

**PSYCHOLOGICAL EFFECTS OF SPINAL CORD INJURY: AN EXPLORATION
INTO THE SUBJECTIVE EXPERIENCES OF SPINAL CORD INJURED PERSONS
AT DR GEORGE MUKHARI HOSPITAL.**

by

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DECLARATION

I declare that the dissertation hereby submitted to the University of Limpopo, for the degree of Masters of Science in Clinical Psychology has not previously been submitted by me for a degree at this or any other university; that it is my work in design and in execution, and that all material contained herein has been duly acknowledged.

B.G. Tshabala (Mr)

Date:

Dedication

I dedicate this work to my Lord and Saviour, Jesus Christ,

whose nurturance, provision and guidance has

been a constant pillar of strength.

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ABSTRACT

Spinal cord injury (SCI) is believed to place the individual at a high risk of psychological turmoil. This study explored the subjective experiences of SCI persons, by exploring the psychological effects of SCI at Dr. George Mukhari Hospital. To achieve this, the primary objectives of the study were to; explore the psychological effects faced by SCI individuals; and explore the impact of these effects in their lives and well-being. Participants included eight SCI persons who were in the rehabilitation programme. A qualitative exploratory enquiry approach was utilised, by conducting semi-structured interviews. Data was analysed using a thematic analysis. Two main themes emerged: the psychological effects of SCI and impact of these effects on the well-being of the person.

The psychological effects faced by SCI persons were linked to diminished independence, intrapersonal changes, altered interpersonal relationships and emotional disturbance. The psychological effects seemed to be devastating to the optimal functioning of the participants. The impact of these effects was perceived as life changing. The impact of the psychological effects of SCI was linked to psychological adjustment. Psychological adjustment referred to the variety coping strategies adopted by participants and their perceptions post injury. The coping strategies included effective and ineffective coping strategies.

Most participants struggled as they attempted to make sense of the effect of SCI. Life post-injury was perceived with mixed emotions that of being hopeful and on other hand fearful; hopeful that their (participants) condition would change for the better, yet fearful as to what if it does not. As to deal with the devastating impact of SCI, participants engaged in a process of reconstructing the self, coming to terms with disability, and striving for maintaining a positive outlook post-SCI.

In conclusion, understanding how SCI persons view themselves post-injury is a prerequisite to the development of appropriate SCI psychological strategies to facilitate optimal functioning. Thus psychological adjustment remains critical in determining the rehabilitation process post injury.

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CHAPTER 1

1.1. INTRODUCTION

Physical traumas (such as spinal cord injury) are life-changing events that bring with it a whole range of issues ranging from the physical trauma, rehabilitation and care to the psychosocial experience of the individual. Therefore to facilitate a holistic approach in the rehabilitation process of individuals with spinal cord injury (SCI), the patient must be seen as a whole that is greater than the sum of its parts, not in isolation (Visser, 2006; Schlebusch, 1990). A patient's biological factors (disease and health), psychological factors (interactional patterns and pathology), as well as social factors (family, work, culture) are considered as all playing interdependent roles (Schlebusch, 2006) in assuring holistic well-being of the individual. This chapter seek to provide a rationale for the study. In addition, it will provide an overview of upcoming chapters.

1.2. RATIONALE FOR THE STUDY

Spinal cord injury (SCI) is a chronic condition that instigates disability and drains resources from the health sector (Blanes, Carmagnani, & Ferreira, 2009). Research (Trieschmann & Devivo et al, cited in Singh, Dhankar & Rohilla, 2008) indicates that through advances in medical sciences, SCI individuals treated and followed in specialised units can have an almost normal life expectancy, but the qualities of their lives are influenced by a variety of psychological, social and environmental conditions. The unexpected event of a sudden traumatic spinal cord injury becomes a defining moment which separates the individual's life into two parts -- before and after injury. While the medical aspect of such an injury could be addressed and maintained to some extent, the psychological impact is devastating and remains one of the indicators in post-injury adaptation or adjustment.

Research (Blanes et al, 2009; Singh et al, 2007; Lund, Nordlund, Bernspang & Lexel, 2006; Krause, Carter, Zhai, & Reed, 2009; Wu & Chan, 2007; Hammell, 2007) conclusively indicates that SCI has an immediate effect on individuals and their support systems with unanticipated changes and unforeseen challenges, encompassing the physical, psychological, economical and social aspects of life. Post-injury SCI individuals and their support systems are challenged to adapt.

According to the Department of Health's (DOH) report, there is no current database in South Africa to record the prevalence of spinal injury (DoH, 2010). However it is estimated that 2000 spinal injuries are treated per annum nationally in the public sector. Most of those treated are young, economically active individuals. Due to the nature of the disparities in the South African health system, most individuals with spinal cord injuries die of complications related to inadequate initial care and lack of psychological services that could assist both individuals and their families.

Furthermore, South Africa has no integrated comprehensive service for spinally injured persons or an integrated social system to help them. The facilities and services for SCI persons' management and rehabilitation vary from province to province. Rehabilitation services criteria are selective because of inadequate resources. Not all provinces have specialised SCI units, and staff shortages in some of the existing ones mean they do not have enough members required for the multidisciplinary team for SCI management. However, due to better management of SCI for those who reach the specialized units, life expectancies for persons with SCI continue to increase (Doh, 2010). Ironically, the provision of life entails financial and societal consequences. In South Africa most of these costs are borne by the State and becomes a financial burden for the nation. Some people may not be covered by

medical schemes, and even for those who are, it is not uncommon for them to be moved to a public institution after the acute phase of management.

Besides the financial consequences impacting on the individual, family and society, there are alterations that may occur in individuals' interpersonal activities and in their relationships with significant others.

Much research has been done on coping strategies, experience, learning and readjustment following a spinal cord injury (Glass, Jackson, Dutton, Charliffue & Orrit, 1997). Some studies examined patient factors, such as gender, race and age associated with psychosocial experiences while others investigate functional status and quality of life, as well as satisfaction with medical rehabilitation (Hampton & Marshal, 2000; Holicky & Charliffue, 1999, Gill, 1999).

Specific physical problems have been studied in South Africa such as sexuality (Walters 2001), urinary complications (Coyle 1996); and impact of pain (Colley & Faul 1997). Van Niekerk (1995) samples 22 youth with serious SCI and examined levels of distress and found them in a comparison group to be more distressed than their uninjured counterparts. Furthermore, McGill's (1998) study assessed the biopsychosocial outcome of patients to their traumatic SCI. Findings of this study suggested that the patients had a relatively poor outcomes when compared to those in Western studies (Dickson, Allan & O'Carrol, 2008; Hammell; 2007; Kennedy, Evans & Sandhu; 2009). These poorer outcomes were attributed to limited rehabilitation and fewer community resources.

Studies on people living with SCI and family responses to acute SCI found that their main concerns were the attitudes of the public toward their disability (Carpenter, 1994; Thomas & Mulhern, 1994). A study in Soweto, South Africa, Kock (1989) found from an occupational

point of view that environmental constraints block the potential of people living with SCI to lead independent and productive lives.

Since these studies were all using mainly quantitative approaches and were conducted in settings completely different from the Dr. George Mukhari Hospital area, the results cannot simply be applied to the researcher's situation. The behaviour of disabled people is greatly influenced by a number of factors, including but not limited too, their environments, their individual social and physical situations, their perceptions of themselves and their disability, and by wider aspects of policy and provision (Trieschmann, 1980).

In view of this knowledge, the researcher deems it necessary to conduct a study in Dr. George Mukhari Hospital, as the contexts of other studies are vastly different from where the participants of this study are drawn.

Furthermore, the vast majority of research into quality of life or psychological adjustment following SCI has adopted a quantitative approach, reflecting researchers' assumptions that quality can be measured quantitatively; that the determinants of quality of life following SCI can be reliably predicted by able-bodied researchers; and that the subjective experience of a life can be objectively and accurately discerned by another person (Hammell, 2007). Such an approach is without its limitations.

While quantitative research to the subject matter is acknowledged for its contribution to the understanding of the impact of SCI on individuals, its focus has been mostly narrow and limited within the predetermined variables to be measured, thus inevitably limiting the range of possible findings. However few studies have focused on the experiential context of SCI and more qualitative research is needed to improve the understanding of those aspects of life that are personally meaningful to SCI individuals (Carpenter, 1994). Furthermore,

rehabilitation of SCI persons concentrates on the physical while the psychological and emotional go untreated (Carpenter, 1994)

Therefore this study was aimed at investigate the subjective experiences of SCI persons exploring the psychological effects of SCI at Dr. George Mukhari. This study, further, hopes to contribute to the research knowledge that highlights the experiential context of SCI. In addition, it is a belief of the researcher that in-depth psychological understanding of persons with SCI is of fundamental importance and that the information gained through this research may contribute to improving the quality of life of SCI persons and further be used for SCI prevention strategies.

1.3. Aim of the study

The aim of the study was to explore the subjective experiences of SCI persons by exploring the psychological effects of SCI and the impact of these effects on their wellbeing at Dr George Mukhari Hospital. The aim sought to explore the following questions:

- What are the psychological effects experienced by SCI persons and
- What is the impact of these effects on the SCI persons' psychological wellbeing?

1.4. Purpose Statement

The purpose of this study was to explore the psychological effects faced by SCI persons and the impact of these effects on their lives and well-being. The study was conducted with SCI persons admitted at Dr George Mukhari Hospital at the Spinal Unit. The study adopted a qualitative, exploratory design in to the inquiry of the subject matter. Literature review highlighted a gap in the body of knowledge regarding SCI persons within the South African

context. Even more so, research done elsewhere has been largely quantitative orientated, thus this research study adopted a qualitative approach.

1.5. Brief overview of research design and methods

The study used a qualitative, exploratory research design. According to Collis & Hussey (2009) exploratory research seeks to gain greater insight about the subject area and is conducted into a research problem when there are very few or no earlier studies to which reference for information about the problem can be made. Few qualitative studies (Magenuka, 2006) on SCI in within the South African context have been conducted.

This study sought to fill this gap in literature by exploring the psychological effects faced by SCI persons and the impact of these effects on their lives and well-being. The following qualitative research methods have been adopted-

- One-on-one semi-structured interviews are interviews that are guided by predetermined questions but not limited to them. According to De Vos, Strydom, Fouche & Delpont (2011) semi-structured interviews are used to gain detailed understanding of a participant's belief about, or perceptions of a particular topic. Eight one-on-one interviews with SCI diagnosed persons were conducted and recorded for transcription and analysis.
- Field notes are notes to cover perceptions in the field (Flick, 2009). Flick (2009) asserts that it's important for a researcher to note impressions after ending the individual field contact. This method of data collection was adopted to supplement data gathered through interviews. The researcher documented the prior and after impressions of each interview conducted.

After data collection, transcription and verification of transcripts, the study adopted a thematic analysis to analyse its data. Thematic analysis in this study refers to the process of an insightful discovery of the underlying meanings of the experiences of SCI persons. Over and above the researcher, there was an inclusion of two Independent Researchers for data analysis process.

1.6. **Overview of the chapters**

The chapter outline of the study is as follows: **Chapter 2** provides an overview of the source literature used. It puts a reader into context with variables used in the study. This includes firstly the spinal cord and its anatomy, spinal cord injury (SCI), the rehabilitation process and the psychological impact of SCI. **Chapter 3** set out the methodology used to gather and interpret data and explains points such as the criteria for inclusion in the study. **Chapter 4** discusses the data analysis and findings of the study. Further highlight the significant themes found and integration of the findings of the study. In conclusion **Chapter 5** contains a brief summary of the study and lists recommendations.

CHAPTER 2

LITERATURE REVIEW

2.1. INTRODUCTION

Chapter 1 stated the background and significance of the study. The literature referred to in outlining the background and significance of the study was concerned mainly with the effect of SCI and the gap that exist regarding the angle of the study.

This chapter discusses the literature review conducted on Spinal cord injury and its psychological effect on the individual's well-being. In this section spinal cord injury from a medical point of view will be briefly discussed, however the central focus of this section will be on psychological challenges accompanying spinal cord injury.

2.2. Section A: The Spinal Cord and Spinal Cord Injury

2.2.1. Spinal Cord

SCI is a complex disability and poses challenges to rehabilitation health professionals. It affects not only the person's ability to walk but also virtually every bodily system with profound psychological and social implications (Wu & Chan, 2007). SCI and its effects are often either underestimated or exaggerated.

Prior highlighting the impact of living with spinal cord injury and its effect on the persons with SCI, it is important to have a concept of the spinal cord itself. Therefore this section will give a brief description of the spinal cord itself and the criterion for describing spinal cord injury.

The spinal cord and its terminal nerves (Cauda Equina) are contained within the bony vertebral column (Dickson, Allan & O'Carrol, 2008). This consists of C-cervical (neck comprising of spinal nerves called C1-8)), T-thoracic (chest comprising of spinal nerves called T1-12), L-lumbar (low back comprising of spinal nerves called L1-5), S-sacral (pelvis comprising of spinal nerves called S1-5) and 1 C-coccygeal (tail) areas (Dickson et. al).

The above mentioned spinal nerves provide common pathways for controlled movement, sensory input, and reflex responses. Specifically, C4 is concerned with the diaphragm; C5 with the deltoids and biceps; C6 with wrist extensors; C7 with triceps; and C8-T1 with the hand. T2-7 is concerned with the chest muscles, while T9-12 with abdominal muscles. L1-5 concerns the leg muscles. S2-5 is significant with bowel, bladder and sexual functioning (Burke & Murray, 1975; Capernter, 1991; Zejdlik, 1992). The spinal cord is the main connection between the brain and the rest of the body. All sensory and motor messages are mediated through the cord. It has a crucial function of conducting impulses for bodily movement. For movement to occur, the appropriate motor-neurons must be active and fire nerve impulses to the muscle.

2.2.2. Spinal Cord Injury

According to Dickson et. al (2008) an injury to the spinal cord can be described by its anatomical level but also the extent of the neurological loss below the lesion (termed 'complete' or incomplete'). In a complete lesion, there is no sensory or motor function and in incomplete, there is some (Dickson et. al, 2008). However this will be discussed further in this section. In addition, the causes, classification, physical effects of SCI and rehabilitation of SCI will be discussed next.

This section seeks to provide the reader with an understanding of the basic concepts of SCI. Thereafter it will provide a context on the psychological effects of SCI.

2.2.3. Causes of spinal cord injuries

Injury to the spinal cord has a variety of causes. The primary causes of SCI include motor vehicle, falls, acts of violence, and sporting accidents such as diving, football, skiing, and rugby (Parker, 2005). In the South Africa context, records at a local rehabilitation hospital indicated that 90% of SCI were as a result of traumatic injuries (Hart, 2000). Traumatic Motor vehicle accidents, violence and sports injuries emerged as the leading causes of traumatic SCI (Parker, 2005). Yarkony, Formal and Cawley (1997) refer to traumatic SCI as “a low incidence, high cost disability, requiring tremendous change in a person’s life style”. Spinal cord injuries can also be as a result of inflammatory or degenerative processes such as multiple sclerosis or tuberculosis of the spinal cord and cancer of the spine, which can occur in all ages, most commonly from young adult age up. Such alternative causes of spinal cord injuries are classified as non-traumatic since they are acquired or developmental.

It is important to note that the causes of traumatic SCI vary geographically. For instance violence is more prevalent in urban areas than in rural areas, and firearms are more frequently used in urban areas in committing crime.

2.2.4. Incidence, age and gender in spinal cord injuries

Research indicates that most new injuries globally occur to young people less than 30 years of age, with approximately 80% being men (Dickson et. al., 2008; Wu & Chan, 2007). Statistics show that 400 to 500 South Africans sustain SCI annually (QASA, 2010). Although

no specific data is available, the incidence of SCI in South Africa is rapidly escalating, particularly in young, male adults (QASA).

Approximately 70% of SCI are the result of trauma while the remainder are attributed to non-traumatic causes (Bromley, 1981).

The fact that patients are often young and male, any change to their physical functioning, sexuality and independence can be detrimental, particularly at a time when they should be in their prime and may have the added responsibility of supporting a wife and young family. According to Mukai and Costa (2008) the majority of spinal injured patients have led very active lives prior to their injury and the physical limitations experienced often trigger feelings of frustration, worthlessness and helplessness. Injury to the spinal cord can take place in various forms, resulting in a wide range of loss of bodily functions. The following part will discuss the classification of spinal cord injuries and its impact on bodily functions.

2.2.5. Classification of Spinal cord injuries

There are varying types of spinal cord injuries, but nearly all are severe. Destruction of a small portion of the cord produces profound motor and sensory changes below the level of the lesion. Spinal cord injuries are named according to the level of neurological injury and classified as either complete or incomplete.

A spinal lesion is regarded as complete when there is no sensory or motor function preserved in the sacral segments S4-S5. Transverse ischaemic necrosis occurs in this type of lesion (Hughes, 2003). The patient lacks sensory function, position sense and voluntary activity below the lesion. These patients have the worst prognosis for recovering neurological function (Burns & Ditumo, 2001). This is due to the fact that all neurological function is lost

below the level of the lesion. Those injuries occurring at the cervical level of the vertebral column (neck) will result in quadriplegia (if complete). Injuries occurring in the thoracic, lumbar, or sacral region of the vertebral column (trunk or low back) will result in paraplegia (if complete) (Dickson et. al., 2008).

