

**THE PERSONAL AND EMBODIED EXPERIENCES OF PEOPLE LIVING
WITH A SPINAL CORD INJURY IN THE OR TAMBO DISTRICT
MUNICIPALITY IN THE EASTERN CAPE**

by

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DECLARATION

I declare that **THE PERSONAL AND EMBODIED EXPERIENCES OF LIVING WITH A SPINAL CORD INJURY IN THE OR TAMBO DISTRICT MUNICIPALITY** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references.

SIGNATURE
(MRS SN MAGENUKA)

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Abstract

The study was undertaken to deepen understanding of living with a spinal cord injury (SCI) in the rural communities of the Eastern Cape Province, South Africa (RSA). The OR Tambo District Municipality, which was selected for its accessibility to the researcher, is virtually rural, the infrastructure is poorly developed and there is low socio-economic activity in the rural areas of the old Transkei.

In the RSA services for management and rehabilitation of SCIs varies from province to province.

A Heideggerian phenomenological approach was used to interpret the meaning of living with SCI persons in a rural community. The purpose was to describe and interpret what being-in-the-world as a spinal cord injured person meant to the participants. A key assumption in phenomenology is that understanding human beings and their actions is best achieved through examination of human experiences. Experience, including experience with living with SCI, offers itself as a record of human encounters, the interface between persons and their world, and experience can only be understood in terms of background and the social context of the experience (Pateman & Johnson 2000: 51).

Phenomenological interviews with ten people living with SCI explored their experience. The overall goal was to increase awareness of their experiences of living with SCI, and to encourage incorporation of knowledge gained into nursing practice. The central question in the study was 'What is it like to live with a spinal cord injury in a rural community?' Data were analysed according to Heideggerian hermeneutic phenomenology.

Two main themes were identified, namely reconceptualising being-in-the-world as a person with a disability; and being-with-each-other: experiencing being excluded, objectified and marginalized. The participants engaged in a process of reconstructing their identities following the traumatic loss of sensory and motor functioning. Data reflect the social and

economic context in which living with SCI is experienced. The respondents' life experiences were influenced by socio-political, economic and historical factors, namely geographic location, poor infrastructure, poverty, low educational status, and unemployment and the community at large. It was noted that participants experienced difficulties in several areas in their daily life realm; naming, coping with health and disability problems, family interactions and relationships, and non-accessibility of amenities, including their own dwellings. In addition, being a person living with an SCI in the rural communities of the OR Tambo District Municipality carries a high physical and social risk due to lack of resources. The inability to live up to generally expected social roles led to role dissatisfaction. There is an urgent need for social support to overcome the negative societal attitudes experienced. They are forced into isolation with a limited social life and are poorly integrated into the communities in which they live. Most of what the participants raised pointed towards inadequate preparation for the outside world. Therefore, a holistic approach to rehabilitation is recommended, as holism means addressing the physical, social, emotional and cognitive needs. Accordingly, the researcher developed guidelines for facilitating community integration.

In conclusion, understanding how people experience living with SCI in a rural community is an essential prerequisite to the development of appropriate strategies to facilitate community integration.

KEY WORDS

Adjustment; experience; Heideggerian; men's health; phenomenology; rural communities; spinal cord injury (SCI).

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“No feast comes to the table on its own feet”.

So it is with this thesis, which required the caring attention of many minds, the work of many hours and the efforts of many hands. I wish, then, to express my gratitude and thanks to the following:

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Dedication

*I dedicate this work to my late parents
Mthawungeni and Nomangesi, my late husband
Namba, and all persons living with a spinal cord injury*

“As humans we live as subjects through our bodies. All understanding, our memory, perception, emotional and cognitive relations to the world, is embodied.”

