' attitude was favorable and understanding (Figure 4.14). This is a positive indication of the employers' willingness to accept individuals with SCI from the sample population in the work environment and make the necessary accommodations for them. The legislation may have assisted to create this attitude. Research has found that employers are more supportive of people they employed pre-injury[8] and as 44% of the sample returned to their pre-injury employment, this may account to the large percentage of employers that were supportive. Four individuals (5.26%) experienced their employers as dismissive and unsupportive. Two of them were injured seven or more years prior to the new legislation in SA and this may have affected the reception they received in the work place post-injury. What is surprising is that these four individuals were all employed at the time of the study. Those individuals who found their employers neutral (27.6%), were also all employed. Of those who reported their employers to be supportive and understanding only 78.43% were employed at the time of the study. The employers' attitude was statistically significant when looking at employment status, but not as one would have expected. Having a favorable, understanding employer resulted in a lower employed to unemployed ratio than a neutral or dismissive, unsupportive employer did (Figure 4.45). Therefore a supportive employer may not be as critical as other factors to employment in this sample population. This was an unexpected result in this study.

Reasonable accommodations were mentioned during the focus groups. These accommodations need to be specific to the individual and the work they did to be effective. As with workplace accessibility, the barrier to reasonable accommodations was funding. This is an aspect where the insurance company could assist if the individual had such a policy. Reasonable accommodations were made or provided for 85% of the sample in phase two who had been employed since injury. This is similar to a Dutch study were 74% of the sample had reasonable accommodations made[57]. It would appear that the provision of reasonable accommodations as stipulated in the Employment Equity Act is being fairly well applied to individuals that were in this sample population.

More than 80% of those who received reasonable accommodations were employed at the time of the study. Interestingly all the participants who did not receive reasonable accommodations in their most current job were still employed. The questionnaire did not gather enough information to be able to determine the reasons for this, but it may be because those who did not receive reasonable accommodations did not require them, or they may have had devices from previous jobs. It could also be that individuals who received some reasonable accommodations still required further accommodations, or even with the accommodations other aspects made it impossible to continue working.

Physical accessibility in the workplace was argued to be vital during the focus groups. This included ramps, parking, toilets, lifts as well as access to the "social" areas of work, such as the canteen. The cost involved was also important. In phase two just over 90% of the reasonable accommodations provided were to overcome environmental inaccessibility (Figure 4.15) and the cost was borne by the employer in over 90% of the cases (Figure 4.16). The fact that the employers paid for these changes is positive. The fact that 90% of the adaptations were for access indicates that many of the workplaces were not compliant with the National Building Standards. Inaccessibility has been shown to be a barrier in employment[61] and a reason for unemployment[36]. This was true for phase two as almost half the sample who had been employed post-injury reported that accessibility had a negative impact on becoming employed post-injury (Figure 4.17). Accessibility is important because if one has difficulty moving in the environment and required assistance, this may be patronising, affecting the individual's professional identity at work and further reinforcing the fact that they are disabled. Consideration should be given to the fact that it takes more effort for a disabled person to get to work and move around than

able bodied individuals. Therefore having to face accessibility issues may make the challenge too great, resulting in them deciding that working is not worth the effort.

Flexibility within the workplace was a reasonable accommodation which emerged from phase one in this study. This included being able to work from home, have more frequent rest breaks, or reduced work hours. If this was not provided by employers participants reported that individuals tried to start their own business so they could have that flexibility. The flexibility is probably needed as individuals living with a SCI often have poorer endurance than prior to the injury[75], or it may be easier to perform the routines such as bowel and bladder care and pressure relief within their home environment. In phase two of the study, those that had worked post-injury, a few had been provided with this flexibility, which included being allowed to work from home, given more frequent rest breaks and reduced work hours (Figure 4.15). In most of these cases the cost of this flexibility was borne by the employer (Figure 4.16). This would indicate that the employers who employed individuals from this sample population take their responsibility seriously and are assisting where possible to ensure employment for individuals post-injury. Interestingly even though only a small percentage of the sample that had been employed post-injury had been provided with this flexibility, the majority of the sample were employed full time and only 10% were self employed. Therefore either individuals were coping without the flexibility in their jobs, or perhaps self employment has its own unique difficulties. Reasonable accommodations were important to the participants of this study, the type of accommodation however, was largely to allow for environmental access. The social aspect of the work environment was also important in phase one of the study.

The qualitative results illustrated the role that colleagues play. The reception of the individual from the in-depth interview, in the workplace was unwelcoming and showed his colleagues' lack of education with regards to his disability. They viewed him as incapable of working and had this mindset before he had even started his job. This was also reflected in the responses to open ended question at the end of the questionnaire in phase two, where people felt they were viewed as a burden rather than a productive worker. To continue working under those conditions requires a special type of motivation. It is human nature to want to be accepted on a social level by ones colleagues. In contract to this almost 75% of the participants from phase two reported that their colleagues were understanding and displayed a favorable attitude towards them (Figure 4.14). This may be due to being better educated with regard to people with disabilities. Thirty percent of those that had been employed post-injury

reported that discrimination by colleagues had a mild to moderate impact on becoming employed post-injury (Figure 4.17). The studies in South Africa have had such poor employment rates that no comparisons can be made and reasons explored for this.

A sense of achievement and career development was a category that emerged during phase one. Being able to perform the work that is required is important so that the individual can have a sense of achievement and compete with fellow colleagues. This will lead to an acceptance on a professional level within the workplace. The need for career development is also as important as it would be for an able bodied individual. These factors were not fully explored in phase two, but it was found that more than 70% of the sample that had been employed post-injury had experienced career development in their current job (Figure 4.13). Career growth has been shown to be important in ensuring job retention post SCI[90] and therefore it is positive to see that this is being provided to most of the participants in this sample.

The final aspect that emerged from phase one under workplace aspects, was the match of the individual's personality to the job they were performing. This was particularly important when an individual could no longer perform his pre-injury job due to the physical nature of the work, but he enjoyed that type of work. Being able to find an alternative that fits within his interests and personality may take some consideration. It was felt that if the correct match was not achieved the individual would not enjoy the work and employment would not be sustainable. In phase two of the study six individuals reported that this had a severe impact on their employment status (Figure 4.17). This situation requires the intervention of an occupational therapist with vocational rehabilitation experience to find the correct job-person fit post-injury[2].

5.14 Service provision in the South African health setting

Service provision within the South African health setting is the final theme that emerged from phase one of this study. It dealt with all the services that should be provided to someone who has had a SCI from the time of injury until returning to work.

In phase two of this study, the participants were almost evenly distributed between those that had their rehabilitation at a private and government hospital and two individuals never having had rehabilitation, which is concerning. However, the number of individuals who haven't received rehabilitation in South African population of individuals living with a SCI is likely to be much higher.

Phase one data revealed that the focus of rehabilitation is mainly on personal management and has unfortunately lost some client centeredness due to the therapist-client ratios. Some individuals may therefore not grasp important aspects during rehabilitation. This concern was captured in a study done in Tshwane (Pretoria) where an individual expressed that he did not grasp much of what was done during rehabilitation[12]. This is concerning as the issues dealt with during rehabilitation are vital to prevent secondary conditions related to SCI and ensuring a reasonable level of quality of life after the injury[72].