An incomplete SCI means that parts of the spinal cord at the level of the lesion are intact, some sensory, proprioceptive (position sense) or motor impulses can still travel up and down the cord. How much sensory/motor function is lost depends on the size and location of the spinal cord lesion. Injuries at the cervical level of the vertebral column (neck) are called quadriparesis (if incomplete). Those injuries occurring in the thoracic, lumbar or sacral regions (trunk or low back) are called paraparesis (if incomplete). A combination and variation of symptoms associated mostly with incomplete spinal injuries, due to damage to different areas of the spinal cord, are grouped as the clinical syndrome of the SCIs. The three most prevalent syndromes are central cord, anterior cord, and Brown-Sequard (Burke & Murray, 1975).

It is important to note that the spinal cord does not have to be severed for irreversible damage to occur. In fact, actual anatomical trans-section of the cord is rare (Meyer, 1989). This is an important point to remember when educating people about their injuries. Often patients are told that their spinal cord was “bruised” instead of severed. They then interpret this fact to mean that they will recover from their paralysis. However, trauma that results in “bruising” or haemorrhaging in the spinal cord can (and often does) cause neurological damage that is just as complete as when the cord is severed.

2.2.6. Physical effects of spinal cord injuries

The type of disability associated with SCI varies greatly, depending on the type and severity of the injury, the level of the cord at which injury occurs, and the nerve fibre pathways that are damaged. The more specific effects of spinal cord injury are determined by the type of nerve that has been damaged. Damage to motor nerves results in paralysis, or loss of control of movement. Damage to somatosensory nerves results in loss of sensation and perception; one can no longer feel touch, pain, temperature, or be able to tell without looking where in space the nerve-damaged body part is positioned (Dickson et al., 2008). This highlights the profound effect spinal cord injuries may have. Paralysis of voluntary musculature can lead to reduced mobility as well as impairment of vocational, and self-care abilities. A host of debilitating and potentially life-threatening physical complications may result. There are primary and secondary physical effects of SCI.

Primary damage is defined as the immediate effects of an injury to the spinal cord. Primary areas of functioning affected by the occurrence of a SCI may include, but not limited to, loss of sensation, impaired mobility, bladder and bowel control, pain or sensitivity to stimuli, muscle spasms, and sexual function. Pain is the most sequelae following a spinal injury. Sixty percent of patients with post-traumatic para-tetraplegia suffer from severe pain (Sjound 2002)

SCI persons are also prone to develop secondary effects. Secondary effects happen as a result of the primary effects in that they develop due to problems arising from primary one. Paralysis or anesthesia, the primary result of SCI, whether partial or complete may lead to the development of further complications in other areas of the body (Donovan, 1981). These may occur during the acute and chronic phase. These secondary effects may include medical problems such as bladder and lung infections and bedsores. Most problems include poorly localized abdominal pain, difficulty with bowel evacuation, hemorrhoids, and abdomen

distension. These problems become more prevalent as time after injury increases (Bergman, Yarkony, & Stiens, 1997).

2.3. SUMMARY

The spinal cord is enclosed and protected by the bony structure of the spinal column. It is subdivided into cervical, thoracic, lumbar, and coccyx. Each division carries out different functions. Amongst these are the control of reflexes and control of bodily movements. Because of spinal cord plays such important functions, damage to it is bound to produce serious consequences. According to Smeltzer & Bare (2004) the most frequent sites of SCI are the lower cervical region (C4-7 and T1) and the area of thoraco-lumbar junction (T12, L1). Damage to the cord in the cervical region (C1-T1 level) will result in quadriplegia or tetraplegia, that is, paralysis from the neck down. Spinal cord injuries (from T2-L1) lead to paraplegia, namely paralysis of the lower body (Smeltzer & Bare).

The impact of SCI on an individual is devastating and it could have a negative effect, on psychological well-being of the individual, as will be shown in the following chapters.

2.4. Section B: The Psychological Impact of Spinal Cord Injury

2.4.1. Introduction

The psychological reaction to spinal cord injury has in the past been conceptualised according to the stages of model of adjustments, however it should be noted that recent research have raised an argument that each individual who has sustained a SCI must be viewed individually, by considering a context in which the individual is in (Dickson et. al., 2008; Flambouras, 2002; Trieschman, 1990). For this reason, the section on psychological effect of spinal cord is discussed on a broad frame of reference by highlight common reaction and psychological changes that may result from a spinal cord injury. But first, research on psychological effect from SCI will be discussed next, and this part seeks to highlight the studies conducted highlighting the psychological effect of SCI. Furthermore, the next part seeks to highlight the gap in the current body of knowledge relation to SCI person within the South African context.

2.4.2. Research on psychological effect of SCI

The detection of psychological problems in individuals following SCI is vital as research suggests that those individuals who experience high levels of anxiety and depression benefit significantly from therapies such as cognitive behaviour therapy (North, 1999).

Factors investigated have included demographic characteristic (e.g. age, gender, marital status), injury-related variables (e.g. level, lesion, age of onset, time since onset, sexuality), personal values and attitudes (e.g. health care orientation, acceptance of disability), vocational and avocational activities (e.g. employment, leisure activity, social roles), intra-personal strengths (e.g. locus of control, coping strategies), and environment resources (e.g.

family relationships, social support) (Hammell, 2007; Parker, 2005; Wu & Chan, 2007). These studies highlight a number of factors, from the above, which influence a person's ability to adjust. These include emotional maturity, degree of family or social support, education level, intellectual development, job, security, financial status, access to the environment, perceived locus of control, level of self-esteem and participation in social and leisure activities.

Research further indicates that persons with SCI face many psychosocial and vocational adjustment problems including depression and anxiety, alcohol and drug abuse, unemployment, and lack of social support (Wu & Chan, 2007; Singh, Dhankar & Rohilla, 2008; Miglirioni, Elfstrom & Tonge, 2008). These problems have each been found in various research studies as relating to a poorer quality of life.

Research has shown that patients with spinal cord injury tend to have reduced self-esteem which can, in turn, lead to lower self-worth and less motivation (Fichtenbaum & Kirshblum as cited in Dickson et. al., 2008). Persistent low self-esteem is detrimental and has the potential to lead to long term depression and even suicide (Dickson et al, 2008). Indeed, suicide has been cited as increasing rate of mortality in spinal injured patients under the age of 55 years (Charlifue & Gerhart, 1991; Dickson et al, 2008)

Martz, Livneh, Priebe, Wuermsler and Ottomanelli (2005 as cited in Wu & Chan, 2007) suggests that adapting to SCI may “involve greater psychological efforts that those mobilised after traumatic events where physical functioning returns to normal”. The difficulty in adjusting to SCI is evidenced in alarming statistics generated by various studies (Hammell, 2007).

SCI requires an immense adjustment to live with, affecting not only the injured individuals but also their support systems (Parker, 2005). Intervention to rehabilitate the affected individual comprises the implementation of different skills to reach maximum functionality, optimally re-integrate clients into their community and adjust emotionally to the effects of the trauma in an altered body (Parker, 2005). These goals cannot be met unless the individual is emotionally stable.

Social and emotional adjustment to SCI can vary considerably from person to person. Some could make satisfactory adjustments, while others remain chronically distressed (Parker, 2005).

As shown above, many studies have contributed in the understanding of individuals with SCI and the need for relevant research documenting their experiences as to design better prevention and intervention strategies. Although many of the studies are not specifically about SCI individuals in South Africa, there is no reason to believe that they apply less to individuals with SIC in South Africa than individuals elsewhere in the world, in spite of different cultures and socio-economic conditions.

Furthermore, whilst the research literature looking at the psychological effects of spinal cord injury continues to grow and develop, there is still a long way to go before we are able to describe the global psychosocial effects of this type of injury on the patient, their family and the staff who care for them in their rehabilitation period and in their life afterwards.

2.4.3. Psychological Effects of SCI

SCI is an injury causing disability, a factor that has different implications for each individual. Some could make satisfactory adjustments, while others remain chronically distressed

(Nosek, Fuhre & Potter, 1995). However physical impairments are barely the tip of the iceberg! The individual with the disability, his/her support systems and lifestyle are affected by the disability. It is uncommon to admit to the fact that disability, whether one's own or that of another can evoke emotion and anxiety. This is often attributed to the fact that disability arouses a sense of vulnerability and dependency (Watermeyer, 2001). Hammel (1995) states that individuals who sustain spinal cord injuries experience the trauma of one of the most devastating of all non-fatal injuries. The goals for these individuals are not of medical recovery, but of adaptation to the circumstances that have been drastically changed.

The SCI affects the psychological well-being of the patients. This is because SCIs usually demand changes in almost every aspect of an individual's life. Personal relationships; the physical structure of the home, employment, education; social and leisure pursuits; and financial position are all influence by the injury. Faced with changes in physique; physical functioning, functional capacities; accustomed activities, financial status, relationships; and plans for the future, these individuals' previous concepts of themselves has shifted. Personal identity is thus affected (Magenuka, 2006)

The above further emphasize that spinal cord injury is a devastating disability which has long term negative consequences to one's life (Magenuka, 2006). The injury occurs suddenly and often without warning, leaving the injured person and family with dramatically altered life situation (Magenuka, 2006).

The literature contains much theoretical discussion about the various ways in which individuals react to the stress of SCI (Bracken & Shephard, 1980; Dunn, 1969; Gunther, 1968; Hammel, 1992; Kerr & Thompson, 1972; Sullivan, 1990; Tucker, 1987; Rolland, 1999; Weller & Miller, 1977). The progression of reaction of the spinal cord injured person has been discussed by many (Bracken & Shephard, 1980; Dunn, 1969; Gunther, 1968; Hammel,

1992; Kerr & Thompson, 1972; Sullivan, 1990; Tucker, 1987; Rolland, 1999; Weller & Miller, 1977) using similar terminologies and frequently noting the resemblance to the process reported in patients approaching death (Kubler-Ross, 1979). However it should be noted according to Flambouras (2002) that there is nothing predictable about the psychological sequelae of SCI. The response is individual and is mediated by both pre-morbid individual characteristics and external factors (Flambouras). Triechman (1990) further emphasize that people living with SCI resent theories (adjustment theories) as a form of victimization by professionals “who write articles about the reactions to spinal cord injury which are based more on theory than fact”.

While this section takes into consideration the existing theoretical literature, however it seeks to highlight various psychological effect of SCI without any sequence to them. Further it acknowledges that within the following list of common psychological effect of SCI, individuals respond differently. Therefore it must be remembered that the population of people with spinal cord injury is heterogeneous in terms of age, level of injury, social class and education and the immediate reactions may be as varied as the pre-injury interactional styles.

According to the various literature reviewed there is a mentioning of one or more of the following common emotional reactions. Most of these emotional reactions have been the focus of adjustment theories (e.g. Kerr and Thompson’s adjustment process, Kubler-Ross’s stages of adjustment, Weller and Miller’s adjustment stages to name a few), which however are not the focus of this section. Spinal cord injury may produce a variety of emotional reactions, including but not limited too: sadness & crying, despair & guilt, fear of losing control, disbelief & panic, helplessness & inadequacy, resentment & bargaining, loss of interests, fatigue & lethargy, loneliness & isolation (discussed below), and withdrawal.

2.4.4. Changes associated with SCI

There are a variety of changes that are associated with a spinal cord injury, thus adjustment to such an event is immensely complex. These changes that accompany SCI may include, but not limited too:

2.4.4.1. Loss of independence/ Inability to control basic bodily functions/ Changes in physical health and functional ability/decline in personal hygiene

Acquired paralysis can generate feelings of loss (Weller & Miller, 1997). This loss is with regard to mobility, control, pleasure sensation, identity, independence, spontaneity and the threat of loss of life at the time of injury (Smith & Sparkes, 2008). A study conducted by Dickson et al., (2008) focusing on the experience of living with a spinal cord injury, found that participants, through individual in-depth interviews, reported an ongoing sense loss, characterised by largely diminishing sense of personal control. This loss of personal control manifested itself in incontinence, emotion and loss movement. Furthermore the study found that that helplessness (discussed below) and embarrassment were common responses. While a loss of independence was associated with inability to control bodily functions, but also with a loss of spontaneity (Dickson et al., 2008).

Furthermore, in relation to physical health and bodily functions, men who have sustained an injury to the spinal cord may experience inability to achieve an erection and reduced fertility, inability to feel when the bowel is full and to empty it voluntarily, inability to sense pressure, heat or cold in parts of the body below the level of the injury (Kendall, Fronke Booth, Miller & Geraghty, 2003). All these happenings further impacts on the psychological well-being of the individual.

2.4.4.2. Changes to role / lifestyle

Spinal cord injury imposes multiple stresses not just for the patient but also for their family. The impact is far reaching and family relationships and roles may be radically changed. Chronic health problems, feelings of frustration, isolation, guilt and even resentment have been reported in family members of individuals with spinal cord injury (Kester, Rothblum, Lobato, Milhous & Spouse, 1998). It has been reported that it is not only the perception of physical disability and distress in the patient that creates emotional difficulties for their families but it is wider ranging factors such as severe financial hardship or the prospect of financial difficulties which are likely to occur as employment is adversely affected (Alfano, Neilson & Fink, 1994).

The above difficulties may lead to role redefinition, and also to lifestyle changes. In example if a father suffered from SCI he will still maintain the role of father and husband, yet the typical roles that he usually fulfilled needs to change such as taking out the garbage or mowing the lawn, and being a provider for the family (Trieschmann, 1992).

2.4.4.3. Uncertainty regarding the future

Individuals with SCI may face uncertainty and unanswered questions about their future. Such questions may include what the course of their health will be and ruminating about the quality of their lives with regard to relationships, intimacy, presentation of self. Spinal cord injury may impose marked changes on aspects of sexual relationships and sexuality. Individuals (especially those who were yet to start a family) may have concerns about whether it will be possible to have children. As the time progresses, feelings of fear

sometimes can become intense in such a way that they have an impact on the person's self-esteem.

2.4.4.4. Sense of helplessness

Helplessness has been described by authors such as Seligman (1975) as a psychological state that frequently results when events are uncontrollable. Seligman (1975) further describes that an event is uncontrollable when one cannot do anything about it, when nothing one does matters. Seligman (1975) sees helplessness as more severe than depression since it totally immobilizes the sufferer. Physical disease can elicit feelings of helplessness because often a person finds his own responses ineffective and is thrown upon the care of others (Seligman, 1975). In the light of SCI diagnosed person, feelings of helplessness result from loss of control in areas that were previously well mastered. Loss of control is experienced in specific areas, such as, loss of independence, loss of ambitions, physical attractiveness, sexual relationships, status and respect in the community (Van Dyk, 2005). SCI persons can as a result of the extreme feelings of helplessness feel that no matter what she or he can do, his or her situation can never be better. At this stage, a SCI diagnosed person may be more likely to try ineffective strategies such as abuse of substances as a way of avoiding feelings of helplessness

2.4.4.5. Disorganisation and Confusion

The psychological consequences of spinal cord injury not only include difficulties with mood but may also extend to an impact on cognitive function which in turn may have an adverse effect on an individual's ability to cope successfully with rehabilitation. Individuals who sustained a SCI may presents with disorganization and confusion in thought-patterns. The degree of such an impact may vary from each individual depending on the extent of the injury, its location and previous cognitive history. Psychological research and intervention

must therefore be aimed in the broadest sense at an individual helping them to adjust in a variety of different areas of their life.

In addition to the above, other aspect of life that may be seen affected after sustaining the SCI include: separation from family and friends (discussed below), changes in body image (discussed below), lack of privacy,

2.4.5. Factors affecting psychological adjustment

Many individuals with severe disability do not consider they will ever adjust, as adjustment implies acceptance, a situation they feel they will never achieve. Rather they tend to use the word “tolerate” getting on with their lives despite their disability. Trieschman (1980) contends that psychological adjustment, rather than intellectual capacity or completeness of injury, is the critical factor in determining the rehabilitation process. There are other several possible emotional and psychological reactions and processes that the person with SCI may experience. These may include, but not limited too, pain, medication, isolation, boredom etc., and are discussed next.

2.4.9.1. Pain

Pain continues to be a problem for individuals following SCI (Ravenscroft, Ahmed & Burnside, 1999; Yeziarski, 1996) and an incidence of between 33% to 94 % has been reported in a number of studies (Basel, 1990 & Levi, Nash & Seiger 1995). Ongoing pain has been shown to be associated with depression (Graig, Hancock & Dickson, 1994). It has been found that a relationship between pain and depression develops over time but changes in pain are more likely to have an effect on depression than the converse (Cairns, Adkins, & Scott, 1996). In a study of 46 patients admitted with traumatic spinal cord injury to a rehabilitation hospital within 2 years of trauma, 46% experienced pain of a moderate to severe intensity and 70% of those with significant pain experienced symptoms of emotional distress. Those

individuals who were experiencing pain, not surprisingly, reported a reduced quality of life compared to those without pain (Anke, Stenehjem, & Stanghelle, 1995).

This data suggests that pain is an important and significant factor in assessing the psychological effects of spinal cord injury and that it makes a major contribution to quality of life. The data also suggests that psychological interventions designed to control pain such as relaxation, distraction or goal setting and pacing techniques should be an important component of the rehabilitation process.