(Dahlberg, Drew & Nystroom 2001:54)

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Chapter 1

Orientation

1.1 INTRODUCTION

South Africa (RSA) has no integrated comprehensive service for spinal cord injured (SCI) persons or an integrated social system. The facilities and services for SCI persons' management and rehabilitation vary from province to province. Rehabilitation services criteria are selective because of inadequate resources. State disability services in RSA are strongly oriented to vocational rehabilitation, and tend to exclude those assessed by professionals as being incapable of paid employment. For example, one province can only refer children and patients who are employed to the single, small unit they have for rehabilitation (Department of Health 2003:2). Other patients are returned to their rural hospitals, with no rehabilitation services, 1 to 6 weeks after surgery (some sent home and die even before the disability grant is through (Department of Health 2003:2).

Thus, in South Africa, the quality of care for SCI is dependent on the injured person's location. Not all provinces have specialized SCI units, and staff shortages in some of the existing ones mean they do not have all the members required for the multidisciplinary team for SCI management.

This study explored the lived experiences of SCI persons, in order to understand and gain insight into the meaning of being a person living with SCI in the rural communities of the Eastern Cape Province. Table 1.1 represents the distribution of the SCI units in the country.

Table 1.1 Distribution of specialised SCI units in RSA according to provinces

Province	Location	Number of beds
Eastern Cape	Umtata (Bedford Hospital)	50 (only 35 in use - 01/09/04)
KwaZulu-Natal	Durban (King George Hospital)	60
Gauteng	PTA Academic Kalafong/Garankua Natalespruit	(small unit) information not available information not available
Western Cape	Conradie	120 (\pm 350 pts per annum) + private rehab facilities
Free State	Pelonome	20
Limpopo, Mpumalanga North West, Northern Cape	None	

Source: Department of Health (2003:3).

1.2 BACKGROUND TO THE STUDY AND STATEMENT OF THE PROBLEM

Disability affects people all over the world, but does not have a “universal character”, as it is shaped by cultural and social factors (Kim & Kang 2003:155). The experience of disabled people varies across cultures as well as across time (Kim & Kang 2003:155). The occurrence of a sudden traumatic spinal cord injury is an unexpected event rendering a person who was previously fit and well completely paralysed and with a permanent disability. The event becomes a defining moment, separating the individual’s life into two parts – before and after the injury. Their life has been changed forever in one second. The person’s reality has been disrupted (Sedler 1987:438).

While working as a clinical nurse in surgical wards and emergency rooms (casualty) in a rural hospital in the Transkei, the researcher became interested in how SCI persons experience living with the disability. Cultural celebrations in that part of the country would inevitably end in “friendly” stick fights among the youth, displaying their skills. It was not unusual for these to turn ugly with a real fight breaking out. These and faction fights that occasionally erupted resulted in participants being killed or maimed from their injuries, as *pangas* (a broad heavy knife of East Africa, used as a tool or weapon) and other sharp instruments were used. Young men who sustained SCI would be flown to a specialized orthopaedic hospital, over one thousand kilometres away. These young men only returned

months or years later in wheelchairs, with urinary and skin problems. The researcher and other nurses often wondered what kind of life these patients had and how they coped.

1.2.1 What is a spinal cord injury (SCI)?

According to Inman (1999), the earliest description of SCI was found in the Edwin Smith Surgical Papyrus, written about 2500 BC (Hughes 1988:78). The patient is described as “one having a dislocation in a vertebra in his neck, while he is unconscious of his two legs and his two arms, and his urine dribbles. Another patient was denied any form of rehabilitation, an attitude that persisted until well into the twentieth century” (Hughes1988:78).

The National Institute of Neurological Disorders and Stroke (2003:5) describes spinal cord injury as occurring when a traumatic event results in damage to cells within the spinal cord, or severs the nerve tracts that relay signals up and down the spinal cord. The most common types of spinal injury include bruising and compression. Other types of injuries include severing or tearing of some of the nerve fibres, usually as a result of a gunshot wound, and also specific damage to the corticospinal tracts of the cervical region of the spinal cord. It should be noted that damage to the spinal cord does not stop immediately after the initial injury, but continues in the hours following trauma. These delayed injury processes present windows of opportunity for treatment aimed at reducing the extent of disability resulting from SCI. Ideally, therefore in order to limit secondary damage, drug therapy (methylprednisone) should commence within the first eight hours post injury (Mitcho & Yanko 1999:61).