In phase two of this study it was concerning that during rehabilitation less than half of the participants were made aware of community resources that they may require after discharged. As discussed, earlier knowledge of these resources can play an important role in individuals' adjustment post-injury and therefore may affect their employment status. More than two thirds of the sample reported that their families were educated about SCI. However, because of the support and understanding that is needed post-injury one would hope that every family would have been educated so they could understand the difficulties the individual living with a SCI may face and assist where needed. The education of an individual's family was significant with regard to employment status (Figure 4.28), but not as one would have expected. The ratio of those employed to unemployed was higher when family members were not educated on SCI. One would expect that if the families had been educated about SCI, the potential that an individual living with a SCI would have been highlighted and therefore the family would support the individual in reaching these goals and therefore improve employment rates. A reason why individuals whose families had not been educated were employed may be due to families performing their own research about SCI and therefore the fact that it was not provided during rehabilitation became irrelevant. They were able to provide the support the individual living with a SCI required to be able to become employed. This may also have been affected by majority of the sample being of a higher socio economic status and therefore having access to these resources.

The lack of vocational rehabilitation in South Africa was apparent in the phase one of the study. Comments such as “we don’t have any work intervention at all” highlighted the problem. If one is not insured, work intervention would be scarce. The reason for this may be that many of the government vocational rehabilitation centres are no longer functional. Funding for posts in this sector has not been provided by the Department of Health because the focus was on service provision in the community and dealing with acute rehabilitation (personal management mentioned earlier). The Labour Department has not provided funding for vocational rehabilitation services to date. The Western Cape still has a unit that provides vocational assessment and treatment, but at the time of the study, it was the only operational government unit in the country. Private vocational rehabilitation can be accessed, but is often only practical when funding (other than that of a medical aid) such an insurance payout, or a Road Accident Fund claim is available. If vocational rehabilitation can be implemented in the major hospitals in all provinces, the gap between willing employers and people with disabilities that are fit for work can be bridged. Non Government Organisations and aspects of the Skills Development Act (learnerships in particular) have tried to fill this gap, but they have not been effective as discussed in the literature review.

In phase two this lack of vocational rehabilitation was confirmed. Employment was only discussed during rehabilitation with half of the sample who were of working age and were not studying or scholars at the time of the injury (Figure 4.5). This supports the qualitative statement that rehabilitation focuses on personal management. Despite this finding not being of statistical significance it is of clinical concern. Employment has been associated with: being able to live an independent adult life, independent living (especially for tetraplegics)[36] and income[8]. Employment has a positive effect on health[37], being significantly associated with quality of life[44,45] and life satisfaction[36]. Due to all of these benefits, it is essential that this is discussed during rehabilitation. It is an essential aspect within the occupational therapists scope of practice[89], even in the acute setting, as employment is one of the main occupations in which an adult should engage[2]. To confirm the lack of vocational involvement during the rehabilitation period, only 38% of those that were employed at the time of the injury (62.07% of the total sample) reported that a member of their rehabilitation team contacted their employer. This was done by the occupational therapist in more than half of the cases. As rehabilitation after a SCI is a lengthy process, it would be expected that someone would be in contact with the employer on a regular basis to

ensure that the individual would have the best opportunity to return to work, if feasible.

In phase two of the study only 20% of individuals who were of employment age and were not studying at the time of injury, were referred to someone post rehabilitation to assist them with employment (Figure 4.5). Individuals would therefore have had to find their own sources of assistance. Less than half the sample had someone assist them to return to work or become employed. Of that group, 41% reported that it was their friends or family that assisted them. The role that health professionals played in assisting individuals to return to work was equal to that of the pre-injury employers (Figure 4.7).

Follow up post discharge was raised as a problem in phase one, especially in the public sector. This was also highlighted as a problem in a study in Tshwane (Pretoria), were the researcher has proposed multidisciplinary follow up strategies for individuals living with SCI in the community[12]. This is essential, as the secondary complications linked to SCI must be prevented or diagnosed as soon as possible to prevent long hospitalisations which affect employment, and could even result in untimely death[72].

The final aspect that emerged from phase one was the standard of nursing in acute hospitals. This affects individuals with SCI when they are stabilised post-injury before being transferred to a rehabilitation hospital, during rehabilitation or when they are admitted to hospital for other medical issues in the course of life. Participants reported numerous disturbing cases where pressure sores developed during hospitalisation. In the study done in Tshwane (Pretoria), participants reported that some of the nurses' attitudes to patients during rehabilitation was unacceptable and unhelpful[12]. This does not provide a supportive environment for rehabilitation. As pressure sores are related to employment post-injury[36], it is essential that nursing staff take the necessary care to ensure pressure sores do not occur while patients are in their care.

Occupational therapists in South Africa are trained to assist in the process of finding a job, making recommendations on reasonable accommodations, advising employers, providing work supports and, if necessary some work hardening and conditioning, with the assistance of physiotherapists[90] to achieve sustained employment. In the sample in phase two it was evident that very little vocational

rehabilitation was accessed, or provided. The high number of individuals what were employed in this study, despite this lack of vocational rehabilitation shows that the other factors are also important in becoming employed for this sample. As employment is seen to be a measure of overall recovery from illness or disability and successful rehabilitation[7], it is essential that this is not overlooked as an important aspect of treatment.

5.15 Conclusion

This study had very few significant results. This may be due to the sample that was skewed and was not representative of the greater population in South Africa. There were also very many aspects that influence employment after a SCI and a bigger sample may have yielded more results that were significant. The high employment rate of 79.55% at the time of the study and 92.13% of the sample who had worked for pay since their injury, is an important result. The factors that were significantly related to employment were: performance of independent pressure relief, maintaining social interaction post-injury, transportation, the number of hours worked per week, the employer's attitude, and the family being educated on SCI during the individual's rehabilitation. The odds of being employed at the time of the study were higher if one worked more than 40 hours a week.

Results that were not statistically significant, but were of clinical importance were: the lack of vocational rehabilitation, the level of educational, the role of endurance in getting a job and emotional support received from family and friends.

The samples from phase one and two produced a vast amount of data, due to the exploratory nature of the study. It was not possible to present all of it in this chapter. What was presented here is a selection of about 80% of the data. The data revealed valuable facts, the beliefs and perceptions of therapists and clients which will be useful for clinical practice and future research.

The final chapter follows and includes the realisation of the aims of the study, a reflection on the whole process, limitations of the study, as well as recommendations for clinical practice and future research.

CHAPTER 6: CONCLUSION

In conclusion, the realisation of the aims and the reflections of the study will be discussed. This will be followed by the limitations and the recommendations for future research.

6.1 Realisation of aims

The aim of this study was to explore the factors that influence employment after a SCI in South Africa. This was achieved, but this was an initial investigation. The aim of designing a self-report questionnaire to investigate employment after a SCI in South Africa in phase one was achieved. The questionnaire gathered information on the factors that have been found to influence employment after a SCI. There were, however, some factors that were not comprehensively captured. A few questions were redundant and did not contribute to the aims and objectives of the study.

The aim of determining the prevalence of variables that impact employment after a SCI in a select sample of individuals living with a SCI in South Africa with internet access and QASA membership was determined. The employment status of these individuals was higher than expected when compared with the norms in international literature[1,9,81]. Aspects such as being able to perform independent pressure relief, maintaining social interaction post-injury, transportation and the employer's attitude were significantly associated with employment post-injury.

6.2 Reflections on the study

The researcher did not initially realize the magnitude of the topic. The number of factors that affect employment post SCI and the interaction they have on each other was not apparent until the end of phase one of the study. The rationale of studies that focus on only limited factors in relation to employment post SCI was therefore better understood.