2.4.9.2. Medication

Following spinal cord injury patients frequently take a variety of medications to help with problems such as pain or spasm. The effects of analgesics on mood and cognitive function have been well documented (Skevington, 1995; Sarafino, 1998). Spasm, however, is frequently treated with the drug baclofen, which is usually well tolerated but some adverse side effects such as sedation, confusion and fatigue, have been reported (Jamous, Kennedy, & Grey, 1994; Sommer & Petrides, 1992).

2.4.9.3. Isolation

Periods of isolation have been found to lead to disturbances of thought and cognition and may result in strange perceptual changes (Lilly, 1994). Other studies have found that patients in intensive care units frequently experience fluctuating states of consciousness, fatigue, distraction, confusion and disorientation, agitation and depression (Kennedy & Hamilton, 1997). A period of isolation, therefore, not only interrupts the progress of rehabilitation but may lead to psychological difficulties.

2.4.9.4. Boredom

Period of boredom have been found to have an impact in the psychological adjustment of the individuals who sustained a SCI. To some SCI persons, due to the nature of their injury they may be confined in a bed or other forms of physical movement restrictions and such may lead to feelings of boredom, worthless and less of a human. Such feelings may maintain the isolation and self-pity perceptions.

2.4.9.5. Medical complications and body image

Following spinal cord injury many patients develop pressure sores which interrupt their rehabilitation and can cause them additional problems (Gosnell, 1973) The development of pressure sores has been found not only to be related to physical factors but is also related to psychosocial factors as well, such as satisfaction with different areas of life and self-concept (Anderson & Andberg, 1979) It has been found that psychosocial variables predict not only the presence or absence of pressure sores but also the extent of them and their persistence (Anderson & Andberg, 1979) The implications for the recognition of psychological problems is therefore important in this particular area. Pressure sores themselves may also have an adverse effect on psychosocial aspects of the individual. Studies have found that they form an important predictor of life satisfaction and general quality of life (Post, De Witte, Asbeck, Van Dijk & Schrijvers, 1998).

Spinal cord injury by necessity frequently results in marked changes in body image for the individual (Stensman, 1989). For many people this change in body image may cause significant psychological trauma and they may require psychological intervention in order to help them reintegrate the loss of their former body image and its effects into their new state (French & Philips, 1991). Other elements of the spinal cord injury experience such as the use

of a halo brace may also further distort and disrupt body image and self-concept, requiring significant psychological interventions in order to help the individual readjust.

2.4.9.6. Cognitive problems / Traumatic Brain Injury

Recent research in the field of SCI had highlighted the presence of cognitive deficits in this particular group of individuals. Studies suggest that approximately 40% to 50% of patients have varying degrees and patterns of cognitive impairment (David, Roth & Richards, 1992). These deficits include difficulties with attention, concentration, memory, problem solving, abstract reasoning, new learning and higher level cognitive skills as well as changes in personality and emotional state (Roth, Davidoff & Thomas, 1989; Strubreither, Hackbusch, Hermann & Stahr, 1997) The factors which contribute to these deficits are varied. Some patients may have sustained a traumatic brain injury at the time of their accident and these may be of varying severity. Others may have secondary 'trauma' as a result of factors such as cerebral oedema, hypoxia and anoxia. Other patients may have a history of previous alcohol or substance abuse which in turn may have led to impairment in cognitive function. Recent studies have also reported cerebral effects in individuals subjected to whiplash injuries alone and clearly many SCI patients have sustained this type of injury during their accident (Strubreither et al, 1997)

2.4.9.7. Stigma/Discrimination/Marginalization

Northway (1997) describes marginalization as the "process through which persons who are seen as relatively different from the norm, are peripheralised; a situation in which groups of people are excluded from useful participation in society". According to Dickson et al. (2008) stigma and societal attitudes towards people with disability (discrimination in terms of

employment, promotion, and dating) and loss experienced in a more social context can result in the individual's inability to maintain their place in the social and economic hierarchy.

According to Scullion (2000) in belabouring the above statement, states that besides the financial consequences impacting on the individual, family, and society, there are alterations that may occur in individual's interaction activities and in their relationships with significant others. Such changes may be attributed to societal devaluation of disabled persons, the daily struggle to accomplish activities of daily living, stress of significant others relationships/role interactions and the loss of satisfaction from vocational and leisure activities which can no longer be accomplished.

While the situation in the South African context has clearly evolved with regard to stigmatisation and discrimination of individuals with disability (including SCI persons) (National Rehabilitation Policy, INDS, 1997), from casual observation, it seems evident that there are still societal attitudes towards people with disability. A South African study by Magenuka (2006) probing into the subjective experience of SCI persons living in the rural areas, found that the experiences of being undermined, thus preventing them from their societal roles, evoked feelings of helplessness and frustration, and did not promote the participants' view of themselves positively. The participants of the study experienced being seen and treated as objects. This had major impact on the psychological well-being from how participants view themselves.

Furthermore, in a case study by Smith & Sparkes (2008), a participant (who sustained a spinal cord injury through a rugby sport) reveals that after the accident "most people he knew...soon stopped to visiting" him at the spinal cord injury rehabilitation centre.

Furthermore, the participant shares that since the injury he has no friends, no one to socialise or speak with. This experience is what Nelson (2001) terms deprivation of opportunity.

2.4.9.8. Family/ Friends/Social supports

Social support is frequently described as having an important positive effect on psychological distress following stressful life events such as spinal cord injury. It is a concept which is defined in a number of different ways; however most research distinguishes between the structural aspects of social support such as the numbers of people available to provide support and the functional aspects of social support such as the perceptions of an individual in terms of how supported they feel by other people (Cairns, Adkins & Scott, 1996; North 1999).

Glass (1994) highlights the importance of social support offered by families soon after the accident and subsequent bed confinement, as the individual experiences restricted vision, so as to counter the effect of experiencing perceptual deprivation, which increases likelihood of hallucinations. Reassurance of worth and social integration support are associated with lower levels of depression (Elliot, Herrick, Witty, Godshall & Spruel, 1992). McColl & Skinner (1995) state that emotional support reduces anxiety through empathic interaction, changes in attitude toward disability, provides emotional release and thus buffer against stress and perceived threats.

Furthermore according to Flambouras (2002) pre-injury personality characteristics such as self- concept, self-efficacy, locus of control and coping styles are considered to be as crucial in determining adjustment to SCI as the external factors of social support, socio-economic status and financial status. The level and extent of injury or functional impairment have not been found to predict adaptation to disability (Flambouras). People with tetraplegia have been

found to be just as capable as those with paraplegia of achieving healthy adjustment (Flambouras).

2.4.10. Psychological Complications

The above mentioned psychological effects may elicit further psychological complications that could lead to a psychiatric diagnosis of the person. While it is not a focus of this paper to discuss the psychiatric implication of SCI, however in the following part the paper seeks to highlight the psychiatric aspect that is deemed relevant in belabouring the psychological impact of SCI. According to Flambouras (2002) a psychiatric diagnosis can be made in about 40% of people with a recent-onset spinal cord injury. The most common psychiatric diagnoses are: substance abuse disorders, conditions attributable to delirium or brain injury, adjustment disorders and depressive disorders.

2.4.10.1. Post-Traumatic Stress Disorder (PTSD)

Post-Traumatic Stress Reaction is frequent in persons following a major life stress. Symptoms fall into physical, cognitive and emotional domains. If not appropriately treated, the symptoms may develop into Post-Traumatic Stress Disorder.

PTSD has been reported following a range of traumatic and life threatening events such as road traffic accidents, medical procedures, assault and disaster to name but a few (Mayou, Bryant, Duthie, 1993; Shalev, Schreiber, Galai, 1993; Duddle, 1991). Given that a significant number of spinal cord injuries are sustained in trauma situations such as road traffic accidents, it may be hypothesised that PTSD following spinal cord injury would be a significant problem. Some authors suggest that symptoms of PTSD are often higher among injured survivors of stressful events than non-injured survivors (Schreiber & Galai-Gat, 1993) PTSD in the field of SCI however has been largely not researched. Small studies do suggest

that it is a significant problem in this population (Mayou, Bryant, Duthie, 1993; Shalev, Schreiber, Galai, 1993; Duddle, 1991).

2.4.10.2. Depression versus grieving reaction

According to Flambouras (2002) there is frequent mention of individuals suffering from “depression” in rehabilitation units. This may have been used loosely to describe people “having a bad day” or to describe Major Depression. Major depression is not a normal and necessary or essential part of the process of adjustment to SCI, but indicates that the person is distressed and not coping (Flambouras, 2002). The presence of depression is not related to level or degree of injury, contrary to popular opinion (Flambouras). The grieving reaction may appear similar to depression, but unlike depression will dissipate over time as the individual learns to live with his or her disability. Mourning or grieving may also present with physical complaints, preoccupation with a former self- image, feelings of guilt, feelings of anger and irritability, and behavioural changes (Flambouras). The important distinction between mourning and depression is that people who are experiencing a grief reaction will be focused on the lost body part and the accompanying secondary emotional reactions (Flambouras). For example, the individual with SCI would bemoan the altered quality of life without independence and limbs. In reactive depression, the focus is self-critical, with feelings of worthlessness, hopelessness, helplessness and withdrawal from others (Flambouras).

2.4.11. Predictors of Psychological Vulnerability

2.4.11.1. Suicide

Suicide is the extreme behavioural response to SCI. Death from suicide has been found to approximately five times as often in the SCI population as in the general population

(Flambouras, 2002). There has been an alarming increase in suicides amongst this group over the last 20 years. It is most likely to occur within 5-6 years post injury and is responsible for 6-10% of all SCI deaths (Flambouras). Passive suicide is thought to account for additional deaths related to self-neglect, leading to recurrent pressure areas, urinary tract infections and pneumonia (Flambouras).

2.4.11.2. Substance Abuse and SCI

According to Delambo, Chandras, Homa, and Chrandras (2010) substance abuse disorders occur more often in persons with disabilities than in the general population. This includes problems related to abuse of prescription medications as well as illicit drugs. In the general population, alcoholism affects 10% of individuals and 5% are addicted to drugs. Persons with any disability experience substance abuse at a rate 2 to 4 times that of the general population. While data indicates that rates of substance abuse vary widely across disabilities, spinal cord and traumatic brain injury populations have been found to have substantially higher rates of substance abuse disorders than the general population (Delambo et al., 2010). Substance abuse prevalence rates approach or exceed 50% for persons with traumatic brain injuries, spinal cord injuries, or mental illness (Delambo et al.). A study by Elliot, Kurylo, Chen, & Hicke, (2002) found that alcohol abuse was not associated with depression or disability acceptance. However, severe alcohol abuse history was associated with pressure sores over the 3 years since onset of SCI (Elliot et al., 2002). This means persons with a prior history of severe alcohol abuse may be at increased risk for pressure sore occurrence during the first years of SCI (Elliot et al., 2002).

Individuals with SCI who abuse substances are more likely to experience anger and anxiety, reduced quality of life, psychosocial distress, social isolation and unemployment, pressure

sores (Delambo, Chandras, Homa, and Chrandras 2010). This is even complicated for persons with substance dependency issues, having a SCI significantly decrease the probability of successful substance abuse recovery (Delambo et al.)

2.4.12. Rehabilitation of SCI persons

As this study focuses on the spinal cord injured person and their subjective experience on its impact, a brief look on the rehabilitation of SCI will be discuss next. Rehabilitation is aimed at facilitating the process of adjustment by health professional and others who are part of the individual's life. According to Ronald (1999), adjustment entails the long haul of day-to-day living with a SCI, and coming to terms with losses and limitations.

When people sustain SCI they need prolonged meticulous care that starts with hospitalisation and extends long after discharge. The predominant approach that underpins health care for SCI persons is rehabilitation. The SCI patient may spend at least four to twelve months in hospital, depending on

- the level of injury, because the higher the injury, the longer the stay
- an uneventful recovery; that is, the absence of complications
- the home facilities, to which the patient is sent

The patients are initially dependent on others and for those with high lesions this dependency may continue, and many may have disappointing levels of neurological recovery (Formal, Cawley & Stiens, 1997). In the South African context, the average stay with initial hospitalisation is approximately four months for paraplegic and six months for quadriplegic (DOH, 2010).

Historically SCI condition was viewed linearly. For instance, Hampton (2000) describes SCI as a “severe traumatic disability that occurs suddenly, affecting both sensory and motor function”. This echoes the traditional medical model which focuses purely on physical (sensory and motor) function. For years literature neglected to include aspects of the individual’s functioning other than sensory and motor functions. The impairment caused by SCI produces a unique experience in disablement for each individual. To understand this experience, one needs to consider the emotional and social factors that compliment motor and sensory aspects. This allows health professionals to deal with person in totality, constantly bearing in mind that different components are affected in varying degrees.

Over the years the definition of SCI has evolved thus prompting for new rehabilitation trends that view SCI persons holistically. For this reason, the aim of current rehabilitation trends/approaches focused on recovery from injury, restoration of independence by way of physiotherapy and exercise programs to maintain suppleness of limbs, preventing contractures and pressure sores, improving muscle strengths especially when there is recovery in motor function. Furthermore, teaching patients transfer to and from wheelchairs (Occupational therapy), psychotherapy and improving body image (psychological intervention), teaching family/caregiver to cope and restoring dignity which is the patients constitutional right.

The ultimate aim is to turn these patients home—able to care for themselves and to avoid morbidity (DOH, 2010). While this remains the main aim of rehabilitation, however the reality is most depressing, especially in the developing countries. The rehabilitation phase is hampered by the shortage of trained manpower to cope with the increased demand of rehabilitation (DOH, 2010). One of the most important changes in the care of SCI persons

has been the shift from hospital to home. Concomitant with this change has been a sizeable amount of time and money the family has to spend on their SCI person/family member.

The financial constraints usually have bearing on the SCI and the family. In order to be able to alleviate some of the problems that the families may be faced with, the SCI patient must acquire as much independence as possible before leaving hospital. Furthermore, after discharge access to health care service depends on the patients' proximity to a hospital with such services, or their ability to meet transport and treatment costs. In most rural areas of the referral hospitals in South Africa, there are no rehabilitation centres working with SCI persons.

Nevertheless, the above view has led to the understanding that SCI disability in itself is influence not only by impairment but also by contextual factors thus involving not only the person with the disability but also the context in which he/she find themselves. Apart from physical barriers in the environment such as architectural obstacles, the attitude of others and that of SCI persons has contribution to the rehabilitation process and outcome.

While there are theories on adjustment after a SCI, however the impact of SCI could never be generalised, but remain unique for each individual case. It is this belief that motivates the relevancy of such a study. This highlights a crucial need in understanding the known and unknown psychological challenges that may hinder progress of rehabilitation after sustaining a SCI.

Stiens, Bergman, Formal (1997) associate certain individual characteristics with successful adaptation. Favourable predictors include young age, female, internal locus of control, developed social skills, employment, access to transportation, financial security, assertive, and problem-solving ability. Specifically, access to sufficient resources encourages the

development of appropriate coping efforts, resulting in greater psychological well-being. Presumably, individuals with higher levels of resources will progress through adjustment cycles faster with better outcomes and fewer recurrent problems (Kendall & Buys, 1998).

2.4.13. Summary and Conclusion

This chapter discussed the literature reviewed undertaken for the study. The literature reviewed was divided into two main components, namely the spinal cord and spinal cord injury, and psychological impact of SCI. The first component sought to provide the background information about spinal cord and what happens when it has been injured. The second component provided an account of the psychological impact of SCI and lastly highlighted that psychological adjustment is critical in determining the rehabilitation process.

Due to its unexpectedness and severity, rehabilitation is intense and aimed at reintegrating the individual who sustained a SCI to community and be an optimal functioning individual. High levels of psychological well-being are associated with adequate social support, perceived high levels of control, high income and more education.

Chapter 3 presents research design and methodology of the study.

CHAPTER 3

RESEARCH DESIGN AND METHODOLOGY

3.1. INTRODUCTION

The study was conducted from a qualitative approach. In this chapter the aim of the study, objectives of the study, research design and research process is presented.

3.2. AIM OF THE STUDY

The aim of the study was to explore the subjective experiences of SCI persons by exploring the psychological effects of SCI and the impact of these effects on their wellbeing at Dr George Mukhari Hospital.

3.3. OBJECTIVES OF THE STUDY

In order to achieve the main aim of the study, the objectives of the study were

- To explore the psychological effects faced by SCI persons; and
- To explore the impact of these effects on their lives and well-being.

3.4. RESEARCH DESIGN

The concept research design refers to is the structure designed to answer the research question (De Vos, Strydom, Fouche, & Delpont, 2011). It includes the planning of the research procedure as well as the procedure for data collection and analysis.

The two most common research designs used in research are quantitative and qualitative research, however mixed methods design is a third newly emerged research design in the last

ten years. Quantitative and mixed methods research designs are beyond the scope of this paper thus will not be described further.