Any damage to the spinal cord is potentially very serious. According to the Quadriplegic Association of South Africa (Qasa) (2003:2), a person with a SCI may experience some or all of the following effects:

- Inability to move limbs.
- Inability to sense pressure, heat or cold in parts of the body below the level of the injury. Without regular monitoring, blood supply to these areas may be diminished, resulting in skin damage.

- Inability to feel when the bladder is full and to empty it voluntarily.
- Inability to feel when the bowel is full and to empty it voluntarily.
- Involuntary muscle spasms below the level of the injury.
- For men, inability to achieve an erection and reduced fertility. Fertility is not usually affected in women with SCI.
- Unusually low or, more rarely, high blood pressure.
- For people who have quadriplegia, inability to regulate body temperature below the level of the injury.
- Changes to the person's self-esteem, body image and emotional being.

Spinal injuries usually occur in the areas of greatest mobility. The most frequent sites of SCI are the lower cervical region (C4-7 and T1) and the area of thoraco-lumbar junction (T12, L1) (Smeltzer & Bare 2004:1926). 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. Injuries above the twelfth thoracic level display upper motor neuron signs such as spasticity and hyperreflexia. Injuries below this level are considered lower motor neuron lesions and display flaccid paralysis and hyporeflexia or areflexia (Wirtz, LaFavor & Ang 1996:25). An injury in the region of the *cauda equina* will cause bowel and bladder dysfunction with variable motor and sensory loss of the perineum and lower extremities. The neurological level of injury is determined by the most caudal neural segment with normal sensory and motor function on either side of the body (Yarkony, Formal & Cawley 1997:S48). Traumatic spinal cord injury is described as “a personal tragedy”, “devastating” and “catastrophic” (Gill 1999:1; Glass, Jackson, Dutton, Charlifue & Orritt, 1997:320; Manigandam, Saravan, Macaden, Gopalan, Tharian & Bhattacharji 2000:559). Figure 1.1 illustrates the functional activities according to level of injury (see appendix 7 for classification and types of spinal cord injuries).