Despite reading widely prior to this project, there were aspects that the researcher discovered during the research process. One such aspect was making contact with leading researchers in the field and gaining access to measurement instruments they

have used to investigate employment after a SCI. The Life Situation Questionnaire[116] that has been designed and used in the USA was only accessed after the completion of this survey instrument. This may have been of assistance in the early phase of this study.

Questionnaire development is based on research principles and is informed by reliable and valid data. The process could be regarded as a study in itself. The qualitative research design in phase one was novel to the researcher. The process of data analysis and the results in phase one yielded a depth of insight that could not be gained from quantitative research.

The in-depth interview was personally inspiring. The story of an individual who went from having no direction or goals prior to injury to achieving his matric, completing a clerical course and gaining employment all with very little assistance, is one of courage and determination. It illustrates that a positive attitude and motivation can overcome many obstacles. It also highlights the value of involving clients in research. They are the experts, as they are the people living with the condition. No research should be conducted without the experts.

This study illustrates that each role player who has input into the life of the individual living with a SCI from the point of injury, has the potential to facilitate employment through their actions and decisions. This ranges from the governmental officials that ensure policies are implemented, nurses ensuring that pressure sores do not develop, to occupational therapists who take their role of assessing and treating the work occupational performance area seriously. The general public can assist by not patronising individuals living with a SCI, insurers by being willing to support beneficiaries return to work and employers by facilitating employment opportunities for those with disabilities. Family and friends supporting the individual living with a SCI, may also have the ability to impact the employment outcome post-injury. As illustrated in the in-depth interview despite the above aspects being either present or absent an individual living with a SCI also has a vital role to play and he or she should be given the opportunity to work.

Based on the barriers to employment that an individual living with a SCI faces each individual who is employed post-injury deserves respect for having overcome numerous hurdles and should be given the recognition and support that is required to maintain their employment.

6.3 Limitations

The following limitations regarding the questionnaire used in phase two may have affected the results:

- The questionnaire that was designed for this study was lengthy. In retrospect, there were some questions which were not necessary to meet the objectives of this study.
- The questionnaire did not adequately assess all the psychological aspects affecting employment post SCI, such as insight, motivation and depression. This was one of the objectives of the study.
- In some cases one short question like number of hospitalisations could have eluded to complications, instead of a lengthy question with options of complications.

During the data collection and analysis of phase one the researcher did not keep track of bias. This could have been captured in a journal which would have helped to achieve neutral interpretation of the data and therefore improved confirmability[108]. However, the data which was of a more factual nature in phase one might not have been as affected by subjective interpretation.

There were several limitations on the sample in phase two. It was a convenience sample and therefore was affected by selection bias. Only individuals with access to email would have received the questionnaire and the majority would have been members of QASA. Further, only those who were motivated to participate in the study would have returned the questionnaire. The sample is therefore not a representative sample of the section of the South African population living with a SCI.

6.4 Recommendations

At the outset of this study, the information from a national statistics register for SCI in South Africa would have been beneficial, if available. At present there is no such a register. A recommendation for a register has been mentioned in previous studies on SCI in South Africa [12,13,17,82]. This information is important, as it would provide the epidemiology, prevalence and incidence of SCI in South Africa. As stated in the

literature review, these facts are essential for the country to be able to plan for costs associated with SCI and provide the services that are required post-injury. It would also provide information on high risk groups and highlight the need for effective prevention strategies. Ideally this register should be initiated by the Department of Health. All SCI's should be captured at the time of admission to a South African hospital. Information should include, but not be limited to the individual's date of birth, age at injury, race, gender, extent of injury and cause of injury. The diagnosing doctor should provide this basic information.

In order to create meaningful and longitudinal data for further studies, a SCI database should be established. This data should be collected by the SCI rehabilitation centers and follow up clinics throughout the country. This could be set up in a partnership between the Department of Health, the Quad -Para Association of South Africa (QASA) and the Southern African Spinal Cord Association (SASCA). It would provide more detailed information than the national statistics register and each individual living with a SCI would be assigned a participant number for life. Initial rehabilitation information such as that contained in the register should be captured, as well as initial functional level, employment status, and then discharge information such as independence, assistive devices issued and plan for employment. Then at each follow-up appointment thereafter, information could be gathered to assist in researching all aspects of life after a SCI. This is done in the USA by the Model Spinal Cord Injury Program[53]. A questionnaire relevant to the South African setting should be completed for each individual living with a SCI at each follow-up post-injury. A relevant questionnaire, such as the Reintegration to Normal Living (RNL) Index which was shown to be reliable and valid for people living with SCI in the Tshwane (Pretoria) metropolitan area[12], could be used. In order to achieve this objective, an increased number of staff will be required at hospitals and clinics where follow-up appointments are held, as completion of the questionnaires would demand extra time of staff. Researches in this field would need to collaborate to capture the data so that it would be available as data sets for ongoing research.

The establishment of such a data base is a lengthy process. In the interim, employment post-injury should still be investigated. This study could be regarded as an initial investigation into employment after a SCI in SA. Further investigation is necessary. The Survey on Employment after a SCI in South Africa, used for this study should be further refined. This survey could then be implemented to determine the employment rate after SCI in the South African population. A more

comprehensive sample population could be gained by conducting numerous studies. Phase two of this study should therefore be repeated with a more representative sample.

A large data set on employment status could be achieved by having the questionnaire completed when individuals access a health care provider, at least one year post SCI. Final year occupational therapy students could use the questionnaire as their research project and gather data during their fieldwork in fourth year in various settings. This could be provided in a hard copy to those who did not have access to email. The Survey on Employment after a SCI in South Africa would, however, still provide only the individuals perceived views of their functioning and mental health. All the gathered data could be added to the existing data set from this study.

An online questionnaire platform, such as Survey Monkey may have made the completion even easier for participants and the recording of data quicker. The survey on this platform could be repeated every five years.

Employment after a SCI is affected by so many factors. With regard to the method of the study, further studies may consider using a more “limited” approach. The affect that specific set independent variables have on employment outcome could be determined, using a forward stepwise logistic regression. Other studies may wish to focus on only a section of variables, such as the psychological, or the demographic aspects affect on employment post SCI.

Since pressure relief proved to be an important predictor to successful employment in this study in phase two, clients must be taught during rehabilitation pressure relieving methods that they can perform independently were possible, as this may impact their employment outcome.

Based on the findings related to limited vocational rehabilitation services received by individuals in this study in phase two, there is a need for occupational therapists working in spinal rehabilitation to assess, or at least screen their client’s work performance area. This will ensure that someone in the rehabilitation team has made contact with the client’s employer.

There is a need for vocational rehabilitation for individuals post their initial rehabilitation. This may require a case management program and vocational services to work together to ensure individuals are not lost in the follow-up process[117]. The occupational therapist should ensure there is a plan for the client on discharge from rehabilitation with regards to work, and/or a referral to a professional who may assist in this regard. Individuals should receive information regarding where they can access vocational rehabilitation or vocational assistance.

The results from phase two illustrate that education and motivation are important aspects in becoming employed after a SCI. Being able to still engage in social interaction also appears to benefit employment. Occupational therapists of other health care providers should ensure that these aspects are addressed during the rehabilitation period.

The qualitative phase revealed that there is a lack of vocational services in the public sector. These services need to be revived. The Department of Labour and Health should consult with the aim to develop an action plan so that these services can be offered to individuals post SCI, but also to all individuals following an injury which impacts their employment.