Since the aim of the current study was to explore the subjective experiences of persons who have sustained a spinal cord injury, the study adopted a qualitative, exploratory design. According to De Vos et al. (2011), an exploratory research design seeks to gain insight into a situation, phenomenon, community or individual. Thus the rationale for this type of methodology was to get a broader insight into the experiences of spinal cord injured persons. Mouton (2001, as cited in De Vos et al., 2011) asserts that the answer to a “what” question would constitute an exploratory study. In line with this, this study seeks to explore what were the psychological effects of SCI and what was the impact of these effects on participants’ psychological wellbeing.

In the following sections, the details of this research design (see diagram 3.1.) are presented.

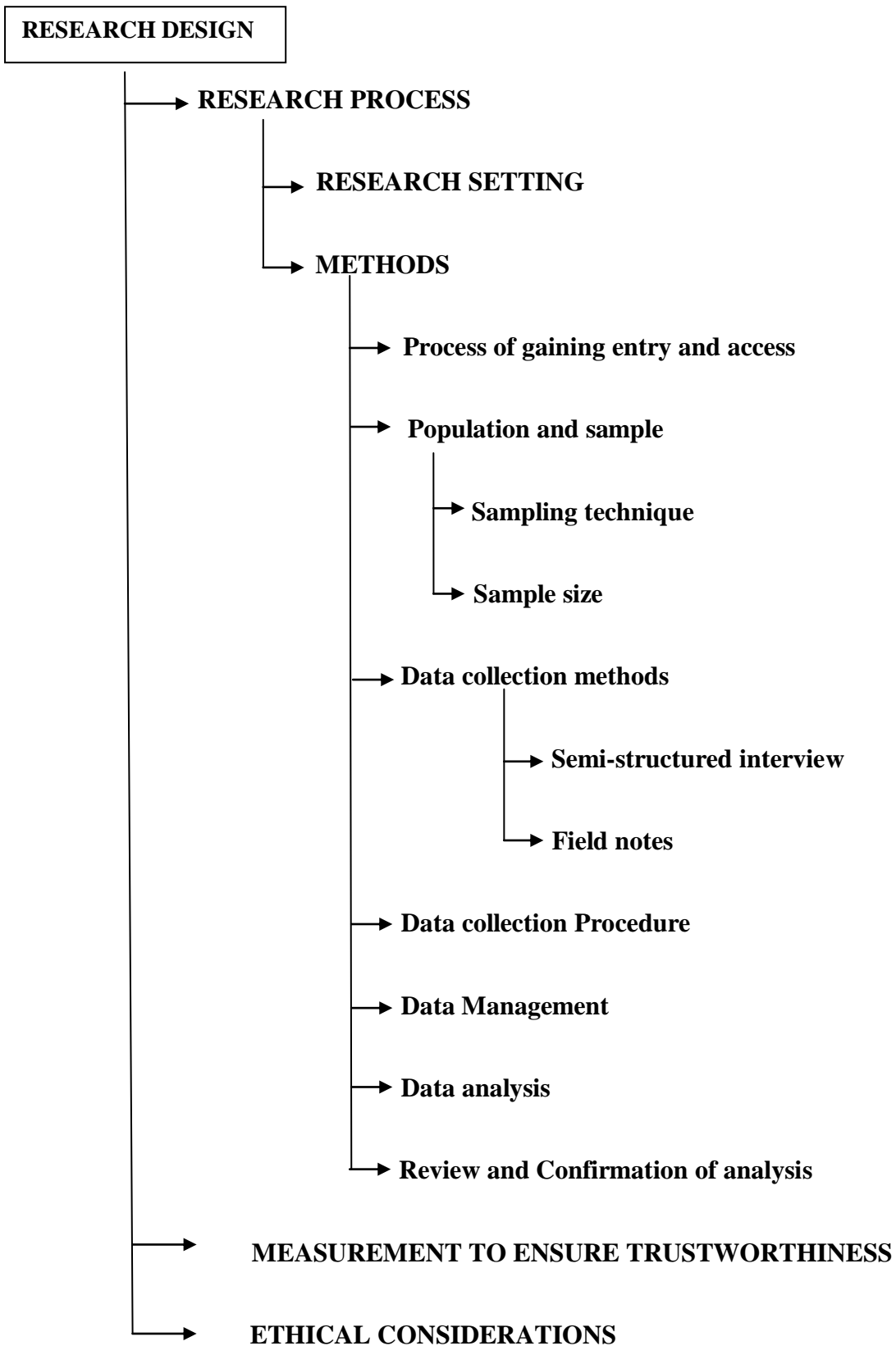


Diagram 3.1. Blueprint of the study research design presentation

3.4.1. RESEARCH PROCESS

The research process is a process of a scientific inquiry, a way of learning and knowing things about us (De Vos et al., 2011). The following section seeks to provide detailed account of the research process undertaken for this study reflected by the research setting and methods used to maximise the validity of the study findings

3.4.1.1 Research Setting

The study is undertaken to deepen understanding of individuals with spinal cord injuries at Dr George Mukhari Hospital at Spinal Unit Ward, Ga-Rankuwa, in Gauteng Province. Dr George Mukhari Hospital is selected for its accessibility to the researcher. Brink & Wood (1998) explain that qualitative data are sensitive to the social, historical and temporal context in which they are collected. They regard contextual sensitivity as of particular importance in that data are not generalised to other contexts, socially, spatially or temporally. Although qualitative findings cannot be generalised in the same way as quantitative studies, according to Neuman (2000) understanding the meaning of a phenomenon in a particular situation gives awareness that can be applied more broadly.

Patients with spinal cord injury, at Dr George Mukhari Hospital, are managed in the spinal unit ward at the hospital, where they are usually discharged home following stabilization of their medical condition. A multidisciplinary team consisting of nursing staff, medical doctors, social workers, clinical psychologists, occupational therapists and physiotherapists perform rehabilitation at the unit where the study will be conducted. It should be noted that access to these health services depends on the patient's proximity to a hospital with such services, or their ability to meet transport and treatment costs.

3.4.1.2 Methods

Methods refer to the research technique and the procedures for carrying out the research (Van Manen, 1990). The researcher planned and executed the study in order to obtain answers to the question of subjective experiences sustained after an SCI. The planning and execution included the process of gaining entry and access, population and sample, data gathering and analysis, including the observation of ethical principles throughout the assignment.

i. Gaining entry and access

According to Flick (2009), the question of how to gain access to the field under study is more crucial in qualitative research than in quantitative research. In this study, the researcher first approached the Medunsa Research Committee (see Appendix 1) to gain permission to conduct the study, explaining the nature, purpose and significance of the study. Once the clearance certificate was obtained from the Medunsa Research Committee, secondly the Clinical Superintendent of Dr George Mukhari Hospital (see Appendix 2) was approached to obtain permission to conduct the study at the hospital. Lastly the Spinal Unit Head Nurse was approached to gain access to the patients who met the research inclusion criteria and access records for medical information of those who participated in the study.

ii. Population and sample

The population refers to the total subjects or aggregates that conform to a set of specifications (Creswell, 2007). According to Creswell (2007), the requirement to define a population for a research project arises from the need to specify the group to which the results of the study can be applied.

In this study, the population consisted of all people diagnosed with an SCI, within the boundaries of Dr George Mukhari Hospital, Pretoria. The target population is a subset of the population (AHRQ, 2011), namely all SCI persons in the hospital who met the inclusion criteria. The choice of participants included *inclusion* and *exclusion* criteria. Inclusion or exclusion criteria refer to standards set out before the study and are used to determine whether a person can or cannot participate in a research study (AHRQ, 2011).

To be included, the participants had to meet the following criteria; have been diagnosed with a spinal cord injury; were 18 years and above at the time of the interview; used a wheelchair; receiving medical treatment, yet stabilised and receiving rehabilitation; be able to communicate in English (written and spoken) and were mentally sound. Those with a neurological impairment; history of acquired brain injury; experiencing serious psychological disorder; spinal cord injured persons who have not yet been stabilised were excluded. Having identified the target population, the sample was selected.

- **Sampling Technique**

Sampling is about making decisions about which people, settings, events, behaviours or social processes to observe (De Vos et al., 2011) Sampling is mainly concerned with representativeness (Collis & Hussey, 2009). There are two sampling methods, namely; probability and non-probability sampling. In non-probability sampling, the probability of any particular member of the population being chosen is unknown (De Vos et al., 2011)

In the present study, the researcher used a non-probability sampling. Specifically, purposive sampling method was used because the researcher sought to study a specific group of people, that is, individuals with spinal cord injuries, for a specific purpose, which is to determine the nature of their psychological challenges. According to De Vos et al. (2011), purposive sampling refers to a sample that is composed of elements that contain the most characteristic,

representative or typical attributes of the population that serve the purpose of the study best. Purposive sampling was chosen as this permitted only those who met the inclusion criteria to participate (for an inclusion criteria see population and sample section above). The initial access to a network of potential participants was gained through working in collaboration with the Spinal Unit Head Nurse.

Locating participants proved to be time consuming and difficult, as some of the admitted patients who sustained a spinal cord injury could not communicate in English and fell in one or more of the exclusion criterion.

- **Sample size**

Researchers using qualitative methods generally study small samples, and even two to five participants can produce data saturation, which is an acceptable indicator of adequate sample size (Collis & Hussey, 2009). The researcher chose a sample of eight (8) because the study aimed to explore the experiences, rather than a measure of the distribution of attributes within a given population (De Vos, Strydom et al., 2011). By the eighth interview saturation was reached when it became clear that no new information was forthcoming.

iii. Data Collection methods

The researcher was the primary data-collection instrument, which is the philosophical underpinning of qualitative research, it obligates the researcher to accept the self as part of the research (Collis & Hussey, 2009) Parahoo (1997) expresses concern that using the researcher as a tool for data collection and analysis may lead to subjectivity in selecting which data to accept or reject. Collis & Hussey (2009) however, states that much of the data gathering depends upon skilful observation, listening, and communication abilities for which psychology perhaps more than any other discipline is prepared.

The researcher made use of the following data collection methods:

- One-on-one semi-structured interviews
- Field notes

➤ **One-on-one interview**

The choice of interviewing as a method of information gathering is based on the premise that an interview provides insight into the present-at-hand mode of engagement with the world because it encourages the participants to adopt a detached and objective perspective (De Vos et al., 2011).

Clarke (1999) identified the following factors that may affect the interview situation:

- The interviewer's values and biases may affect the truthfulness of the respondent's account.
- The interviewer's personal characteristics, such as; age, gender, social class, religion may impact on respondents' answers.
- Misdirected probing and inappropriate wording of questions can change the validity of information collected

Thus, the interviewer as an instrument should always be conscious of the interpersonal dynamics within the interaction and take into account during the interview and later in the analysis of the finished interview. The above aspects and skills that facilitate communication when conducting the interviews guided the researcher in this study.

For this study the researcher used a semi-structured one-on-one interview with an open-ended beginning. A semi-structured one-on-one interview is a research data collection method whereby a researcher seeks to gain a detailed picture of a participant's beliefs about, or perception or accounts of, a particular topic (De Vos et al., 2011). The semi-structured

interview followed an interview guide (Appendix 3). An interview guide was designed by the researcher as to purposely cover specific areas. In addition, the researcher used probing techniques including reflection of feelings where necessary to elicit more discussion. According to Collis and Hussey (2009) to ensure that maximum information is gathered, it is essential to make use of probing techniques that ask interviewee questions that require them to elaborate on their initial statement. Probes are questions asked in response to what the interviewee has said and asked to gain greater understanding of the issue under study (Collis & Hussey). The aforesaid authors indicated that probes are used in unstructured or semi-structured interviews.

According to Neuman (2000) a qualitative researcher listens and observes careful what is being said and how it is said, thus taking into cognizance both the verbal and non-verbal signals. The use of semi-structured interviews enabled the researcher to observe behaviour in different logical levels, that is, enabling the researcher to listen to what the participants was saying (content level) and how it was said (process level). The researcher was also able to observe congruency between the participant's verbal and non-verbal communication. Many of the above behaviours are implicit and can only be observable when one conducts interviews.

In addition to the semi-structured interview, a biographical information sheet (Appendix 4) was used to gather biographical information of participants. This information was gathered for follow-up purposes (if necessary) until the study is completed.

The chosen method is not without limitations and strengths. Creswell (2007) mentioned the following strengths and limitations regarding interview as a method of data collection-

- **Strengths**
 - Useful when informants cannot be directly observed

- Informants can provide historical information
- Allows researcher “control” over the line of questioning.

- **Limitations**

- Provides “indirect” information filtered through the views of interviewees
- Researcher’s presence may bias responses
- Not all people are equally articulate and perceptive

➤ **Field notes**

In order to enrich the tape-recorded interviews, the researcher made use of field notes. According to Eisenhardt (2002) field notes are running commentary to oneself, an important means of accomplishing an overlap of data analysis with data collection. Field & Morse (1994, as cited in De Vos *et al.*, 2011) describes field notes as a written account of the things the researcher hears, sees, experiences and thinks in the course of collecting or reflecting on the data obtained during the study. While De Vos *et al.* (2011) describe different types of field notes, it should be noted that for this study, personal notes were adopted as field notes (Field Notes Sample Appendix 5). In the personal notes describe the researcher’s reactions, reflections and experiences during the interview (De Vos *et al.*)

The researcher integrated the field notes during analysis and discussion.

Similarly to the interview method, Creswell (2007) mentioned the following strengths and limitations to field notes as a research data collection method-

- **Strengths**

- Researcher can record information as it occurs
- Unusual aspects can be noticed during the observation
- Researcher has firsthand experience with informant

- **Limitations**

- “private” information may be observed that researcher cannot report
- Researcher may not have good attending and observing skills

iv. Data collection Procedure

The researcher conducted all the interviews. The researcher firstly obtained a clearance certificate from the Medunsa Research Ethics Committee. Thereafter he requested permission to conduct the study from the Director of the Clinical Services at Dr George Mukhari Hospital and from the sister-in charge of the Spinal Unit. The Spinal Unit manage and provide rehabilitation for persons who have sustained a SCI.

After being granted permission to conduct the study at the spinal unit of Dr. George Mukhari Hospital, the researcher with the assistance of the head nurse identified participants which meet the criteria of inclusion in this study. The researcher approached each participant and arranged a convenient time for the interview with him/her. Prior to conducting each interview, the nature and purpose of the study was explained and questions were invited. While questions were invited for clarity, all participants consented to participate after the explanation of the study was given and they did not raise any questions.

On the day of the interview, after obtaining the informed consent from each participant, a biographical data sheet was completed by hand. The participants were reminded that the interviews will be recorded to assist with the analysis of data and they can withdraw from the process at any time. To facilitate each interview a narrative approach and an open-ended interview guide was used. In addition, the researcher made use of open-ended questions to elicit the discussion. He also used the reflections to make the interviewees to feel understood.

Probing was used to elicit more discussion during the interviews. The probes used were determined by the course of the conversation. The interviews were semi-structured and were recorded on a recorder for later transcription and analysis. Each interview was given about 60 minutes to allow each individual enough time to express him/herself. Questions included but not limited to following sample of questions:

- Where would you like to start about what happened to you?
- How was your life prior the diagnosis of SCI?
- Since the diagnosis how has life been like for you?
- What has been the major change in your life since then?
- How are you coping?
- What are your everyday stressors?
- What is your view about the future?

The interviews were recorded with the participants' consent. A secluded room at the spinal unit was requested and utilised.

All the participants were most willing to tell their stories. The researcher was vigilant of the participants' emotional cues, and adopted silent probing, when necessary. In addition, the researcher gave interviewees "permission to withhold thoughts about something intensely important to them" which acknowledged "their sovereignty as human beings" (Dahlberg, Drew & Nystroom 2001).

The researcher kept field notes for each interview as a supplementary source of data and documented the setting, the questions and experiences. Morgan (1994) asserts that interview data should be interpreted within the situational as well as textual context. In other words, the data can be more illuminating if supported by the researcher's situational understanding of events that took place.

v. Data Management

Data management is an administrative process by which the required data is acquired, validated, stored, protected, and processed, and by which its accessibility, reliability, and timeliness is ensured to satisfy the needs of the data users (Business Dictionary, 2012). A digital recorder was used, which marked the date, time and code for each participants' interview. The interviews were then downloaded to a computer. Each interview was transcribed verbatim soon after recording interviews. Pauses were noted on the transcript with three dots, while a series of dots denotes gaps or long pauses. Transcribed data was revisited after three days of each transcribed interview, and this was to ensure accuracy in the transcribing process. The researcher further interacted with the data through highlighting sections of the transcripts, proposing ideas about its meaning, considering what really stood out from the descriptions and pondering what might be absent.

vi. Data Analysis

Data analysis is a way of reducing data complexity so that it is more manageable to the researcher (Nueman, 2000). According to Terre Blanche & Kelly (2002) qualitative analysis involves staying close to the data, interpreting it from a position of empathic understanding.

The present study followed a qualitative method of data analysis. Thematic analysis was used. According to Morse & Field (1995:139) "Thematic analysis involves the search for and identification of common threads that extend throughout an entire interview or set of interviews". Thematic analysis in this study refers to the process of an insightful discovery of the underlying meaning of the experiences of SCI persons.