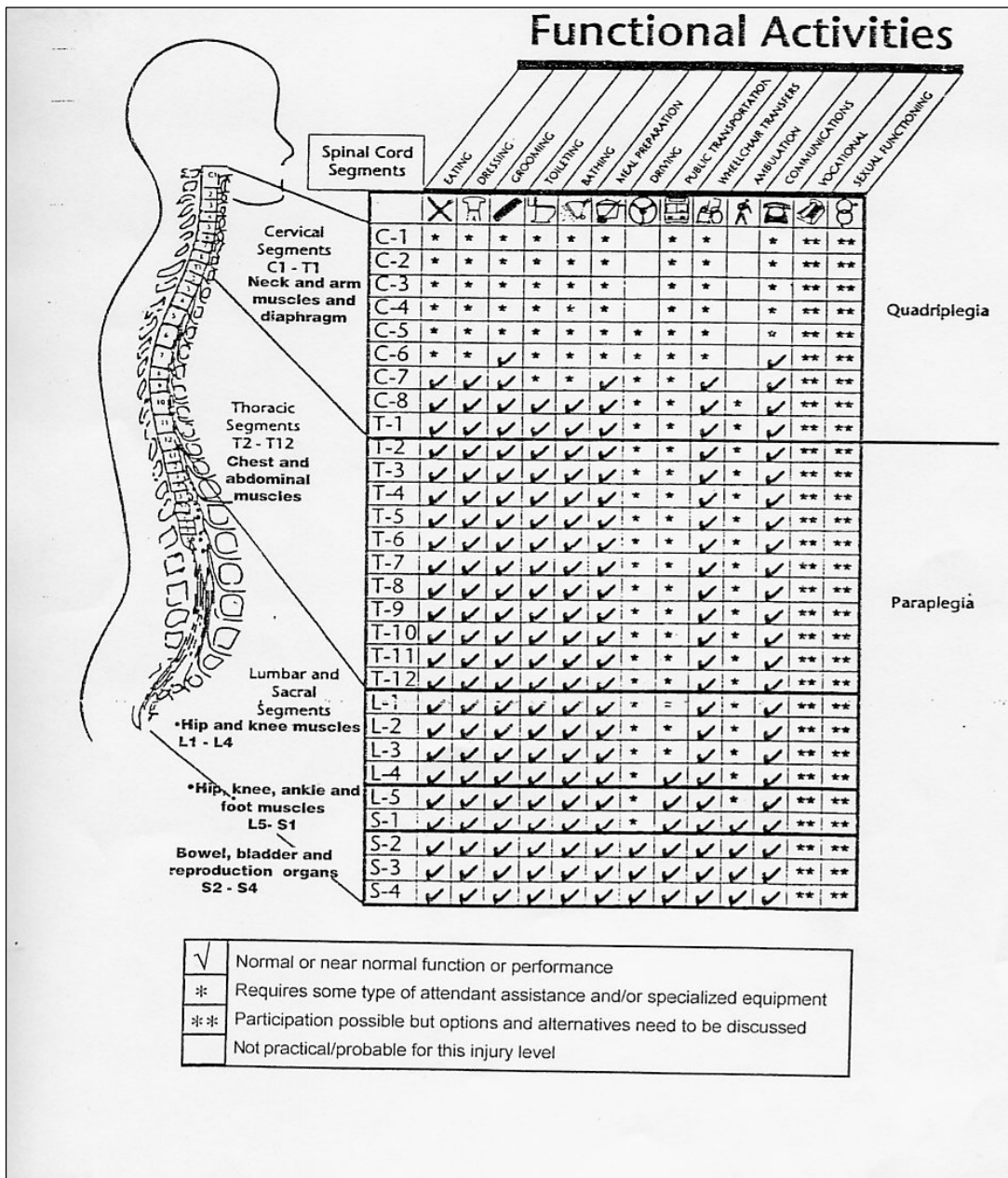


Figure 1.1
Spinal cord injury functional chart

Source: Murphy (1999:57)

1.2.2 Causes of spinal cord injuries

Injury to the human spinal cord has a variety of causes. The most common cause is mechanical trauma, with a spectrum of culturally derived accidents, such as motorbike, diving in shallow waters, playing violent sports (notably rugby), being a victim of criminal acts (stabbing, low velocity gunshot wounds) or occupational injuries, mostly in the construction industry (Sjolund 2002:251). Spinal cord injuries can also be caused by inflammatory or degenerative processes such as multiple sclerosis or in tuberculosis of the spinal cord, which can occur in all ages, most commonly from young adult age up. Later in life, ischemic SCI may result from occlusion of arterial branches due to thrombosis or dissecting vascular phenomena (Sjolund 2002:251).

The causes of traumatic SCI vary geographically. Violence is more prevalent in urban areas than in rural areas, and firearms are more frequently used in urban areas in committing crime.

1.2.3 Incidence, age and gender in spinal cord injuries

Yarkony et al (1997:S48) refer to traumatic SCI as “a low-incidence, high cost disability, requiring tremendous change in a person’s life style”. South Africa has no database to record statistics related to spinal injury to date. Qasa (2003:1) estimate the incidence of SCI as between 400 and 500 per year, and 1:20 000 person is living with SCI. These figures are based on those clients who receive care from public sector facilities. There could be more if statistics from private institutions were to be considered. In the USA, the incidence of these injuries is estimated at about 10 000 new cases each year (Young, 2003). According to Young (2003:2), the US has the highest number in the world of SCI due to gunfire with 1 500 to 2 000 new cases per year, and these statistics do not differ substantially from wartime situations. It is estimated that there are approximately 183 000 to 250 000 people in the USA with SCI (Hampton & Marshal 1999; Christopher Reeve Foundation 2003). Sjolund (2002:251) puts the incidence of SCI in the Western world at one to two cases per 100 000 inhabitants per year.