Occupational therapists working in the community need to advocate for their clients living with SCI. They need to assist those who want to work by ensuring some of the modifiable aspects that facilitate employment, that have been highlighted in this study, are addressed. These may include accessing education, providing information on accessible transport or legislation and work seeking skills to name a few.

6.5 Final Conclusion

This two phase study yielded numerous results due to its exploratory nature. Despite few results being statistically significant, there were many that are of clinical importance. These results need to be used to inform rehabilitation and vocational rehabilitation practice for individuals living with a SCI. The high employment rate found in this study in a select population, proves that employment after a SCI is not only possible, but should be the goal for successful rehabilitation post a SCI for all individuals.

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APPENDICES

Questions to be asked at the Focus groups **Appendix A**

Welcome: Introduce myself and give background.

Purpose: My research has 2 phases, the 1st is to compile a questionnaire that will be used to sample the quadpara database. This focus group is going to explore the variables that are essential in return to work after a spinal cord injury. The discussion will then be transcribed arranged into themes which will form the basis of the questionnaire.

The focus group is going to be recorded. They will be stored according to the HPCSA's guidelines and you will not be identified by your names. I will also be taking notes during the group.

Are there any questions?

I have provided you with an information sheet and consent form. If you have no further questions and are happy to be included in the group, please sign the consent form (and a witness) and return them.

1. Please introduce yourself and tell us what area of vocational rehabilitation you have had experience.

2. What is employment, what do we classify employment as? What does it mean to be "employed"? any ideas on that.
    a. money involved, there it something to sustain their livelihood

3. The next question then is, what are the factors in the SA context that play a role in the employment of someone after they have had a SCI?
    a. Patient abilities
    b. Acute rehab (initial rehab)
    c. Long term rehab /follow-up
    d. Employment
    e. Legislation

4. Who should be involved in SCI vocational rehabilitation? (acute and post acute?)
    a. Who would be involved in the team to help someone RTW?

L: I think we need to terminate this group, I know a lot of people need to go. Is there anything pressing you feel we haven't covered?

L: thank you all very much….

Questions to be asked at the in-depth interview **Appendix B**

Welcome:
Purpose: My research has 2 phases, the 1st is to compile a questionnaire that will be used to sample the quadpara database. This interview is going to explore the variables that are essential in (return to work) employment after a spinal cord injury. The discussion will then be transcribed arranged into themes which will form the basis of the questionnaire.

The interview is going to be recorded. They will be stored according to the HPCSA's guidelines and you will not be identified by your names. I will also be taking notes during the group.

Are there any questions?

I have provided you with an information sheet and consent form. If you have no further questions and are happy to be included in the group, please sign the consent form (and a witness) and return them.

1. Would you give a brief history of your injury?

_____

_____

_____

_____

_____

_____

2. Where did you have your rehabilitation?

_____

_____

_____

_____

3. Which team members were involved?

4. Did they talk about work at all? Make plans to find you a job?

5. Did what was your education level before injury?

6. Were you employed pre-injury?

7. Did you have training post injury?

8. Who was involved in helping you during the training?

9. Did anyone help you to find a job? Were any OT's physios etc involved? (LONG term follow up after injury)

10. What role did your employer play?

11. Did legislation play a role?

12. What were the most important factors that made it possible for you to find work and keep it?

    a. Physical abilities?

    b. Coping / emotional issues?

    c. Support structures?

    d. Practical issues – transport?

What made it possible for you to get a job when so many others haven't been able to do so?

_____

_____

_____

_____

THANK YOU!

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG

Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Mrs LA Michell

CLEARANCE CERTIFICATE	**M090528**
PROJECT	Investigating Return to Work Following a Spinal Cord Injury
INVESTIGATORS	Mrs LA Michell.
DEPARTMENT	Department of Occupational Therapy
DATE CONSIDERED	09.05.29
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 09.08.19 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable

cc: Supervisor : Mrs D Casteleijn

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

Information sheet: In-depth interview **Appendix D**

8 March 2010

Good day,

I am Lauren Michell, a part-time lecturer and student doing my masters in Occupational Therapy at WITS University. I am investigating the return to work process after having a spinal cord injury.

I invite you to consider participating in this study.

Before agreeing to participate, it is important that you read and understand the purpose of this study, the study procedures and your right to withdraw from the study at any time.

I am doing this study as there has been limited research in the process of returning to work after a spinal cord injury in South Africa. I would like to determine if there are any factors which facilitate or hinder returning to work. I also want to determine the role vocational rehabilitation and the South African legislation play in being able to go back to work. As a professional with experience in this area I would like to invite you to form part by being involved in an individual interview.

I am in the process of compiling the questionnaire to be used in this study. The interview will assist in providing information relevant to the South African context on spinal rehabilitation and vocational rehabilitation which must be included.

The interview will be recorded and I will take notes during the discussion, but your name will not be written down. The recording will only be reviewed by me and codes will be used during the analysis of the discussion and not names. Complete confidentiality will not possible, but all recordings will be carefully stored as per the HPCSA guidelines.

The interview will last approximately 45 minutes on the 24th of March at 10h30. The interview will be held at Chris Hani Baragwaneth hospital – occupational therapy department.

Your participation in this study is entirely voluntary; you may withdraw at anytime without having to give a reason.

This study will not benefit you personally, but your contribution can assist in gaining an understanding of the employment status of individuals with paraplegia and tetraplegia and the problems associated with going back to work within a South African context. It is hoped that the results can be used to assist paraplegics and quadriplegics being able to return to work in the future.

Should you require counselling following the focus group, this will be available from Dr R Crouch at the WITS School of Therapeutic Sciences, free of charge. She can be contacted at 011 717 2147 to make an appointment.

If you have any questions, do not hesitate to contact me on 083 695 2248.

Thank you.

Kind regards,

Mrs L Michell

Good day

I am Lauren Michell, a part-time lecturer and student doing my masters in Occupational Therapy at WITS University. I am investigating the return to work process after having a spinal cord injury.

I invite you to consider participating in this study.

Before agreeing to participate, it is important that you read and understand the purpose of this study, the study procedures and your right to withdraw from the study at any time.

I am doing this study as there has been limited research in the process of returning to work after a spinal cord injury in South Africa. I would like to determine if there are any factors which facilitate or hinder returning to work. I also want to determine the role vocational rehabilitation and the South African legislation play in being able to go back to work. As a professional with experience in this area I would like to invite you to form part of the focus group.

I am in the process of complaining the questionnaire to be used in this study. The focus group will assist in providing information relevant to the South African context on spinal rehabilitation and vocational rehabilitation which must be included.

The group will be recorded and I will take notes during the discussion, but your names will not be written down. The recording will only be reviewed by me and codes will be used during the analysis of the discussion and not names. Complete confidentiality will not possible, but all recordings will be carefully stored as per the HPCSA guidelines.

The focus groups will last approximately 2 hours. I plan to have one group and if necessary a second one two weeks later. The proposed dates are the last week of the 25th of January and the 8th of February 2010. The group will be held at the OT Department at WITS University.

Your participation in this study is entirely voluntary; you may withdraw at anytime without having to give a reason.

This study will not benefit you personally, but your contribution can assist in gaining an understanding of the employment status of individuals with paraplegia and tetraplegia and the problems associated with going back to work within a South African context. It is hoped that the results can be used to assist paraplegics and quadriplegics being able to return to work in the future.

Should you require counselling following the focus group, this will be available from Dr R Crouch at the WITS School of Therapeutic Sciences, free of charge. She can be contacted at 011 717 2147 to make an appointment.