This allowed the researcher to analyse the data according to what was said and how it was said in relation to the context. The researcher listened to each interview from the recorder and

transcribed the content of all interviews verbatim. Thereafter field notes which mainly consist of behavioural observations of each participant were added into the written content of all interviews. The researcher read the content of all interviews several times so as to familiarise and immerse himself in the transcribed interviews (Durrheim, as cited in Terre Blanche & Durrheim, 1999). The researcher used highlights and wrote next to each line as same feelings were often expressed at different times during the interview, and across interview. Thereafter thematic analysis was done from each interview one at a time. In line with the interview guide used in the data collection process, themes, sub-themes and significant phrases from each interview were identified and are presented in the next chapter. Thereafter themes, sub-themes and significant phrases of all the participants that are similar have been put together and discussed.

vii. Review and confirmation of analysis

Eight unmarked interview transcripts were submitted to two accredited qualitative researchers (see the attached Qualitative analysis Certificate—Appendix 6) with the purpose and objectives of the study. The identified researchers used Tesch’s inductive, descriptive coding technique (in Creswell, 1994:155-156) applied to qualitative interviews. The following six steps were followed:

1. The coder obtained a sense of the whole by reading through the transcriptions independently. Ideas that came to mind were jotted down.
2. The coder then selected one interview and asked: “What is this about?” thinking about the underlying meaning of the information.
3. When the coder had completed this task for several respondents, each interview was coded separately; thereafter a list was made of all topics.

Similar topics were clustered together and formed into columns that were arranged into major topics, unique topics and leftovers.

4. The coder took the list and returned to the data. The coder tried out a preliminary organizing scheme to see whether new categories and codes merged.
5. The coder found the most descriptive wording for the topics and turned them into categories, then endeavoured to reduce the total list of categories by grouping together topics that related to each other.
6. The data belonging to each category was assembled in one place and a preliminary analysis performed.

After the above a consensus discussion followed between the researcher and the coder. Consensus was reached regarding the overall subjective experience of people with SCI.

Furthermore, the analysis of both coding techniques (that which was adopted by the researcher and co-coders) revealed inter-coder reliability in uncovering similar themes and sub-themes. Inter-coder reliability is a measure of agreement among multiple coders for how they apply codes to text data (Burka, *et al.*, 2008). However, no means were made to confirm this through the use of standardized procedures that confirm inter-coder reliability.

3.4.2 MEASURES TO ENSURE TRUSTWORTHINESS IN THIS STUDY

According to Babbie and Mouton (2001) trustworthiness is an approach to clarifying notions of objectivity as it is manifested in qualitative research. A number of authors (Leininger, 1994 as cited in Collis & Hussey, 2009; Scott, 1990 as cited in Flick, 2009; Lincoln & Guba, 1999 as cited in De Vos *et al.*, 2011) have suggested various criteria which can be used to

assess the quality of qualitative research. However, this study adopted four criteria suggested by (Lincoln & Guba 1999, as cited in De Vos *et al.*, 2011).

- **Credibility** is concerned with whether the research was conducted in such a manner that the subject of the inquiry was accurately identified and described (De Vos *et al.*, 2011). This includes a prolonged engagement, persistent observation, triangulation, referential adequacy, peer debriefing and member checks (De Vos *et al.*). Benner (1994) states that as part of the credibility of a project, the investigator lays out preconceptions, biases, past experiences and perhaps even hypotheses that make the project significant for investigation, and how these may affect the interpretation. In this study the researcher outlined his own preconceptions, biases and assumptions, reasons for conducting the study and prolonged engagement with the participants.
- **Transferability** is concerned with whether the findings can be applied to another situation that is sufficiently similar to permit generalization (De Vos *et al.*, 2011). De Vos *et al.* (2011) asserts that to strengthen the study's usefulness for other settings, making use of more than one data-gathering source, making use of data from different sources, and by defining clearly the parameters of data collection are recommended ways. To ensure transferability for this study the researcher made use of interviews plus field notes to supplement information from the interviews, viewed findings in collaboration with findings from other sources, and clearly provided the "how" data was collected and analysed.
- **Dependability**- an inquiry must also provide its audience with evidence that if it were to be repeated with the same or similar respondents (subjects) in the same context, its findings would be the same (De Vos *et al.*, 2011). In this study, the researcher described the context of the study. The researcher strived to make explicit decisions

taken about methodological and analytical choice so that another researcher can follow the decision trail and also through the use of co-coders.

- **Conformability** refers to whether the research process has been described fully and it is possible to assess whether the findings flow from the data (Collis & Hussey, 2009). For this study, the research process has been explicitly described and the data collection tool attached as to meet the condition for conformability.

3.4.3. ETHICAL CONSIDERATIONS

Given the vulnerability of people diagnosed with an SCI, it was paramount to safeguard their interests at all times; that is, their situation should not be exploited. Ethical considerations in research are mainly to protect the informants from harm. The following four ethical considerations (Flick, 2009) were adhered to:

- **Respect of persons**

Respect of persons refers to respecting the research participants' values and decisions (Flick, 2009). To ensure the respect of persons (De Vos *et al.*, 2011), informed consent (see Appendix 7) was obtained from the participants and prior the interview detailed information about the research was provided. Confidentiality was maintained through the anonymity of responses and participation was voluntary.

- **Beneficence**

Beneficence refers to maximising possible benefit and to minimise possible harm by the research on human subjects (De Vos *et al.*, 2011). To ensure beneficence the researcher was

vigilant to non-verbal cues, and there was no undue probing. Rather than causing harm, it was envisaged that being invited to share their experiences would be therapeutic, allowing the participants to recall and relate their experiences. Some indicated that it brought some form of relief to ‘talk about this’. Participants were invited to make use of the psychological services present at the hospital should they deem necessary to seek psychological intervention.

- **Non-maleficence**

Non-maleficence refers to avoiding harming participants (Flick, 2009). Due to the potentially distressing nature of recollecting traumatic experiences (the injury and subsequent disability), the researcher was particularly sensitive to the participants’ needs. That they could withdraw anytime was emphasised. The ethical obligation to care was at all times seen to override the need to gain information for the purpose of the study.

- **Justice**

Justice refers to the equal treatment of all people (Flick, 2009). To ensure justice the researcher remained courteous and made known to participant that they have a choice and will not be coerced into answering sensitive questions. To further assure justice permission from hospital management and approval from Medunsa Research Committee was obtained.

3.5. CONCLUSION

This chapter described the research design and research setting, participants and the methodological process used to collect and analyse data. The researcher provided an audit trail by outlining the procedures, processes and ethical issues considered.

Chapter 4 presents the research findings and discussion. The three major themes deal with how participant perceive their condition, deal with situation and outlook on life post SCI event.

CHAPTER 4

RESEARCH FINDINGS AND DISCUSSION

4.1 INTRODUCTION

This chapter firstly presents the participants' characteristics as to provide the reader with a context of who were the data collected from. Secondly this chapter presents the research findings and discussion regarding the central themes and sub-themes that emerged from the data analysis process.

4.2. PARTICIPANTS' CHARACTERISTICS

The characteristics as presented below were compiled from the participants' biographical data (see table 4.1.).

➤ **Gender**

Out of eight people who participated in this study, six of the participants were males and two were females. According to Dickson et al. (2008) approximately 80% of those who sustained SCI are men.

➤ **Age**

The participants' age ranged from 20 to 42 and their age at injury from 19 to 42, with an average of 26 years. Research indicates that most new injuries globally occur to young people less than 30 years of age (Dickson *et al.*, 2008; Wu & Chan, 2007). The distribution of the participants in terms of age; five were injured under the age of 30 years, three being males and two being females. According to Dickson *et al* (2008), these young people were about to embark upon the potentially most productive period of their lives.

➤ **First Language**

In terms of language spoken, four of the participants were Tswana speakers; three were Pedi speakers and one was a Tshivenda speaker. This sought to indicate that all participants were not English first language speakers. This had an impact to some extent in that in-depth detail information could not be achieved; however, saturation was achieved as evident by repeating themes (Collis & Hussey, 2009). According to Collis & Hussey (2009) saturation is concerned with the researcher being fully immersed and understanding the project.

➤ **Marital status.**

Persons who sustained an SCI who were interviewed six were single at the time of injury and still so at the time of the interview (see table 4.1). Two persons were married at the time of injury. Marital status was asked to determine one of the life roles that the participant is fulfilling. Dijkers (1999) showed that married individuals reported the highest satisfaction with living and those who were separated, the lowest. In this study, both married persons reported that they experience spousal support. However, it was not the aim of this study to do satisfaction with life comparisons amongst the participants.

➤ **Race**

This information was requested as to gain insight in how individuals from different races react to having sustained a SCI. All eight participants were Black. This was no surprise since the hospital is situated around a community that is predominantly black. The study did not intentionally set out to utilise only black participants, it remained open to participants from any ethnic group.

➤ **Cause of the injury**

Six of injuries were related to road accidents (MVA), of whom one was a pedestrian, and five participants were passengers in a vehicle. According to research traumatic motor vehicle accidents, violence and sports injuries emerged as the leading causes of traumatic SCI (Parker, 2005). The remaining two participants sustained their injuries from falling from the mountain and while picking up a heavy water bucket.

➤ **Education level and employment**

Only three participants were at tertiary level with their education, and five participants reached high school, yet never completed it. It is not surprising that employment opportunities for the sample were in low paying jobs for the two participants who were employed at the time of injury. There is a possibility that a chance for re-employment after the SCI is very slim. All eight participants remained unemployed since the injury occurred until the time of the interviewing.

Table: 4.1. Participants' characteristics (N=8)

Code	Cause	Gender	Level of injury	Type and extent	Age at Injury	Marital status	Education	Occupation at time of injury
A1	Fell from mountain chasing monkeys	M	T-12	Paraplegia complete	18	Single	Grade 11	Learner
A2	MVA	M	C5-6	Quadriplegia complete	21	Single	Grade 11	Learner
A3	MVA	M	T 3-4	Paraplegia Complete	20	Single	3 rd Year Tourism	Student
A4	Picking Heavy water bucket	F	L1	TB Spine	21	Single	1 st year HR	Student
A5	MVA	M	C5-6	Quadriplegia complete	31	Married	Grade 9	Labourer
A6	MVA	F	T2-3	Paraplegia	22	Single	1 st year Public Management	Student
A7	MVA	M	T11-12	Paraplegia	42	Married	Grade 8	Driver
A8	MVA	M	T4,5-6	Paraplegia	33	Single	Grade 8	Unemployed

4.3. PRESENTATION OF RESEARCH FINDINGS AND DISCUSSION

The above sought to present the characteristics of the participants of this study. The data collected and analysed from the above participants' elicited central themes that were common to the participants regarding their experience of SCI.

Prior the presentation of the findings, it is important to note that there are two main objectives that the data collected and analysed sought to answer that is; (1) what are the psychological effects experienced by SCI persons; and (2) what are the effects on the impact to persons with SCI regarding their psychological well-being? In this paper the concept "SCI persons" refers to the concept of the "participants".

The data analysis yielded two central themes supported by sub-themes (see diagram 4.1.).

The two central themes were:

(1) the psychological effect of SCI. The psychological effects were linked to **diminished independence, intrapersonal changes, altered interpersonal relationships and emotional disturbance.**

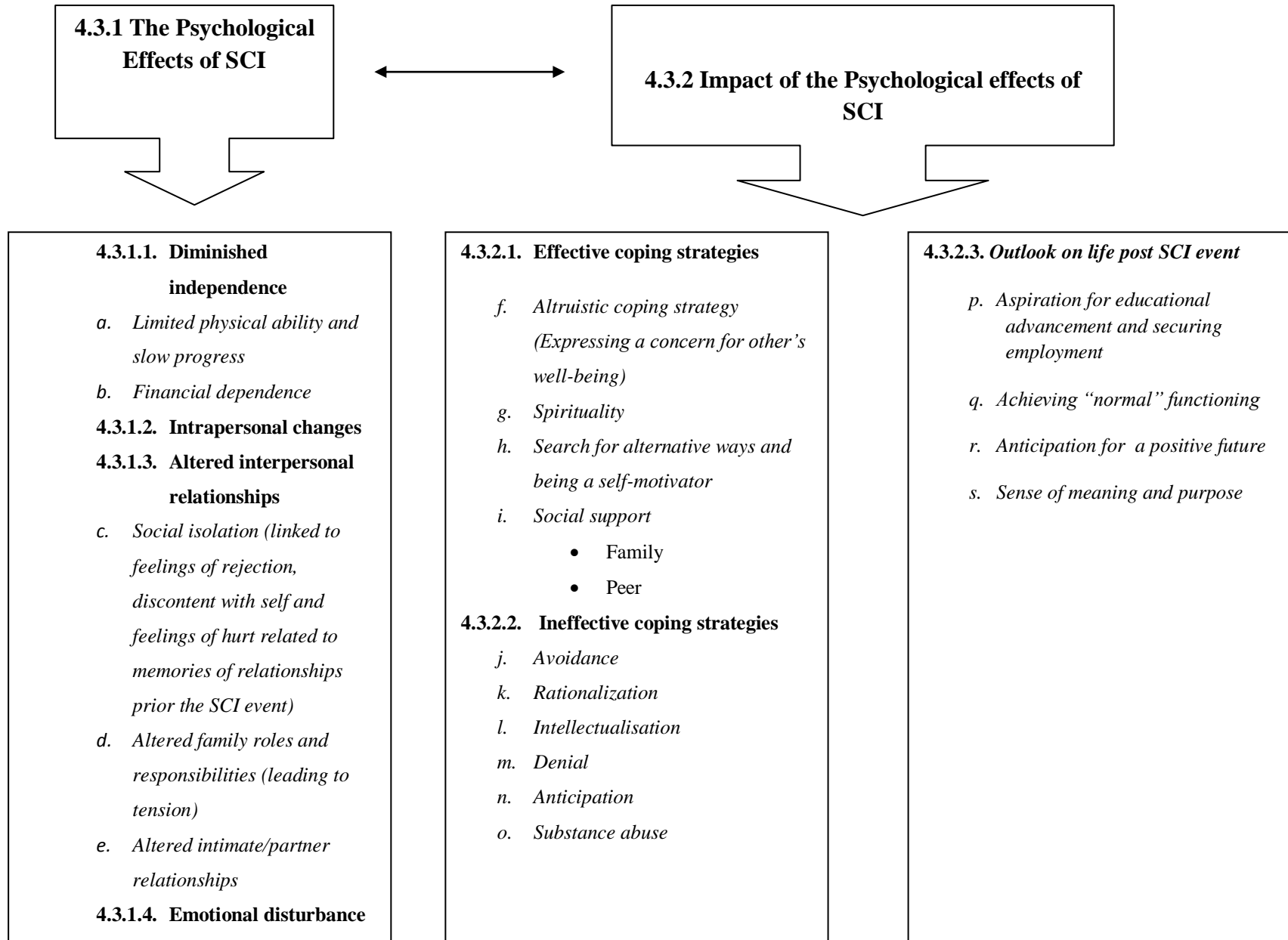
(2) The impact of the psychological effects of SCI. The impact was linked to **effective coping strategies, ineffective coping strategies and outlook on life post SCI event.**

A discussion of the themes and sub-themes, supported by the verbatim quotes from participants follows. The verbatim quotes will be presented in italics.

For the easy read, the findings will be presented in the following structure:

- Label theme or subtheme with a descriptive label
- Give a brief explanation of what the label means based on the findings
- Sub-themes are numbered alphabetically
- Next provide the participant quotes to substantiate the findings
- Then discussion after a central theme based on the researcher's interpretation of the findings and supported by literature. Where necessary a brief discussion under a sub-theme and literature is provided to provide more insight of the findings.

Diagram 4.1.
Overview of central themes and sub-themes and sub-categories reflecting the subjective experience of SCI persons in terms of the psychological effect of SCI on their life and wellbeing



4.3.1. The Psychological Effects of SCI

The psychological effects refer to the effects that relates to the emotions and perceptions held by the participants on the basis of evaluating their physical and psychological condition. Living with a SCI emerged as a life changing event (“my life is a new one”) with pervasive effects on the psychological well being of the participants.

“I was an active somebody before, but now I am no longer that person” (p2)

“My life has changed a lot” (p3)

“my life has been terrible...you cannot do anything....because you just have to lie down on the bed” (p4)

“life has changed automatically”(p2)

“I have tried to come to terms that I must accept it” (p6)

Participants of the study reported that their injury has been a life changing event where almost all aspects of their lives has been touched, thus indicating an alteration in their perceptions of “being-in-the-world”. The altered perceptions were noted in the way that they described (compared) their life before and after the SCI. Past events and life styles were seemingly re-examined by them in order to find an explanation. Life post-injury was complicated by with *diminished independence, intrapersonal changes, altered interpersonal relationships and emotional disturbance.*

4.3.1.1. Diminished Independence

Participants compared their prior ability to act independently in most spheres of their life with the reality of diminished independence post SCI. The raw data indicated that participants’ (a) *limited physical ability and (b) their financial dependence created the most distress.*

a) **Limited physical ability and slow progress**

Limited physical ability refers to the physical barriers brought about limited mobility. This limited mobility is linked to the self-care activities. Slow progress refers to the perception held by participants in examining their current emotional and physical state following the accident. For this reason life is perceived to be stagnant and frustrating as they (participants) are not recovering as quick as they would wish. In line with this participants shared the following experiences:

“I am no longer able to do things on my own...I am depending on people to help... “99% of the things people help me because I cannot grab things with my hand” (p2)

“I cannot do stuff...normally as I use to” (p3)

“I believe it is going so slow...life is too slow” (p5)

“If I want to go somewhere I will have to struggle first to catch a taxi” (p8)

b) **Financial dependence**

Financial dependence refers to the limited financial status that brings about the dependency for survival on others. All of the participants come from varied situations characterized by differences in education level, low paying jobs if they were employed, and unemployed as student/learners. Such conditions placed them in a severe context of experiencing financial hardships in being able to attend to some needs that required finances. Many aspirations of the participants were compromised by a severe lack of resources. Access to resources and material goods is through adequate finances. For some of the participants in this study, the disability meant perpetual poverty. Participants reflected on their financial dependence as indicated by the verbatim quotes below.