According to Yarkony et al (1997:S48), the highest incidence of traumatic SCI commonly occur among older adolescents and young adults; SCI is a male-dominated injury, and in the USA, most victims are single, white males with a median age of 26 years. Sjolund (2002) states that traumatic SCI commonly affects males at a ratio of 4 males :1 female. The Christopher Reeve Foundation (2004), however, puts the figure at 82% male and Kennedy, Evans, Berry & Mullin (2003:44) found that 56% of injuries occur between the ages of 16 and 30, with the most common age being 19.

The incidence of patients who were at least 60 years of age at the time of injury has risen. The increase in age at onset of the injury is of concern as there is a direct relationship between increase in age and mortality. Survival rates for spinal injuries are highest among persons in their teens and twenties (Price, Makintubee, Herndon & Istre 1994:38). The cause of death in SCI persons appears to be age related, with respiratory complications being more common in older adults, while subsequent injuries and suicides are more common in younger adults (Kennedy et al 2003:45; Frisbie & Ashokwe 1993). George (1996) (in Kennedy et al 2003:45), however, found that despite many reports of increasing depression with age there is evidence that perceived quality of life is not necessarily worse for older adults, even those with chronic illness. Moreover, older individuals may have developed expectations that are more commensurate with adaptation and may be able to cope with life stresses (George 1996). However, older persons with SCI have an increased risk of developing coronary artery disease than the general population because of decreased venous return as blood pools in paralysed limbs, among other things (Bergman, Yarkony & Stiens 1997:S56). Kennedy et al (2003:45) express concern that the elevated mortality and morbidity amongst older adults with SCI might propagate the view that they may not benefit much from rehabilitation.

1.2.4 Emergency care of SCI

The care and treatment of persons with a suspected SCI begins with emergency medical service personnel, who must evaluate and immobilize the patient at the site of injury. Any movement of the person, even resuscitation efforts, could cause further injury. The primary goal of the emergency medical personnel for the SCI is to prevent further injury to the spinal cord while the injured is being transported to a trauma centre. The cervical spine is

immobilized in a hard collar with the injured person in a supine position to completely immobilize the spine. Maintenance of an adequate airway, cardio-pulmonary resuscitation, and fluid management are required to ensure survival and limit secondary damage (Yarkony et al 1997:S48). Transportation should be by ambulance, or preferably air lifted. Even with much improved emergency medical care, many people with SCI nevertheless die from respiratory problems before reaching hospital.

The South African situation is not ideal for certain sectors of the population, particularly in outlying areas. Some accident victims are handled by ordinary members of the community and transported over bumpy roads, in a private vehicle to a local hospital. These people cannot make use of ambulance services because they have no means of summoning one if the local trader is away; ambulances are unavailable, or they take a long time to respond.

As a result of unavailability of qualified medics at the site of injury, what should have been only a bone fracture then complicates into a real spinal cord injury and/or turns an incomplete to a complete injury. Furthermore, the patients may have to wait for some time in a general surgical ward before transfer to a SCI unit. According to the Department of Health (2003:4), a delay between the injury and admission to a spinal unit could be anything from one to six weeks for rural patients, and within that time some die or deteriorate, develop pressure sores or pneumonia. Ventilatory failure and aspiration often occur in the first five days after injury (Bergman et al 1997:S53). Those who survive face several physiological problems for the rest of their lives.

1.2.5 Physiological 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. In addition to severe SCI causing loss of control of voluntary movement, loss of sensation and reflex function below the point of injury, the autonomic activities such as breathing, bowel and bladder control are also lost. Other symptoms such as pain or sensitivity to stimuli, muscle spasms, and sexual dysfunction may develop over time. Pain is the most disabling sequelae following a spinal injury. Sixty percent of patients with posttraumatic para-tetraplegia suffer from severe pain (Sjolund 2002:250). Pain is

“often characterized by ‘lancinating bursts or paroxysms’ of pain that are superimposed against a background of constant aching and burning, below the level of injury. Most SCI persons may experience phantom pains and may suffer chronic pain. Chronic pain syndromes usually develop months to years after injury” (Wirtz et al 1996:25). McDonal and Fish (2002:125) state that effective treatment for pain remains elusive.