If you have any questions, do not hesitate to contact me on 083 695 2248.

Thank you.

Mrs L Michell

Consent form: Return to work following a spinal cord injury

I have read and understand the study outlined in the information sheet. I agree to participate in the research.

Name: _____

Signature: _____

Witness: _____

Date: _____

Good day,

I am Lauren Michell, a part-time lecturer and student doing my masters in Occupational Therapy at WITS University. I am investigating employment after having a spinal cord injury.
I invite you to consider participating in piloting the questionnaire for this study.

Your participation in this study is entirely voluntary. You may choose if you wish to return the questionnaire. By completing the questionnaire you are agreeing to participate in the study.

Before agreeing to participate, it is important that you read and understand the purpose of this study.

I am doing this study as there has been limited research in the employment after a spinal cord injury in South Africa. The study has two parts: the first part is developing a questionnaire and the second is sending it out as a survey. I would like to determine if there are any factors which make returning to work easier or harder. I also want to determine if vocational rehabilitation and the South African legislation play a role in being able to go back to work.

To assist in the piloting of the questionnaire I would require that you:

- Complete the attached questionnaire, timing how long it takes you,
- Provide feedback on any questions or instructions that you did not understand,
- Return the Questionnaire to me via email,
- Possibly receive a phone call or email from me to clarify your feedback on the questionnaire.

This will assist me to know if the questionnaire is user-friendly and how long it takes to complete. I will then conduct the full survey.

Your answered questionnaires will be saved anonymously and your return email deleted once I have emailed or phoned you.

I estimate it will take approximately 20 minutes to complete this questionnaire.

This study will not benefit you personally, but your contribution can assist developing a questionnaire that can be used in gaining an understanding of the employment status of individuals with paraplegia and quadriplegia (tetraplegia) and the problems associated with working within a South African context after a spinal cord injury. It is hoped that the results can be used to assist paraplegics and quadriplegics being able to return to work in the future.

This study has received ethical clearance from the WITS Human Research Ethics Committee (Medical): M090528.

If you have any questions, do not hesitate to contact me on 083 695 2248 or email me at lauren.michell@wits.ac.za

Thank you.

Kind regards,
Lauren Michell

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	**Employment after a spinal cord injury (SCI) in South Africa** **Pilot Questionnaire**	**Lauren Michell 2010**

START TIMING

Please read all the questions carefully and attempt to answer all the questions that apply to you.

If you cannot remember the exact number for a certain question please estimate the number as accurately as possible, rather than leaving the question blank. If possible please provide specific information where requested.

The questions either allow you to:

- fill in a box with letters or numbers (move your cursor to the box and click on it and enter the text),
- click on the box and then your response from the drop down boxes .....,
- check boxes by clicking on them. ☒.

You will not have to complete all the sections, please read the instructions in the red boxes as to what you are required to complete.

A	**Demographic information**		
Please complete this section			
1	What is your current age?	years	
2	Which province do you live in?	**...**	
3	What is your gender?	**...**	
4	To which group do you belong?	Black	☐
		Asian	☐
		White	☐
		Coloured	☐
		Other: (please specify)	
5	What is your highest level of education?	**School:** ... **Post school:** ...	
6	What is your marital status?		☐
		Married / living with a partner	☐
		Divorced / separated	☐
		Widowed	☐
		Other (please specify):	
7	What is your family's combined monthly income?	R	

8	Were you the bread winner of the family before your injury?	.....	
B	**Injury details**		
Please complete this section			
1	What was the date of your injury?	/ / **day/ month/year**	
2	How old were you when you were injured?	years	
3	What was the cause of your injury?	Motor vehicle accident ☐	
		A fall ☐	
		Diving accident / sport injury ☐	
		Assault / stabbing ☐	
		Gun shot ☐	
		Other: (Please specify):	
4	Indicate the type of paralysis.	**...** Please specify the level of your injury: eg T6:	
5	Did you have any other injuries at the same time as the spinal cord injury?	Yes ☐ **Please indicate what it was ...**	No ☐
6	Did you have any serious medical conditions prior to your SCI?	Yes ☐ Please specify:	No ☐
7	Do you receive adequate physical support from your family and friends?	...	
8	Do you receive adequate emotional support from your family and friends?	...	
9	How functional are you at home?	...	
10	Do you have a caregiver?	Yes ☐	No ☐
		Is he/she a family member?	
		Yes ☐	No ☐
		Has it placed strain on your relationship?	
11	How much pain do you have?	...	
12	Which of the following describe your bowel routine? (may check more than one answer)	Manage independently ☐	
		Require assistance ☐	
		Affects my ability to leave the house ☐	

13	Which of the following describe your bladder routine? (may check more than one answer)	Manage independently ☐ Require assistance ☐ Affects my ability to leave the house ☐	
14	Which of the following describe your pressure relief routine? (may check more than one answer)	Manage independently ☐ Require assistance ☐ Affects my ability to leave the house ☐	
15	Check the complications you have had since the SCI and indicate how long you had them.	**Complication** / **Duration** Pressure sores ☐ weeks Urinary tract infections ☐ weeks P eumonia ☐ weeks Depression ☐ weeks Other: (please specify) weeks	
16	Which of the following statements describes your social functioning after the injury.	**...**	
17	Have you had a mentor (someone with a SCI) who was able to encourage and assist you after your SCI?	**...**	
18	Have you received or are you waiting to receive a payout?	Yes ☐ Indicate which (you may choose more than one): Workman's compensation ☐ Road accident fund ☐ Insurance payout ☐ Other (please specify):	No ☐
19	Is transportation problematic for you since your injury?	...	
20	What transportation do you now use?	Drive my own car ☐ Have a driver ☐ Public transport ☐ None ☐ Other: (please specify):	
22	Where did you have your rehabilitation?	Government hospital ☐ Private hospital ☐ I did not have rehabilitation ☐ **Name of the hospital:**	
23	How long were you in the above hospital?	weeks	

24	Were you made aware of resources in the community that would benefit you after the injury during your rehabilitation?	...	
25	Was your family educated about a spinal cord injury and how to assist you during your rehabilitation?	...	
26	Was employment/ work discussed while you were at a rehabilitation centre?	...	
27	Were you referred to someone to assist you return to work or find employment following hospital discharge?	...	
28	Did anyone help you to return to work or find work?	Yes ☐ Please specify who:	No ☐
27	Did someone from the rehabilitation team contact your employer?	Yes ☐ Please specify who it was: Physiotherapist Occupational therapist ☐ Social worker ☐ Doctor ☐ Psychologist ☐ Nurse ☐ Other : (please specify):	No ☐
C	**Work Information** **Pre-injury work information**		
Please complete this section			
1	What was your work status at the time of your injury?	Employed full time ☐ Employed part time (<20 hours a week) ☐ Volunteer ☐ Student ☐ Unemployed ☐	**Continue to complete section C** **Go straight to section D**
2	How long were you at your job before you were injured?	years	
3	Prior to your injury in what industry or field did you work in?	.....	
4.	What was your job title within that industry?		
5	In which sector of the labour market did you work?	Formal ☐ Please specify: ...	Informal ☐ Please specify: ...