“I do not have money to take care of my child” (p1)

“Now when I need money I have to wait for...that grant” (p2)

“There is no money to pay for the placement...I am struggling with money now” (p5)

“I do not know where I can get money anymore” (p7)

The chances of some of the participants improving their living conditions remain remote. Furthermore financial hardships, jeopardize their roles of being responsible parents in terms of providing for their families. The fight for financial survival adds to the stress of the physical and emotional constraints of SCI. Manns and Chad (2001) further supports that finances affect the quality of life. The participants (especially those who were breadwinners prior the injury) in this study and their families, it could be hypothesized, they will remain trapped in poverty if their psychological and physical conditions show no improvement

The poverty will affect their quality of life negatively, as they cannot access or afford the basic needs. On the basis of observational notes, it is without doubt that finances remain a formidable source of stress affecting most persons living with SCI. Furthermore, challenges in finances force a change in lifestyle of persons with SCI.

4.3.1.2. Intrapersonal changes

Intrapersonal changes emerged closely related to an altered self-esteem and identity changes. Self-esteem refers to a set of beliefs a person has about himself/herself in terms of respect and worth, and has a major role to play in psychological well being. There are two sources of self-esteem namely; internal factors, such as the degree to which people like, approve or accept themselves and external factors, such as; achievements, success, possessions, physical appearance and praise from others. The participants in the study depended on varying degrees in both factors.

“I was somebody who use to sport” (p2)

“I have learned something...when you are on the wheelchair and when you are walking is two different things” (p1)

“I do not think they will look at the guy in a wheelchair...I wonder how I am going to be treated...will things be normal again” (p3)

“I am paralysed” (p5)

“I am just a helpless person” (p5)

“I never thought in life that one day...I will be like this” (p4)

The participants' loss of body functions became a loss of sense of self. The self-image was altered after a SCI and persons with SCI had to “carve out” a new identity based on feelings of self-worth and of being valued.

Work on coping with change in body image seemed particularly pertinent to the participants. However, they (participants) struggled to maintain an integrated self-image post the injury and seemed very concerned of how they will be perceived by others in their community.

4.3.1.3. Altered interpersonal relationships

Due to changes in their mobility and independence, persons with SCI are faced with various changes in their lives including altered interpersonal relationships. The participants perceived changes in their interpersonal relationships linked to *social isolation, altered role definition and responsibilities, and altered intimate/partner relationships.*

c) Social isolation

Isolation from friends, stigmatization, and restricted mobility seemed to be experienced by all the participants. In line with this, participants shared the following:

“I am paralysed...my friends are far away from me” (p5)

“My friends....others are gone and others are still around” (p1)

“People tell me look at your friends they are now gone” (p2)

“I no longer see a lot of people that I use to see before” (p6)

Increase in the participants’ perception of social isolation, some of them (participants) referred to the struggle for resilience. Sometimes the overwhelming and oppressive nature of their circumstances made them wish they had died. Suicidal ideations were accompanied by feelings of regret or wishes that the individual had not done what he/she did on the day of the accident.

“it is better to be dying...I am just a helpless person...there is nothing I can do for myself...I just ask myself why was I going there...only me who got injured out of nine people” (p5)

Krause (1998) showed that active engagement in life enhances adjustment or subjective well being, while others refer to the problem of unstructured free time following SCI.

d) Altered role definition and responsibility

The psychological effects of SCI are far reaching in family relationships and roles maybe radically changed. Perturbed about past responsibilities and the fulfillment of these roles, participants perceived irreversible changes in their different roles assumed prior the accident.

“My wife now must buy the clothes for the children, pay rent, electricity and installment...because I am no longer able” (p5)

“I am a breadwinner at home...I do not know where I can get money anymore” (p7)

“I have accounts I have to pay” (p7)

“I do not have money to take care of my child” (p1)

e) **Altered intimate/partner relationships**

Altered intimate/partner relationships refer to alteration in spouses interactions. Life satisfaction is related to family relationships, intimacy, presentation of self and stress management. The participants were no different in that their condition, not only impacted their self-perception, but also the comparison of the self in relation to others in terms of intimate relationships.

Variations in perception of intimate relationships were observed between; single, unmarried, unemployed to married, previously employed participants. Male participants were more conscious about the impact of SCI on their ability to pursue or maintain intimate relationships in comparison to female participants.

Married participants reported high-levels of support from their significant others:

“my wife has told me...to be strong...and not to worry”(p7)

“She is now supporting me, the children and the rent” (p5)

Even though spousal support was acknowledged, the participants expressed fear of not wanting to be a burden to their spouses:

“When it comes to month end, my wife is supposed to share the money. She is working at the restaurant....that time when I was working is was better...but now things are difficulty...she cannot leave the job....that is why I will be going to the placement” (p5)

“I am a breadwinner at home....I have accounts to pay...and if I am not working like this....there will be nothing....my wife will be nothing...” (p7)

“I hope my hand will work...so that I can clean myself...and so that I can manage something...do something for myself...unlike my wife cleaning...changing nappy...that thing”
(p5)

Young and single male participants, found it difficult to maintain existing relationships, and starting a new relationship was a concern. They showed a lack of confidence, and feelings of being unattractive:

“When I came to the hospital...she (girlfriend) has not been coming to see” (p1)

“If I do not get a lover I guess...I do not take it seriously” (p2)

“I will not get a girlfriend anymore.....since I am here....I do not think they will look at the guy in a wheelchair” (p3)

Intimate relationships were also expressed with regard to sexuality and sexual functioning by male participants. According to Althof and Levine (1993), the physical sexual relationship for the male who experiences SCI is fraught with changes, losses and needs. Males with SCI encounter losses such as the inability to initiate sex, the loss of spontaneity, and the loss of physical satisfaction. Moreover, sexual concerns cover areas ranging from societal roles imposed on men, for example; how will he now protect and provide for his family’s future? Regarding physical dimensions, for example; will he be able to achieve an erection? Finally psychological factors such as; how will anyone find him attractive in a wheelchair?

As male figure in their families with an expectation of them to be providers, participants felt stripped of those roles and responsibilities:

“I do not have money to care of my child” (p1)

“I have to be a man...I must take care of them...now I do not know how is it going to happen” (p2)

“I am fighting for my life...another thing is the children...every time I call my children...they say...daddy, we need this and that, and they do not understand that I am no longer working...I am paralysed” (p5)

“My children, they still need a father ...they still need support” (p7)

In rating the importance of sexuality to males with SCI, Comarr (1971:378) states, “These men do think of sex, I believe (after nearly 25 years of observation) that the paralysis of the limbs among these patients would be secondary if they could carry on a normal sex life”. This remained true for the participants of this study. One participant expressed that is utmost worry about his condition, as its impact on his sexual functioning and how this will impact on his intimate relationship:

“I worry...that I am not going to have sex anymore....obviously as a man...I have a girlfriend, and when she is visiting...she is looking forward to enjoy making love with me...then we have a problem...she might start somewhere...because my manhood (pointing at his genitals) does not function” (p8)

Others felt due to the lack of sexual functioning, infidelity seems to become have prominent:

“She is cheating me” (p1)

The above findings, may further demystify the notion that disabled persons are not sexual beings, they are not interested in sex and sexuality. Despite the physical limitations, disabled persons have needs, and the disability does not eliminate sexual feelings.

4.3.1.4. Emotional disturbance

Emotional upheaval has been a cut-across theme for participants and was reflected by mixed emotional experiences. In this context emotional disturbance means the unstable emotional state as per context of a participant. Participants experienced a range of emotions as elicited by a number of factors such as; financial concerns and worry fear of the future for self and others, concerns about post injury functioning, embarrassment linked to physical disability.

One participant's highlighted his emotional turmoil by sharing:

“Sometime I am worried...and sometime I feel better” (p7)

Clinical impressions of the participants showed mixed emotional experiences, included but not limited to; numbness, anger, regret, anxiety and depression. Most of these emotions were associated with lack of predictability and sense of control often experienced by persons with SCI, and perceived inadequacy at being able to cope with future consequences of the injury. This is supported by research that has documented that negative emotional reactions are not inevitable following a spinal cord injury (Kennedy & Rogers in Kenny, Duff, Evans and Beedie, 2003).

4.3.1.5. Discussion on the Psychological effects of SCI

The first objective of the study was to explore the psychological effects of SCI on the well-being of persons with SCI. The findings describe living with a spinal cord injury as a life changing event with negative effects on the psychological well being of the person. The psychological effects were compared to life prior to the SCI to life post-injury with participants expressing satisfaction with life prior to the event. The unexpected event of a sudden traumatic SCI has been highlighted by the findings as a defining moment which

separates the SCI persons' life into two parts before and after injury. The focus of this study was on the life after injury. According to literature reviewed (Krause *et al.*, 2009; Blanes *et al.*, 2008; Singh *et al.*, 2007; Wu & Chan, 2007; Lund *et al.*, 2006) the psychological effects of SCI are devastating and remains one of the indicators in post-injury adaptation or adjustment.

For the participants of this study the psychological effects of SCI were linked to life post-injury as complicated by; *diminished independence, intrapersonal changes, altered interpersonal relationships and emotional disturbance*. These psychological effects of SCI remain contextual for person with SCI at Dr George Mukhari Hospital, as literature reviewed suggested that individuals who sustained a SCI must be viewed individually, taking into consideration the context in which the person with SCI is in (Dickson *et al.*, 2008; Flambouras, 2002). However, no matter what the psychological effects are, literature reviewed emphasize the effect residing in the number of factors such as; emotional maturity, degree of family support, financial status, educational level, jeopardize coping strategies, perceived locus of control, level of self-esteem and participation in social and leisure activities which all influence a person's ability to adjust.

A number of authors (Singh *et al.*, 2008; Miglirioni *et al.*, 2008; Hammel, 2007; Wu *et al.*, 2007) concur that persons with SCI face many psychosocial and vocational adjustment problems including; depression and anxiety, unemployment, lack of support, loss of self-esteem, and suicidal ideation. Each of these difficulties has been in research studies as relating to a poorer quality of life.

Literature reviewed showed that persons with SCI respond differently to the psychological effects of SCI. However, what remains common is that adapting to SCI may involve greater psychological efforts (Wu *et al.*, 2007). Since social and emotional adjustment to SCI can

vary from person to person, the impact of psychological effects of SCI remains an everyday struggle.

4.3.2. The impact of the psychological effect

The impact of psychological effects was linked to psychological adjustment. Being-in-the world with a SCI means adjusting to the functional limitations associated with the condition, where adjustments is defined as emotional acceptance of the disability into one's self-concept.

“I felt the pain at the first time...because my life was changing...but now I am alright” (p1)

“I am feeling like myself as a changed person...before I was having this thing of anger...but I have tried to come into terms that I must accept it” (p2)

“...my life has changed a lot. The moment they told me that I cannot walk again...it was like yoh!! (sigh)...but then somehow...I have to accept” (p3)

In this study as way to preserve and enhance the self and restoring self-esteem, the participants sought after a variety of coping strategies. For them to make sense of what happened and to maintain some equilibrium, they made determined efforts to handle the situation by employing certain coping strategies.

According to Lazarus and Folkman (1984), coping strategies are constantly changing, cognitive and behavioural efforts used by an individual to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person. Participants' initial reaction to the injury was to preserve the self and, as such, they engaged in various emotional reactions including denial and hope, denying its seriousness and hoping

it would soon pass. Coping allowed an individual to enhance his self-image and to acquire a realistic appraisal of his/her strengths and weaknesses.

In this study participants portrayed and reported various strategies they utilize to cope with their condition. These strategies are differentiated to; effective and ineffective.

4.3.2.1. Effective coping strategies

As aforementioned, coping strategies are strategies adopted by an individual to assist him/her to function better in a given situation. Thus, effective coping strategies could be defined as strategies that lead to stress reduction and improved functioning for an individual. For this study participants adopted various coping strategies that could be deemed as effective, and this was supported by clinical impressions as participants were observed to be smiling, laughing, freely engaging with both the researchers and others, congruent where their verbal cues matched with non-verbal cues, and seemed mobilized in dealing with their condition.

f) Altruistic coping strategy

According to Nagel (1970), altruism means not abject self-sacrifice, but merely a willingness to act in the consideration of the interests of other persons, without the need of ulterior motive (cited in Andreoni, Harbaugh & Vesterlund, 2007). According to Farsides (2007), empathy can be a vital determinant of altruism. Empathy can be defined as showing a deep understanding and respect for another person and endeavouring to understand their life world (Avis, Pauw & Van der Spuy, 2004). Empathy allows individuals to appreciate the world from someone else's point of view. As part of finding ways to deal with their conditions, participants exhibited empathetic gestures to other persons with SCI. This facilitated them to effectively cope with their everyday stresses as they assist others to cope with their condition. Participants shared being a motivator for others in the following:

“I am coping because I have a child and the child needs me” (p1)

“I have met many people who are in a wheelchair...and I get to talk to them” (p2)

“I met other people in a wheelchair....I tell them to go out....so that they not afraid of what people may think about them...now they feel strong.” (p6)

The participants found shared discussion and problem-solving to be particularly helpful. The sharing context amongst participants provided an environment for them to vent and find support from each other.

“In this ward, everybody is on the wheelchair...and I was asking myself how they feel...because I use to feel terrible about my situation” (p4)

“I tell others who are like me...to let us be strong and pray...and take care of ourselves” (p6)

The participants also promoted their self-image by projecting self-worthiness, through; taking part in religious activities, feeling independent, helping other persons with SCI who were worse off, and most importantly believing that they were as efficient as anyone else. Gill (1999) emphasizes that whatever form of involvement enhances a person’s self-worth and self-esteem. Finding a way to normalize their situation helps them to accept an acceptable body image and feeling normal is vital to psychological health.

g) Spirituality

Spirituality played a major role in helping some of the participants accept and thus find a reason for living and putting up with the stresses of living with SCI. Spirituality refers to the “subjective perception and experience of something or someone greater than himself”

(Howard 1996:182). According to Taylor (1983) positive interpretations of the trauma serve to reduce the attacks on the person, and serve as a “vehicle for self-enhancement”.

Positive meanings can be constructed; it produces significantly better psychological adjustment. Participants sought for positive interpretations of their conditions through spiritual-seeking. Participants perceived that their experience of disability resulted in a stronger sense of spirituality. Furthermore spirituality also served as a support during difficult times:

“I am just praying for God to help me” (p5)

“I am still hoping that only God can do a miracle...I have that strong belief” (p3)

“I read the Bible that I never use to read” (p4)

“What I know is that my God will never leave me alone” (p8)

“I ask God to give me a strong heart...only God knows why this happened” (p6)

By emphasizing benefits, individuals continue to believe that the world is a good place to be. Lustig (2005) showed that making sense of the loss and finding benefits are associated with positive adjustment following the loss, and further that finding meaning can release someone to go on and try to live with the condition. In this study, the participants were doing all they could to get on with their lives. This was evident from the interactions during data collection that the participants had not given up on life.

h) Search for alternative ways and being a self-motivator

Participants found coping with their condition by assenting to the condition, on the one hand, and reframing its meaning, on the other. Through a process of reflection, participants recognized and confronted the ramifications of the injury, and the regrouping, choosing to

move one and learning to get back into the world. According to Sedler (1987) acknowledging is admitting the truth about what happened and the prior reality must ultimately be relinquished. Embracing the reality that they more likely never to be able to walk again, despite rehabilitation interventions, the majority of the participants felt a need to search for alternatives to regain lost adaptive skills or device other means of coping with everyday needs. This further encouraged them to be self-motivated to change the course of their situation no matter what it takes.

“...but now I can do all things...such as washing and taking the bath” (p1)

“I am thinking what I can do...and having to teach myself” (p3)

“I can still do everything while on the wheelchair ...I cope” (p6)

“I have come a long way from 2006 till now...I have learned many things and coped” (p1)

“I tell others to learn to do things for themselves....must not tell their mother” (p2)

For these participants, it became apparent that accepting one’s situation involves making an effort to become reconciled to how things are and it comes about through rational thinking “making most of what capacity I have left”. According to Manns & Chad (2001) coping with SCI is more of an adjustment to the disability as opposed to acceptance. Being able to do something that felt meaningful was important to the participants, who did not want to be a burden.

i) Social Support

Support from others that is social support is crucial, in general. Perceived social support is an important component of; quality of life, coping, and positive long-term adjustment (Clayton, Robert & Chubon, 1994). Wineman, Durand & Steiner (1994:295) define social support as “the degree to which individuals’ needs for socialization, tangible resources, cognitive

guidance, social reinforcement and emotional sustenance are met through interaction with the social network; the social network includes people whom the individual identifies as important.” Triechman (1980: 92) describes social support as “information leading the person to believe that he is cared for or loved and/or esteemed and valued, and to believe that he/she belongs to a network of communication and mutual obligation.”

According to Gill (1999), support systems play a vital role in helping a person to adjust and cope with SCI. These support systems can be primary (family and friends) and/or secondary (health care professionals, the community and spiritual). Richardson (1997) contends that a person with a physical impairment due to SCI may not be disabled from living a full life if; social prejudices in the home, workplace, public buildings, and transport are absent and wheelchair access is present. The participants described the social networks available to them, and how it was experienced. These social networks included **family, and peer support.**

- **Family support**

Some participants had been in their homes and communities after the SCI, while others had not been. However, participants who had not been to their homes and communities since the SCI, could foresee, similar experiences to that shared by those who have been discharged, but were readmitted for various reasons.

While the overall family support was perceived as an important part in aiding the participants cope with their condition. However, some families were supportive but others were experienced as lacking understanding and sensitivity. There was stark contrast between palpable family support and feeling utterly alone among the participants.

Participants who felt supported by family shared the following:

“My family supports me a lot” (p2)

“I’m closer to my little sister” (p4)

“They are always concerned and try...to come here” (p6)

“...my wife supports me....” (p5)

Feelings of loneliness, a sense of aloneness, aimlessness and boredom, were felt at times:

“I am not happy to be at home everyday....doing nothing” (p2)

This is supported by literature reviewed which showed that to some SCI persons, due to the nature of their injury they may be confined in a bed or other forms of physical movement restrictions and such may lead to feelings of boredom, worthless and less of a human (Krause, 1998).

Feelings of being a burden and reliance on people for survival were also felt at times:

“It affected my family...most of the time people have to worry about eish! ...we have to bath him...do this for him.”(p2)

Some of the participants did not have much choice; they had to fit in with the family routine. That was the extent of dependency they experienced. The circumstances left them utterly powerless.

One quadriplegic participant felt that his parents’ response restricts his effort to achieve independence:

“...but another problem was my mother...she did not want me to go out” (p2)

From the clinical impressions, the researcher realized the seriousness of family involvement or lack of it in the care of their family member who were paralysed and have lost control of bladder and bowel movements, becomes an important determinant in the psychological well being of the participants.

While most participants had shared experiences on the basis of how they have interacted with their family members, others felt that restrictions in their families are linked to encountering physical barriers:

“....not being able to go out....the passage may be too small for the wheelchair”(p3)

“....the space...the furniture is so tight” (p8)

Inaccessibility of amenities posed insurmountable problems for the participants in relation to carrying out activities of daily living and maintaining a sense of well being and security. Cogswell (1968) opines that it is easier to establish a self-image of independence and personal worth in the sheltered social environment of the hospital where the doors are wide, pavements are smooth, toilets are adequate, and the needs are met than the world outside. Some participants, expressed feelings of frustration linked to restricted mobility around their homes, and in general.

While mostly mobility restriction was linked to space, mode of transport and using of hands to wheel the wheelchair, some participants shared feelings of being stuck related to their inability to even push their wheelchair due to lack of upper limbs movement. One quadriplegic participant expressed that since he received a technology advanced remote controlled wheelchair that has positively impacted his psychological well-being on self-perception.

- **Peer support**

Holicky and Charlifue (1999) revealed that those who are satisfied with the level of social support they receive display greater overall psychosocial adjustment, as well as less overall functionality disability.

Chan (2000) showed that people living with SCI related how their friends would find excuses not to have them round or even turned down invitations. Thus, a spinal cord injury may be handicapping not because it imposes actual physical limitations, but because it interferes with social relations (Kreuter 2000). Peer support, like family support, was perceived in different terms. While most participants felt that after the accident most of the people who they perceived to be close friends left them few friends remained post-injury.

Some participants felt abandoned by their peers:

“I am sitting on wheelchair...friends are now gone” (p3)

“...but now friends changed. I mean I no longer see them” (p2)

“I am paralysed...my friends are far away from me” (p5)

Some participants felt supported by their peers:

“Friends...two of them have stuck around” (p4)

“I have friend that tells me that...its alright...and that he will stick with me all the time” (p2)

“I thought I had no friends...but I do...they always come here and visit” (p6)

Some participants felt even though their former friends have left them, they felt encouraged to make new friends who could accept them unconditionally.

“it is easy for me to make friends” (p2)

“My friend...is alright now...but I do not have the one I had before the accident”(p1)

Some participants, as a way to addressing isolation, adopted means that could keep the feelings of belonging in the peer group. However, sometimes the means adopted had repercussions to their health. Gill (1999) emphasizes that after a traumatic event an individual strives towards the ideal of being and feeling normal. In this study, the participants were engaged in behavioural attempts to live as normal as possible despite the SCI and its effects.

One paraplegic participant attempted to find normality:

“I was drinking....I just want to please my friends...I wanted the company of my friends” (p1)

As a result of manoeuvring to fit in, the above participant had to be re-admitted to the hospital for the management of a pressure sore. Manns and Chad (2001) showed that people with SCI regard themselves as the same person as before the accident, “I am no different; just get around on wheels”.

Some participants adopted coping strategies which differs to the aforementioned strategies.

4.3.2.2. Ineffective coping strategies

While the above strategies were adopted by participants to deal with their conditions, the following strategies are mechanisms adopted by participants to protect themselves from the condition’s impact and its emotional turmoil. However, they are named ineffective because

they prevent participants to deal with the condition optimally. In this regard, ineffective coping strategies could be described as eliciting high levels of stress and complicate everyday functioning. Having experienced an emotional turmoil linked to setbacks brought in by the SCI, lack of self-confidence, feelings of guilt and personal inadequacy, participants used the following strategies to protect themselves. These strategies are defined as less adaptive, and their adoption is observed through higher levels of distress.

These strategies are inadequate, thus becoming counter-productive to the psychological well-being of the person. Their counter-production is linked to their effect to cloud the individual's awareness, cut him/her off from reality, or undermine his/her functioning and relationships. To compensate to lack or limitation of certain aspects about their conditions clinical impressions about the participants and data analysis reveal the following coping strategies.

j) **Avoidance**

By definition, avoidance is a strategy in which an individual intentionally or unintentionally turns to the unconscious thoughts, desires, or emotionally loaded situation in order to avoid thinking, speaking or putting them into question (Phaneuf, 2008). The individual therefore avoids anxiety, fear or other inconveniences (Phaneuf, 2008). Avoidance could be either be mental (avoiding to talk/think about something) or physical. In avoidance, individuals simply find ways of avoiding having to face uncomfortable situations, things or activities.

The participants appeared to have engaged in a cognitive and behavioural efforts referred to as "distancing" which means detaching oneself from the problem and minimizing its significance (Hanson & Ahlstrom, 1999). Distancing is another word that could be used to describe avoidance:

“they told me that I was in a car accident...and I was like “a car accident”...I said do not explain further, I do not want to hear it....I am feeling okay...I will not ask the doctors why me....only God knows why this happened...I just feel like I am on a journey or something...like the day I told the lady at the OT....and she told me...”what if you will never walk again...how will you feel?....I said “ I will feel normal...it’s a brand new life for me....I will not have a problem with anything” (p6)

“I do not think about it much...if I told myself that” (p4)

k) Rationalization

Rationalization is a strategy through which an individual gives him/herself a more or less logical explanation for an act or decision produced by unconscious impulses (Phaneuf, 2008). In this study, while the participants’ reasoning appeared logical. However, they masked reality and they avoided undertaking a genuine self-assessment of their feelings. This elicited anxiety and tarnish an already re-conceptualized self-image, which is upheld through the process of rationalization.

According to Bishop (1980), the behaviour of focusing on the bright side of an otherwise bad situation can also be interpreted as “selective ignoring” which is another form of coping strategy. Through a process of selective ignoring, participants applied reasons of how come they choose to perceive their condition in the way they do. The participants in this study were no different; even participants with high levels of injuries hoped for recovery:

“the doctor said...I will not be able to walk again...I took it for granted, because I know my God is alive, even if the doctor can say that, but the final word comes from my God....I believe one day I will leave this wheelchair...I do not care what the doctor said, it is the way

he sees it. My life is full of stories...I am always struggling to survive until right now....after this...I believe that God wants to show me something.”(p8)

l) **Intellectualization**

Overcome by shock, and in disbelief of their conditions, some participants sought to relate their experience in an abstract and detached thinking to control or minimize overwhelming emotions. This strategy is referred to as intellectualization. It is the avoidance of emotion by focusing on facts and logic (Phaneuf, 2008).

One participant used intellectualization to minimize the greater impact of having been diagnosed with a SCI:

“I love people and I am a friendly guy...and sometimes... I am just too normal...I do not feel like...even people...I just tell them if I may not walk again...joking...something like that...I read a lot books...there was this one that I read...titled Think Big....that motivated...like this guy does not have both hands and legs...but then he can still do a lot...too much” (p3)

m) **Denial**

Denial allowed participants to hide from reality that is too hard to cope with. Through denial participants functioned by ignoring or misrepresenting thoughts or experienced that would be upsetting if accurate, for instance the true nature of their disability was denied. Lustig (2005) concurs that in adjustment to SCI, denial is viewed as “negation” of the consequences of the impairment allowing the individual to maintain a sense of competence and self-esteem based on the pre-injury functioning.

Participants in this study adopted denial as way to minimize any personal threat, loss of physical abilities or the possibility that one will not completely recover.

“I just ignore it everyday...I just wake up...I just ignore...I just told myself that it is going to be fine...then I do not think about it much...if I told myself that...” (p4)

“Now I cannot tell the truth (about what if he does not walk again)...what...I am still hoping that I will walk again” (p7)

Triechmann (1988) showed that denial can play an important function in helping individuals to cope with traumatic experiences. In this study, most participants were under the age of 35, when their injuries occurred. It is not unusual for them to express disbelief at the timing of injury in relation to their age.

n) **Anticipation**

To give themselves strength to deal with the situation, some participants thought about the moment when their body will release sensations to bodily areas currently not active. Participants hope they will no longer be dependent on others; they will make their own ways and enjoy life. For this, participants were in anticipation. Anticipation allows a person to experience in advance the emotions associated with a given situation (Phaneuf, 2008). This coping strategy becomes counter-productive in that participants at times inevitably expected negative outcomes from their situation thus eliciting feelings of anxiety and worry.

“I have been thinking...the first time when I was in the hospital at Rustenburg...I did not think that I will be fine...they told me that it would take a long time to recover...and as time went on when I was admitted here...I started worrying” (p5)

o) Substance abuse

Literature reviewed indicated that substance abuse disorders occur more often in persons with disabilities than in the general population (Flambouras, 2002). Individuals with SCI who use; illicit substances are more likely to experience anger and anxiety, reduced quality of life, psychosocial distress, social isolation and unemployment, pressure sores (Delambo et al., 2010). This is even complicated for persons with substance dependency issues, having a SCI significantly decrease the probability of successful substance abuse recovery (Delambo *et al.*, 2010).

Participants of the study were not exempted from experiencing substance abuse as a way to deal with their condition:

One of the participants shared the following after being re-admitted for a pressure sore management:

“I was drinking...going to the tavern six to six...sleeping at the tavern and go home in the morning” (p1)

4.3.2.3. Outlook of life post SCI event

The participants were found to yearn for independence, and therefore life post-SCI was characterized by a feeling of hopefulness and being future oriented. Participants appeared to be trying to hold on to what might have been had the injury not occurred. For this outlook on life post SCI event refer to the hopes and wishes maintained by the participant in making sense of the life after the accident.

This was expected, since following an unexpected shift in life circumstances as a result of disability, the usefulness of existing schema for understanding the world are likely to be

challenged. In coming to terms with the disability most participants expressed hope for the better future for themselves. Coming to terms meant that individuals had resigned themselves to the realities of what happened and that nothing could be done to change the situation.

The participant expressed hopes of returning to their earlier state of health and everyday life as it was before the injury. The outlook of life post SCI event was linked to “*aspiration for educational advancement and securing employment, achieving “normal” functioning, anticipation for positive future experiences, and searching for meaning and purpose*” were expressed as aspects of life that participants gave weight to achieving a quality of life and psychological well-being, regardless of the level of injury and functional ability.

p) Aspiration for educational advancement and securing employment

While it is beyond the scope of this paper to view life satisfaction amongst the unemployed and employed individuals. However, what remains is that participants of this study expressed their life post-SCI as being striving towards being independent through finding and securing employment opportunities and study further. This seemed to provide the participants with reasons for living.

Participants expressed the following in striving for an optimistic outlook on life:

“I want to do sport...basketball...together with my studies” (p1)

“I will do what I want on a wheelchair...go back to school...study and have my own future”
(p2)

“I am going to be a business woman...and always praising God” (p6)

“I want to become a businessman even if I do not know what kind of a business...but I like to have a business...and I will have it”(p3)

q) **Achieving “normal” functioning**

While the concept of “normality” is a self-definitive concept, in this context normality for participants meant striving towards the ideal of being and feeling normal. In order to boost their self-esteem, the participants saw themselves as capable, except for the fact that they used a wheelchair for moving around. Normalization helps them maintain an acceptable body image and feeling normal is vital to psychological health.

One participant who had not been home since the accident, expressed hopes of achieving normality outside the hospital territory:

“being at home I think it is going to be normal...I know it is going to be tough for me there and there...I cannot walk the way as I use too...but I know when time goes...I get use to it...I know I am a strong person” (p6)

All participants expressed wishes to be valued as a normal by others, and for this matter they were observed adopting strategies to maintain a sense of normalcy.

“hmmm!!...you can’t tell me its other people, because you have to accept yourself...I’m walking with a wheelchair...” (p1)

“In future I want to see me doing something...I don’t want to sit like this and say...I’m disable...and been seen as normal”(p2)

“I will have to find someone I love...one who will understand the condition...and she can treat me like a normal person” (p3)

“I always put a smile on my face...that is who I am...you will never see me angry...the way they talk to me is just being normal” (p6)

Expressions of future experiences were noticed as affirming them as being with a sense of determination and value.

r) Anticipation for a positive future

In sustaining a traumatic event, participants were faced with a challenge of re-evaluating their pre-injury wishes and dreams were still possible to achieve in the aftermath, despite the feelings of being shocked. The participants expressed undying hope to aim and forge a brighter future for themselves:

“In future I want to see myself doing something...I do not want to sit like this...I am disabled...I want to do something...I can be able to go to school...having work maybe” (p2)

“I am still hoping that there is a positive future...just want to see myself one day...driving whatever ...”p3)

“I want to do sport...basketball...together with studies” (p1)

The hope to recover made them keep track of small gains and hold on to the possibility of getting better and achieving their future. As participants grappling the impact of their condition in all aspects of their lives, they sought for meaning and purpose despite the odds.

s) Sense of meaning and purpose

Suffering triggers a search for meaning in which the individuals (victims) have a powerful need to make of their lives. SCI is an acquired disability, which means the need to search for meaning of the injury is in the individual's total life sphere.

Most of the participants' attempted to continue to make sense of the injury:

“I have come a long way from 2006 and now...it has been five years in a wheelchair...I have learned many things and cope...I have also met many people who are in a wheelchair” (p1)

“I am still trusting that I will walk again...I will get out of this wheelchair...I still trust that” (p7)

“I am not going to drag a wheelchair for the rest of my life. That is what I know” (p8)

“Yes, I am accepting it...it is the way it is...I have to cope....as long as I stay positive” (p3)

As participants engaged with all aspects the future and working towards shaping the future in a way they want it for themselves, they maintain an optimistic outlook to life. They perceived each increment of progress as worthwhile, even though it fell short of their original hopes.

Contrary to the optimistic outlook on life post SCI event participants’ perceptions about the future was accompanied by underlying fears. Participants could not bring themselves to face the fact that from then on, they would never walk again, it was too devastating

While fear was a common underlying thread amongst the participants in viewing the future, few participants verbally acknowledged that fear:

“from now onwards...I have not been thinking...I do not know my future...I just pray day and night to see myself getting strong to fight these...how would I survive...I do not know”(p5)

“Sometime I start to think about my future...then I start to worry” (p7)

This was expected, since following an unexpected shift in life circumstances as a result of disability, the usefulness of existing schema for understanding the world are likely to be challenged.

Nevertheless despite the reality of the participants' context, characterized by loss of independence and lifestyle changes, remaining hopeful and foresee a positive future stood-out in their perception about the future.

4.3.2.4. Discussion on the impact of psychological effect

The impact of psychological effects remains devastating and life-changing event. Persons with SCI are faced with adjustment difficulties to find a sense of well-being. Participants being overwhelmed by the traumatic event of SCI and experiencing emotional overload have provoked the abovementioned impact of psychological effects in terms of coping strategies. However, it is by no means that these strategies highlight pathological problems for the participants, for that is beyond the scope of this research. Thus it should be noted that these strategies emerged clinically at the time of data collection. Research supports that different coping mechanisms will predominate at different points in an individual's functioning (Cramer, 2007).