6	What was the physical intensity of your work?	**Sedentary:** Sitting most of the time, but may involve walking or standing for short periods	☐
		Light work: exerting 9 Kg of force 33% of the time and 4.5 Kg for 34-66% of the time. Or negligible amount of force constantly to move objects	☐
		Medium: exerting 9 to 23 Kg of force 33% of the time, 4.6 – 11 Kg for 34-66% of the time or 4.5 Kg of force constantly to move objects.	☐
		Heavy: Exerting 23 Kg to 45 Kg of force 33% if the time, or 11Kg to 23 Kg for 34-66% of the time, or 4.5 to 9 Kg to constantly move objects	☐
		Very Heavy: Exerting more than 45.5 Kg of force 33% of the time, or 23 Kg for 34-66% of the time to move objects, or more than 9 Kg to constantly move objects.	☐
7	Did you return to the same employer after your injury?	Yes ☐	No ☐
		Did your job description change after your injury? ...	Why did you change jobs? (you may check more than one answer)
			You could not perform the physical aspects the job ☐
			Your workplace was inaccessible to a wheelchair and changes could not be made ☐
			You are not skilled in another area that you could be placed in ☐
			You were on sick leave for too long ☐
			Other (please specify):
8	Were any of the following involved in negotiations with your employer after your injury?	Union representative	☐
		Lawyer	☐
		Other: Please specify:	

D	**Work information** **Post injury employment**		
1	Did you want to work after your injury?	...	
2	What is your current work status?	...	
3	Have you worked for pay since your injury?	Yes ☐	No ☐ **Please go to straight to Section E if you answered "no"**
4	How many years after your SCI did you start working?	... year(s)	
5	How many jobs have you had since your SCI injury?	...	
Please complete question 6– 18 related to your most recent job			
6	What industry or field do you work in?	.....	
7	What was your job title within that industry?		
8	In which sector of the labour market do you work?	Formal ☐ Please specify: ...	Informal ☐ Please specify: ...
9	What is the physical intensity of your work?	**Sedentary:** Sitting most of the time, but may involve walking or standing for short periods	☐
		Light work: exerting 9 Kg of force 33% of the time and 4.5 Kg for 34-66% of the time. Or negligible amount of force constantly to move objects	☐
		Medium: exerting 9 to 23 Kg of force 33% of the time, 4.6 – 11 Kg for 34-66% of the time or 4.5 Kg of force constantly to move objects.	☐
		Heavy: Exerting 23 Kg to 45 Kg of force 33% if the time, or 11Kg to 23 Kg for 34-66% of the time, or 4.5 to 9 Kg to constantly move objects	☐
		Very Heavy: Exerting more than 45.5 Kg of force 33% of the time, or 23 Kg for 34-66% of the time to move objects, or more than 9 Kg to constantly move objects.	☐
10	How many hours do you work on average per week?	**...** hour(s)	
11	Did you have retraining for your post injury job?	Yes ☐ Who provided this training?	No ☐

12	How you would you describe your employer's attitude towards your return to work, or employing you post injury?	....			
13	How you would you describe the majority of your colleagues' attitude to your return to work, or employment post injury?	....			
14	Do you think you were discriminated against at work due to your disability?	...			
15	Do you have a chance to be promoted / develop your career?	...			
16	Is the work environment adequately accessible?	...			
17	Were any reasonable accommodations made?	Yes ☐ Indicate all the accommodations and who paid for them:	Reduced work hours	☐ ...	No ☐ I am not entitled to reasonable accommodations ☐
			Allowed more frequent rest breaks	☐ ...	
			Building made accessible, ramps, lifts, toilets	☐ ...	
			Restructuring of your job tasks	☐ ...	
			Transportation provided	☐ ...	
			Provided an assistant	☐ ...	
			Allowed to work from home	☐ ...	
			Provided adaptive equipment (voice activated software, motorised wheelchair)	☐ ...	
			Other: (Please specify)	☐ ...	

18	Please rate the problems you had returning to work or becoming employed after your injury:	Did not play a role	Had a mild impact	Had moderate impact	Had a severe impact
A	Reliable, accessible transport	☐	☐	☐	☐
B	Environmental barriers (inaccessible workplace)	☐	☐	☐	☐
c	Discrimination by colleagues	☐	☐	☐	☐
d	Required retraining due to a lack of skills in jobs you can now perform	☐	☐	☐	☐
e	Being sick (pressure sore, respiratory infections, bladder infections)	☐	☐	☐	☐
f	Employer's lack of commitment	☐	☐	☐	☐
g	Poor endurance and stamina	☐	☐	☐	☐
h	Bowel and bladder routines	☐	☐	☐	☐
i	Inadequate social support from friends and family	☐	☐	☐	☐
E	**Unemployment post injury (unemployed or a volunteer)**				
1	Would you like to work?	**...**			
2	Please indicate your current source of income? (you may select more than one option)	Government disability grant			☐
		Insurance payout			☐
		Family members financially support			☐
		Other (please specify)			

3	**Rate the impact the following factors had on you not working:**	**Did not play a role**	**Had a mild impact**	**Had moderate impact**	**Had a severe impact**
a	I can't do my pre-injury job.	☐	☐	☐	☐
b	Working takes too much effort now	☐	☐	☐	☐
c	Transport to work is inaccessible	☐	☐	☐	☐
d	Health related issues – I am not well enough to work	☐	☐	☐	☐
e	I am unable to manage bowel and bladder routines to be able to work	☐	☐	☐	☐
f	The jobs that I can now do, do not suit my personality	☐	☐	☐	☐
g	I require too much assistance to work	☐	☐	☐	☐

h	I cannot find a job	☐	☐	☐	☐
i	It is not financially viable for me to work	☐	☐	☐	☐
j	I have decided to retire early	☐	☐	☐	☐
k	I have inadequate support from family and friends	☐	☐	☐	☐
l	**What other factors played a role: Please specify:**				
Please complete this section					
1	Are you aware of legislation affecting people with disabilities?	**...**			
2	To your knowledge has the legislation had an impact on your employment status post injury?	...			

Please add any comments you feel would be beneficial to this study:

Thank you for completing this questionnaire. It is much appreciated. The results will be used as a starting point for determining the employment and rehabilitation needs for individuals with a spinal cord injury in South Africa.

STOP TIMING

Time it took: minute's seconds

PLEASE COMPLETE THE PILOTING QUESTIONS ON THE NEXT PAGE.

1. Please list the questions that you did not understand or could not answer and explain why.

Question number:	**Explain the problem**
E.g.: B4	I do not know what level of paralysis I have

2. Please indicate if the questionnaire was easy to complete

Yes ☐	No ☐
	Please specify the reasons:

3. Please comment on *any* improvements that can be made to the questionnaire:

Please **save** this word document and return it as an attachment to lauren.michell@wits.ac.za

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG	**Survey on Employment after a Spinal Cord Injury (SCI) in South Africa**	**Lauren Michell 2011**

Please read all the questions carefully and attempt to answer all the questions that apply to you.

If you cannot remember the exact number for a certain question please estimate the number as accurately as possible, rather than leaving the question blank. If possible please provide specific information where requested.

The questions either allow you to:

- fill in a box with letters or numbers (move your cursor to the box and click on it and enter the text),
- click on the box and then your response from the drop down boxes .....,
- check boxes by clicking on them. ☒.

You will not have to complete all the sections, please read the instructions in the red boxes as to what you are required to complete.