A study by Hanson, Burkelew, Hewet and O'Neal (1993) investigated the possibility of important differences between the types of coping strategies used immediately after injury and several years post-injury. The findings indicated that the relationship between specific coping strategies and adjustment changes over time. It was shown that higher levels of self-blame were associated with high levels of psychological distress. However, five to six years later, the importance of self-blame to psychological distress had diminished. This finding supports that the aforementioned findings remain relevant and accurate for a certain context in which participants of this study found themselves, thus they cannot be generalized.

Other complications that maintained participants to adopt ineffective coping strategies; included unresolved grief, unresolved family conflict, former ineffective habits in handling

situations perceived as stressful, blaming tendencies, perception of unsupportive social system, self-questions, ineffective interactional styles maintained by self-blame, seeing one as victim, overly independent, dysfunctional family traits and suicidal ideation. Gill (1999) points out that adjustment can be negatively affected by; limited social support, a sense of hopelessness, low self-worth, a fragmented family system, and non-religious or non-spiritual beliefs that could lead to poor coping. It is not the scope of this research to compare coping strategies, however highlight strategies found used by the participants' of the study and indicate how they further complicated or less complicated their psychological well-being after sustaining a SCI.

Despite the type of coping strategy adopted by the participants of this study, during the interviews, it became apparent that two explanations were common to all the individuals as they described their experiences. The first was wishing to be valued as normal and the second was the use of strategies to maintain a sense of normalcy. To this end, life continued for the participants. For this, the participants in the present study did not see injury as the end of the road, but were able to focus on positive things, and have plans for the future.

4.4. RESEARCHER'S EXPERIENCE OF FIELDWORK

The researcher encountered an unanticipated major delay in gaining approval thus gaining access to the research site. It took four months to be given ethical clearance by the Medunsa Research Ethics Committee. After this hurdle was cleared, there were no more major difficulties.

The researcher was welcomed at Dr George Mukhari Hospital Spinal Unit. The researcher shared some similar background with the participants, in terms of race. He addressed the participants with their preferred names which indicated warmth and respect and the

participants referred to the researcher by his name. That approach bridged the social class gap. Listening to their experiences, the researcher experienced a ranged of emotions including sadness, empathy, anger and having a need to mobilise participants that seem stuck in their process for adjustment and adaptation.

Two quadriplegic participants, with limited physical mobility and usage of the hands, profoundly impacted the researcher. It is not easy to meet with people in hopeless situations and have nothing to offer. However, ‘we have to listen to accounts of experiences and emotions for which we may have no remedies’ (Madjar & Walton 1999: 7). The heightened level of dependency was formidable. Both expressed the wishes of how much if their hands could work, their adjustment and adaptation could yield positive psychological well-being. Due to the lack of mobility of upper limbs, a placement is perceived as preferred accommodation as not to over-burden their families.

4.5. CONCLUSION

This chapter presented the characteristics of the participants selected for this study and on how the participants subjectively experienced their SCI with regard to their psychological well-being. Two main themes emerged: the psychological effects of SCI and impact of these effects on the well-being of the person.

The psychological effects faced by persons with SCI were linked to diminished independence, intrapersonal changes, altered interpersonal relationships and emotional disturbance. The psychological effects seemed to be devastating to the optimal functioning of the participants. The acquired paralysis generated feelings of loss. This loss was with regard to mobility, control, pleasure, identity, independence, spontaneity and threat of loss of life at the time of injury. In this study, participants perceived their loss of dependence linked to

limited physical ability and slow progress, as well as financial dependency, thus relying on others for survival.

The impact of the above effect was perceived as life changing. The impact of the psychological effects of SCI was linked to psychological adjustment. Psychological adjustment referred to the variety of coping strategies adopted by participants and their perceptions post-injury. The coping strategies included effective and ineffective coping strategies. Most participants struggled as they attempted to make sense of the effect of SCI. Life post-injury was perceived with mixed emotions that of being hopeful and on other hand fearful; hopeful that their (participants) condition would change for the better, yet fearful as to what if it does not. For this reason to deal with the devastating and irreversible impact of SCI, participants attempted to engage in a process of reconstructing the self, coming to terms with disability, and striving for maintaining a positive outlook post-SCI.

In this chapter the impact of a SCI on the psychological well-being of participants was highlighted and remains significant in determining the adjustment and life satisfaction post-SCI for the participants.

Chapter 5 discusses the reflection, limitations of the study, makes recommendation for further research and conclusion.

CHAPTER 5

REFLECTION, CONCLUSIONS AND LIMITATIONS

5.1. INTRODUCTION

Chapters 1 to 4 highlighted the nature of the study, the literature underpinning the study, the methodology used and findings of the current study. This chapter begins by providing a reflection on the findings of the study, thereafter highlights the strength and limitations of the study, and lastly recommendations for future research.

5.2. REFLECTION ON THE STUDY FINDINGS

The study set out to explore the subjective experiences of SCI persons exploring the psychological effects of SCI at Dr. George Mukhari Hospital. To achieve this, the primary objectives of the study were to; explore the psychological effects faced by SCI individuals; and explore the impact of these effects on their lives and well-being. The researcher chose a qualitative approach for its valuing of whole persons who create meanings; considering of contextually meaningful experience and seeking to understand the daily living and practical concerns. This approach was chosen because it allows for a detailed account of participants' experiences, it offers itself as a record of human encounters; the interface between persons and their world.

According to Collis and Hussey (2009) experiences and the people that embody them are constituted by past experiences, present situations and future aspirations and potentialities. Thus, experience is not just something that happens to a person; it is something the person lives and therefore embodies his or her life. Experience refers to the subjective involvement of persons with their world.

In this study, the experience of being diagnosed and living with SCI was sought through exploration of the participants' perceptions of that experience. The overall goal was to raise

to awareness the experiential context of SCI and hope to encourage incorporation of knowledge gained into psychological interventions. The central question in the study was “what has been the impact of SCI in your life and how do you cope with the impact”?

Within the study the impact of SCI emerged as a life changing event with negative effects on the psychological well being of the participants. Sustaining a SCI was highlighted as a personal event. For the participants their experience was of being thrust suddenly into self-conscious living, forever confronted by; physiological, psychosocial and environmental challenges. The SCI body could no longer be relied upon the person could not flee from danger, could not always go where they wish to go and further, also determines how others in their environment respond/react to them.

Through the analysis of their data, it was clear that the sudden loss of movement due to paralysis had tremendous impact in all aspects of their lives. Various issues; such as finances, mobility, self-image, future are the aspects touched by the participants as being disrupted by the SCI. The psychological effects were linked to diminished independence, intrapersonal changes, perceived changes in interpersonal relationships and an emotional roller-coaster.

For the participants, lived time was disrupted by their injuries. The smooth flow of life was suddenly arrested and the taken-for-granted future disappeared and was replaced with uncertainty. Their lived time was spent waiting and hoping for the return of motor function; being bathed, clothed and fed, taken back and forth whenever required, put to bed, financial dependence and able to access amenities with ease.

The participants were keen to talk openly about their experiences and their predicament. The keenness was accompanied by mixed emotions, such as; a sense of hope, anger, hopelessness, courage, helplessness, denial, numbness and discouragement. A sense of wanting to

overcome obstacles prevailed, if only some aspect such as the finances, body movements and support could be in their favour.

The sudden and immediate nature of disruption was reflected in the ways the participants engaged in denial of the reality or permanence of paralysis, namely inability to walk again. Furthermore, besides the impact of SCI on them personally, the participants were impacted by how their supporters responded to their condition. The presence and actions of others impacted on their; perceptions of reality, safety and security. The participants were concerned about being a burden to their families and yet had limited options of how they could address their constant unstable emotions towards their social supporters.

In response to their disrupted lives, they haggled to find strategies to aid themselves deal with the impact of SCI. As they engaged with the process of psychological adjustment, coping strategies differentiated between effective and ineffective, became apparent for participants to find “normality” for themselves.

Despite the significant impact the SCI had on their functionality and psychological well-being, participants strived to hold on to and never give up on hope. Hope for a better future was observed fostering an ability to empower the participants to wish for and imagine things in a way acceptable for them. The way in which participants came to terms with their situation highlighted the role of spirituality in a person’s life. Another significance was the need for social support and the searching of alternative ways to regain some independence for themselves. According to Marks (2000) people with disabilities often state that the most difficult thing they have to deal with is not their disability, but how people react to them. The study findings support such findings.

The participants showed the urge to want to gather their lives when they made efforts to get the lives under-control and reconceptualise their being-in-the world (through a process of

letting go of a former identity and achieving “normality” with the identity post-injury) and the resolution to continue with life within the limitations imposed by the disability.

The study findings highlights that SCI due to trauma is an uncommon condition that has a significance on the injured person’s functional, medical, economical as well as psychological. Assistance from family, friends, various health care professionals and community is vital in the adaptation process which in this study was perceived with mixed perceptions. Psychological well-being remains the crux for effective rehabilitation programmes.

5.3. LIMITATIONS OF THE STUDY

- The findings of this study are derived from a purposive sampling process; therefore, the generalizability of the findings is limited
- While it was not the intent of the study, 6 of the participants were males, 2 of participants were females. The researcher’s gender could have prohibited discussing matters considered taboo, since female participants refrain from sharing about the impact of SCI on their sexuality.
- The “time since their injury” differed from participant to participant. This could possibly have influenced their current experience about the extent of an impact SCI has had on their psychological well-being. It could be argued that positive psychological adjustment may be achieved over time as a person with a disability improves.
- It was not established whether any of the participants had suffered from depression or related conditions pre-morbidly. A pre-morbid tendency could have impacted their manner in which they reacted to the experience of SCI.
- Some participants had not received any psychological intervention, thus used the interview as part of a therapeutic process for them to find a coping strategy. The

intense emotions shared could have been influenced by the fact that to some it was the first time to reflect and speak about what happened.

- Not all participants were of the same culture or education background which could be considered an influencing factor owing to the fact that the less educated individual may find self-expression a daunting task, and may often respond to the some questions with fewer details. Prior the interview it was never established how fluent are the participants in English as a spoken language.

Despite these limitations, the researcher is of the opinion that the study offers substantial awareness into the impact of SCI from the subjective point of view of those who are living with.

5.4. RECOMMENDATIONS

Based on the findings of this study, the researcher makes the following recommendations:

- Further research comparing psychological effect of SCI and psychological adjustment post-SCI between quadriplegic and paraplegic clients would be useful to provide health professionals to tailor their service delivery effectively and provide appropriate intervention to aid clients post-discharge.
- A holistic approach in the delivery of care be adopted for SCI persons and begin with rehabilitation, which addresses the whole person and targets psychosocial functioning and extends to community support programme. Holistic approach refers to the inclusivity of other professions with the medical system as well as other personnel that may be in contact with the SCI persons within their homes.
- Provision of appropriate SCI psychological interventions aimed to address the needs of the persons with SCI in real life situations. For instance, participants wished there was support on how best to handle life after SCI especially post-hospitalisation.

- How to deal with their emotions within the comfort of their communities.
- The aim of rehabilitation is to teach clients with SCI how to achieve an optimal independent and satisfying life style in their community. There is a great need for health institutions to provide long-term follow-up services, especially psychological assistance aimed at integration learning for the clients.
- Education as a tool to change behaviour is necessary to deal with the lack of knowledge about disabled people, and for this family therapy at secondary and community education at tertiary level is necessary in supporting the physically challenged individuals to lead “normal” lives.

5.5. CONCLUSION

What is significant with this research is not the finding of psychological effect of SCI and its impact on the person with SCI well-being, yet it confirms the need for appropriate SCI psychological interventions in a supporting context of SCI persons by clinical psychologists. Diversifying and responding to per SCI person’s psychological support, in the form of coaching and mentoring is novel. The researcher envisages the application of coaching psychological interventions would improve the devastating effect of SCI on post-injury.

The limitation of having conducted the study in a specific context with a particular type of people provides an opportunity for further research and comparison of findings that may be done elsewhere for persons with SCI in South Africa. Further attention in ensuring optimal functioning of an individual post SCI remains an area of further research for the field of clinical psychology and other health professionals who are involved in the SCI persons’ rehabilitation. Thus this chapter sought to provide a reflection of the study, discussed the limitations, and made recommendations for practice and further research.

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APPENDIX 3

Interview guide

Since the interview followed a semi-structured format, the following interview guide was used:

- **Life prior to the SCI diagnosis**

Exploratory question (s): How was your life prior the diagnosis of SCI?

What was important to you?

How was your relationship with your significant others (friends/family)?

- **Impact of the SCI: Emotionally, Socially and Interpersonally; and Economically**

Exploratory question (s): Since the accident how has been your life?

What has it been like to be diagnosed with a SCI?

How do you see yourself now?

How are you relating to others?

How do you perceive others relate to you now?

What are the changes in your life that have come about since the accident?

What/who is your most constant source of emotional support?

- **Coping mechanisms**

Exploratory question (s): How are you coping with the whole situation?

What are your everyday stressors/struggles?

How do you cope with everyday stress?

What is your perception of life?

If you were to summarize your life currently what would you say?

- **Future outlook**

Exploratory question (s): From now onwards how do you see life to be like for you?

What is your view about the future?

APPENDIX 4

Biographical Data Sheet

1. 1. Gender
Male Female

2. Age group:
18-25 26-35 36-50 51-55

3. First Language
English Afrikaans Tswana Sotho
Other, specify.....

4. Marital status
Single Married Divorced Cohabited

5. Race
Black White Coloured Asian
Other, specify.....

6. Education
No formal school Elementary School Junior high school High School
College Graduate School

7. Employment status
Employed Unemployed

8. Major financial source
Self Self and family Family Welfare
Other, specify.....

9. Living arrangement
Living alone Living with family Living with friends
Living in an institution

10. Lesion of SCI (e.g. T6, C5).....
11. Date of Injury.....
12. What was the cause of the injury.....

APPENDIX 5

Field Notes Sample

Date: 30/05/2011

Interviewee number: P1

Time: 10:38-11:24

General Impression:

The participant spoke clearly, transparent and maintained an open body posture. He seemed more open and optimistic, however seemed defensive when asked about his sex life. The participant wheeled himself into the interview room. The room utilised for an interview was secluded and quiet, except intermitted there was movement of people walking through the veranda. However there were no distractions.

Researcher's feelings:

Prior the interview, I felt motivated and energetic since this was my first interview for the study. I got to the hospital early and set-out the space to be used for interview. Through-out the interview I felt that I had to be alert not to move into a therapeutic role since the content shared by the participant elicited empathy from me.

Post interview, on one hand I felt sense of achievement of knowing that there is progress in the data collection. On another hand I felt such a sense admiration of how the participant has mobilised himself post-his injury despite the physical and psychological challenges.

Summary of Observation

The Individual expressed satisfaction with life prior to SCI. SCI lead to the individual experiencing emotional upheaval, isolation from friend and the need to please friends. The individual reflex concern for others opinion and are suspicious of others. The individual cope with SCI via acting out behaviour and rationalization of behaviours and situation. A positive outlook is evident in terms of education and physical activities.

Date: 31/05/2011

Interviewee number: P2

Time: 10:33-11:35

General impression:

The participant spoke with such determination and transparency. He had severe difficulties with his mobility since his hand movement was challenged; however he had a remote control

wheelchair which made mobility easy. In his speech he constantly remained reflective of how things have been for him, and how he hates the fact he is 99% dependent on his others to attend to his everyday needs. His engagement elicited an impact of wanting to be friends with him by the researcher.

Researcher's feelings:

Prior to the interview, I had eaten something to boost my energy levels. Having noticed the defensiveness of the first participants on questions that related to his sex life, the researcher was aware of not repeating the same. As the interview progressed, I felt more at ease with the participant since his impact was that of being welcoming and engaging.

Post interview, it seemed like that the participant hardly gets to talk about himself, thus spoke a lot during the progress of the interview and I felt drained after the interview.

Summary of Observation

The individual expressed appreciation with life prior to SCI. After SCI the individual expressed concern that his life changed drastically. The individual expressed mixed emotional experience as well as feelings of responsibility for his family. The individual copes with the changes in his life by expressing his concern about his family and by making use of available support groups. A positive outlook is evident in terms of education and physical activities.

APPENDIX 7

Informed consent

UNIVERSITY OF LIMPOPO (Medunsa Campus) CONSENT FORM

Statement concerning participation in a Clinical Research Study.

Name of Study: Psychological effects of spinal cord injury: An exploration into the subjective experiences spinal cord injured persons at Dr George Mukhari Hospital

I have heard the aims and objectives of the proposed study and was provided the opportunity to ask questions and given adequate time to rethink the issue. The aim and objectives of the study are sufficiently clear to me. I have not been pressurized to participate in any way.

I understand that participation in this Clinical study is completely voluntary and that I may withdraw from it at any time and without supplying reasons.

I know that this study has been approved by the Research, Ethics and Publications Committee of the Faculty of Medicine, University of Limpopo (Medunsa Campus) / Dr George Mukhari Hospital. I am fully aware that the results of this study will be used for scientific purposes and may be published. I agree to this, provided my privacy is guaranteed.

I hereby give consent to participate in this study.

.....

Name of Recipient

.....

Place

Date

Witness

Statement by the Researcher

I provided verbal information regarding this study.

I agree to answer any future questions concerning the study as best as I am able.

I will adhere to the approved protocol.

Bhekani G. Tshabalala

Name of Researcher

Signature

Date

Place