A	**Demographic information**	
Please ALL complete this section		
1	What is your current age?	years
2	Which province do you live in?	**...**
3	What is your gender?	**...**
4	To which group do you belong?	Black ☐
		Asian ☐
		White ☐
		Coloured ☐
		Other: (please specify)
5	What is your highest level of education?	**School:** ... **Post school:** ...
6	What is your marital status?	Single ☐
		Married / living with a partner ☐
		Divorced / separated ☐
		Widowed ☐
		Other (please specify):
7	What is your family's combined monthly income?	R

8	Were you the bread winner of the family before your injury?	.....	
B	**Injury details**		
Please ALL complete this section			
1	What was the date of your injury?	/ / **day/ month/year**	
2	How old were you when you were injured?	years	
3	What was the cause of your injury?	Motor vehicle accident ☐	
		A fall ☐	
		Diving accident / sport injury ☐	
		Assault / stabbing ☐	
		Gun shot ☐	
		Other: (Please specify):	
4	Indicate the type of paralysis.	**...** Please specify the level of your injury: eg T6:	
5	Did you have any other injuries at the same time as the spinal cord injury?	Yes ☐ **Please indicate what it was ...**	No ☐
6	Did you have any serious medical conditions prior to your SCI?	Yes ☐ Please specify:	No ☐
7	Do you receive adequate physical support from your family and friends?	...	
8	Do you receive adequate emotional support from your family and friends?	...	
9	How functional are you at home?	...	
10	Do you have a caregiver?	Yes ☐	No ☐
		Is he/she a family member?	
		Yes ☐	No ☐
		Has it placed strain on your relationship?	
11	How much pain do you have?	...	
12	Which of the following describe your bowel routine? (may check more than one answer)	Manage independently ☐	
		Require assistance ☐	
		Affects my ability to leave the house ☐	

13	Which of the following describe your bladder routine? (may check more than one answer)	Manage independently	☐
		Require assistance	☐
		Affects my ability to leave the house	☐
14	Which of the following describe your pressure relief routine? (may check more than one answer)	Manage independently	☐
		Require assistance	☐
		Affects my ability to leave the house	☐
15	Check the complications you have had since the SCI and indicate how many times you have had them.	**Complication** ☐	**Number of times**
		Pressure sores ☐	
		Urinary tract infections ☐	
		Pneumonia ☐	
		Depression ☐	
		Other: (please specify)	
16	Which of the following statements describes your social functioning after the injury.	**...**	
17	Have you had a mentor (someone with a SCI) who was able to encourage and assist you after your SCI?	**...**	
18	Have you received or are you waiting to receive a payout?	Yes ☐ Indicate which (you may choose more than one):	No ☐
		Workman's compensation ☐	
		Road accident fund ☐	
		Insurance payout ☐	
		Other (please specify):	
19	Is transportation currently problematic for you?	...	
20	What transportation do you now use?	Drive my own car	☐
		Have a driver	☐
		Public transport	☐
		None	☐
		Other: (please specify):	
22	Where did you have your rehabilitation?	Government hospital	☐
		Private hospital	☐
		I did not have rehabilitation	☐
		Name of the hospital:	
23	How long were you in the above hospital?	weeks	

24	Were you made aware of resources in the community that would benefit you after the injury during your rehabilitation?	...		
25	Was your family educated about a spinal cord injury and how to assist you during your rehabilitation?	...		
26	Was employment/ work discussed while you were at a rehabilitation centre?	...		
27	Were you referred to someone to assist you return to work or find employment following hospital discharge?	...		
28	Did anyone help you to return to work or find work?	Yes ☐ Please specify who:		No ☐
29	Did someone from the rehabilitation team contact your employer?	Yes ☐ Please specify who it was:		No ☐
		Physiotherapist	☐	
		Occupational therapist	☐	
		Social worker	☐	
		Doctor	☐	
		Psychologist	☐	
		Nurse	☐	
		Other : (please specify):		
C	**Work Information** **Pre-injury work information**			
Please ALL start this section				
1	What was your work status at the time of your injury?	Employed full time	☐	**Continue to complete section C**
		Employed part time (<20 hours a week)	☐	
		Self-employed	☐	
		Volunteer	☐	**Go straight to section D**
		Student	☐	
		Unemployed	☐	
2	How long were you at your job before you were injured?	years		
3	Prior to your injury in what industry or field did you work in?	.....		
4	What was your job title within that industry?			

5	In which sector of the labour market did you work?	Formal ☐ Please specify: ...	Informal ☐

6	What was the physical intensity of your work? (how heavy were the objects you used and how often did you move them)	**Sedentary:** Sitting most of the time, but may involve walking or standing for short periods	☐
		Light work: exerting 9 Kg of force 33% of the time and 4.5 Kg for 34-66% of the time. Or negligible amount of force constantly to move objects	☐
		Medium: exerting 9 to 23 Kg of force 33% of the time, 4.6 – 11 Kg for 34-66% of the time or 4.5 Kg of force constantly to move objects.	☐
		Heavy: Exerting 23 Kg to 45 Kg of force 33% if the time, or 11Kg to 23 Kg for 34-66% of the time, or 4.5 to 9 Kg to constantly move objects	☐
		Very Heavy: Exerting more than 45.5 Kg of force 33% of the time, or 23 Kg for 34-66% of the time to move objects, or more than 9 Kg to constantly move objects.	☐

7	Did you return to the same employer after your injury?	Yes ☐	No ☐	
		Did your job description change after your injury? ...	Why did you change jobs? (you may check more than one answer)	
			You could not perform the physical aspects the job	☐
			Your workplace was inaccessible to a wheelchair and changes could not be made	☐
			You are not skilled in another area that you could be placed in	☐
			You were on sick leave for too long	☐
			Other (please specify):	

8	Were any of the following involved in negotiations with your employer after your injury?	None	☐
		Union representative	☐
		Lawyer	☐
		Other: Please specify:	

D	**Work information** **Post injury employment**			
Please ALL start this section				
1	Did you want to work after your injury?	...		
2	What is your current work status?	...		
3	Have you worked for pay since your injury?	Yes ☐	No ☐ **Please go to straight to Section E if you answered "no"**	
4	How many years after your SCI did you start working?	... year(s)		
5	How many jobs have you had since your SCI injury?	...		
Please complete question 6– 18 related to your most recent job				
6	What industry or field do you work in?	.....		
7	What was your job title within that industry?			
8	In which sector of the labour market do you work?	Formal ☐ Please specify: ...	Informal ☐	
9	What is the physical intensity of your work? (how heavy are the objects you use and how often do you move them)	**Sedentary:** Sitting most of the time, but may involve walking or standing for short periods		☐
		Light work: exerting 9 Kg of force 33% of the time and 4.5 Kg for 34-66% of the time. Or negligible amount of force constantly to move objects		☐
		Medium: exerting 9 to 23 Kg of force 33% of the time, 4.6 – 11 Kg for 34-66% of the time or 4.5 Kg of force constantly to move objects.		☐
		Heavy: Exerting 23 Kg to 45 Kg of force 33% if the time, or 11Kg to 23 Kg for 34-66% of the time, or 4.5 to 9 Kg to constantly move objects		☐
		Very Heavy: Exerting more than 45.5 Kg of force 33% of the time, or 23 Kg for 34-66% of the time to move objects, or more than 9 Kg to constantly move objects.		☐
10	How many hours do you work on average per week?	**...** hour(s)		

11	Did you have retraining for your post injury job?	Yes ☐ Who provided this training?	No ☐
12	How you would you describe your employer's attitude towards your return to work, or employing you post injury?	....	
13	How you would you describe the majority of your colleagues' attitude to your return to work, or employment post injury?	....	
14	Do you think you were discriminated against at work due to your disability?	...	
15	Do you have a chance to be promoted / develop your career?	...	
16	Is the work environment adequately accessible?	...	

17	Were any reasonable accommodations made?	Yes ☐ Indicate all the accommodations and who paid for them:		No ☐	I am not entitled to reasonable accommodations ☐
		Reduced work hours	☐ ...		
		Allowed more frequent rest breaks	☐ ...		
		Building made accessible, ramps, lifts, toilets	☐ ...		
		Restructuring of your job tasks	☐ ...		
		Transportation provided	☐ ...		
		Provided an assistant	☐ ...		
		Allowed to work from home	☐ ...		
		Provided adaptive equipment (voice activated software, motorised wheelchair)	☐ ...		
		Other: (Please specify)	☐ ...		

18	Please rate the problems you had returning to work or becoming employed after your injury:	Did not play a role	Had a mild impact	Had moderate impact	Had a severe impact
A	Reliable, accessible transport	☐	☐	☐	☐
B	Environmental barriers (inaccessible workplace)	☐	☐	☐	☐
c	Discrimination by colleagues	☐	☐	☐	☐
d	Required retraining due to a lack of skills in jobs you can now perform	☐	☐	☐	☐
e	Being sick (pressure sore, respiratory infections, bladder infections)	☐	☐	☐	☐
f	Employer's lack of commitment	☐	☐	☐	☐
g	Poor endurance and stamina	☐	☐	☐	☐
h	Bowel and bladder routines	☐	☐	☐	☐
i	Inadequate social support from friends and family	☐	☐	☐	☐
E	**Unemployment post injury**				
Complete if you are currently unemployed or a volunteer					
1	Would you like to work?	**...**			
2	Please indicate your current source of income? (you may select more than one option)	Government disability grant ☐			
		Insurance payout ☐			
		Family members financially support ☐			
		Other (please specify)			
3	**Rate the impact the following factors had on you not working:**	**Did not play a role**	**Had a mild impact**	**Had moderate impact**	**Had a severe impact**
a	I can't do my pre-injury job.	☐	☐	☐	☐
b	Working takes too much effort now	☐	☐	☐	☐
c	Transport to work is inaccessible	☐	☐	☐	☐
d	Health related issues – I am not well enough to work	☐	☐	☐	☐
e	I am unable to manage bowel and bladder routines to be able to work	☐	☐	☐	☐
f	The jobs that I can now do, do not suit my personality	☐	☐	☐	☐
g	I require too much assistance	☐	☐	☐	☐

	to work				
h	I cannot find a job	☐	☐	☐	☐
i	It is not financially viable for me to work	☐	☐	☐	☐
j	I have decided to retire early	☐	☐	☐	☐
k	I have inadequate support from family and friends	☐	☐	☐	☐
l	What other factors played a role: Please specify:				
F	**Legislation**				
Please ALL complete this section					
1	Are you aware of legislation affecting people with disabilities?	**...**			
2	To your knowledge has the legislation had an impact on your employment status post injury?	...			

Please add any comments you feel would be beneficial to this study:

Thank you for completing this questionnaire. It is much appreciated. The results will be used as a starting point for determining the employment and rehabilitation needs for individuals with a spinal cord injury in South Africa.

Please **save** this word document and return it as an attachment to leilane.mackay@wits.ac.za

Good day

I am Lauren Michell, investigating employment after having a spinal cord injury in South Africa. I invite you to consider participating in this study if you have been diagnosed with paraplegia or quadriplegia (tetraplegia). Your employment status is not important. Your participation in this study is entirely voluntary. You may choose if you wish to return the questionnaire. By completing the questionnaire you are agreeing to participate in the study.
Before agreeing to participate, it is important that you read and understand the purpose of this study and the study procedures and your right to withdraw from the study at any time.
I am doing this study as there has been limited research into employment after a spinal cord injury in South Africa. I would like to determine if there are any factors which make returning to work easier or harder. A Survey on Employment after a Spinal Cord Injury in South Africa has been designed to gather this information.
If you choose to participate in this study you would need to:

- complete the Survey on Employment after a Spinal Cord Injury in South Africa,
- save the survey,
- return it via email to the WITS Occupational Therapy department's secretary, Leilane Mackay at leilane.mackay@wits.ac.za

Please do not type your name on the survey, or save the survey under your name. When Leilane receives your email she will print the questionnaire and then delete your email, so that I don't know who has emailed the questionnaire. This will ensure that your information remains confidential.
It should take a maximum of 25 minutes to complete this survey.
This study will not benefit you personally, but your contribution can assist in gaining an understanding of the employment status of individuals with paraplegia and quadriplegia (tetraplegia) and the problems associated with going back to work within a South African context. It is hoped that the results can be used to assist individuals with paraplegia and quadriplegia (tetraplegia) with employment in the future.
This study has received ethical clearance from the WITS Human Research Ethics Committee (Medical): M090528. If you have any questions, do not hesitate to contact me on 083 695 2248 or lauren.michell@wits.ac.za

Thank you.

Kind regards,

Mrs L Michell
Part-time lecturer and MSc(OT) student, WITS Occupational Therapy Department

Category	Variables
Demographics	Present Age
	Country of residence
	Legally allowed to work in SA
	Highest level of education
	Gender
	Culture
	Marital status[9]
	Number of dependent children
	Province of residence
Disability information	Date of injury
	Time since injury[56]
	Age at time of injury
	Cause of injury
	Level of impairment
	Initial perception of functional abilities
	Perceived disability[62]
	Control over the environment
	Social support
	Pain
	Independence at home
	Length of hospital rehabilitation
	Rehabilitation hospital
	Medical complications
	Mobility aid used[91]
Pre-injury employment information	Job satisfaction prior to injury
	Employment status at time of injury
	Type of work/ job title
	Physical intensity of work[56]
	Time at job prior to injury
	Hours worked per week
	Earnings per month[118]
	Amount of sick leave taken per year
Post-injury employment information	Transportation
	Workman's compensation, Road Accident Fund or insurance payout
	Value of the worker role[119]
	Current employment status
	Are you self employed
	Date return to work
	Change of jobs[44] and how many[35]
	Length of employment at each job, post injury
	Reason for changing jobs[44]
	Gradual return to work
	Rate your current job satisfaction
	Type of work
	Physical intensity of work[56]

	Hours worked per week
	Earnings per year[118]
	Sick leave taken per year
	Retraining for job[56]
	Employers attitude to employment
	Discrimination at work
	Colleagues attitude towards you
	Reasonable accommodations: What was done? Was it necessary? Were further adaptations needed?
	Problems experienced in return to work
	Personal view about returning to work[120]
Unemployed	Work motivation[9]
	Reason for not working
	Source of income
Legislation[1,35]	Did you lose your job after your disability?
	Awareness of legislation
	Effectiveness of legislation
	Discrimination in the job application process
Occupational therapy intervention[83,121]	Involvement of OT in the return to work process
	Services received which aided employment
	Other professions involved in the return to work process
Current needs	Vocational assistance currently needed

Feedback	Recommendation	Action taken and reason
Section B, question 15 on complications after the SCI required a response in weeks. (the duration of the complication)	Request the number of times the complication has occurred as people will guess the duration(s)	Corrected as suggested
Employment status questions did not have a category for self-employed persons	Add an additional category	Additional category created for section C1 and D2 – “Self employed”.
Some of the questions pressurised individuals to respond and they wanted to give more information.	Additional comments sections were requested.	As the questionnaire was lengthy and it is an initial investigation these comment blocks were not included.
Section A, question 6 the option of single had been accidentally removed	Replace the option “single”	Corrected as suggested
Questionnaire was reported to be easy to complete and follow.		