SCI persons are also prone to develop secondary medical problems, such as bladder and lung infections and bedsores. Other common problems are electrolyte disturbances, especially hypercalcemia, deep venous thrombosis leading to pulmonary emboli, heterotopic ossification and urinary tract infection including renal stones (Bergman et al 1997:S54-56), are common. Neurogenic bowel dysfunction presents significant problems in both acute and chronic stages. Most problems include poorly localized abdominal pain, difficulty with bowel evacuation, haemorrhoids, and abdominal distension. These problems become more prevalent as time after injury increases (Bergman et al 1997:S54).

An emergency condition, which can lead to cerebral infarction, intracerebral haemorrhage, seizures, myocardial infarction or even death, with episodes that are common and unpredictable during the first year after the injury, but can occur at any time throughout the individual’s life, is known as autonomic dysreflexia/hyperreflexia. It occurs as an uninhibited sympathetic response to a variety of noxious stimuli, emanating most commonly from the urinary, gastrointestinal, integument and reproductive systems, even constrictive clothing, and fluctuations in temperature. An episode of autonomic dysreflexia is characterized by paroxysmal hypertension, anxiety, sweating, piloerection (goose flesh) below the level of injury, a pounding headache, sweating above the level of injury and at times bradycardia, nasal congestion and chills without fever (Wirtz et al 1996:26). A person may experience one or several of these symptoms.

According to Erikson (1980:431), autonomic hyperreflexia was first recognised by Anthony Bowlby, who in 1890 reported profuse sweating and erythematous rash of the head and neck initiated by bladder catheterisation and concurrent with a return of sole reflexes in an 18-year old boy with SCI. Again in 1917, Head and Riddoch described excessive sweating associated with bladder distension. Erikson (1980:431) notes further that [not](#) until 1947

was paroxysmal hypertension included in a complete syndrome description by Guttman and Whitteridge.

Since spinal cord injury affects every physiological system within the body, it has numerous consequences. Because of these consequences many patients require re-hospitalisation after their acute injury. The risk of readmission decreases with time after the injury. Wirtz et al (1996:26) refer to Davidoff et al's (1990) comparison of characteristics of patients who were readmitted with those who were not. They found that the readmitted group were less educated, had a longer rehabilitation, and had lost motor function. However, Burnett, Cife, Kolakowsky-Hayner and Kreutzer (2001:114) warn of shortcomings, such as non-representative sampling, limited follow-up, small sample size and univariate statistical analysis, in some studies on reasons for rehospitalisation and associated risk factors.

1.2.6 Life expectancy after a spinal cord injury

Post-war advances in emergency and rehabilitation services have allowed many patients to survive. Prior to the early 1940s, 80 to 90% of people living with SCI died within weeks (Inman 1999:26). Some with chronic ill-health did manage to live for two to three years before they succumbed to sepsis, mainly from urinary tract infections and pressure sores (Inman 1999:26). In the period before and between the two World Wars, survival following an injury to the spinal cord was poor (Oliver, Zarb, Silver, Moore & Salisbury 1988:1). Prognosis for persons with SCI improved after the development of specialized centres during World War II for comprehensive care, under the leadership of Sir Ludwig Guttman in England and Donald Munro in the US (Bergman et al 1997:S53). Guttman founded the first spinal unit at Stoke Mandeville in 1944. By the late 1940s, such patients were enabled to move back into the community and could live for ten years (Trieschmann 1988:2). Since that time, cumulative survival in the US has risen to about 88% of what would be expected in the absence of injury, during the first twelve years after injury, with even better survival for younger patients (De Vivo, Richards, Stover & Go 1991:154).

Specialized SCI units have several benefits that can be accomplished if the recommended drug therapy is commenced within the first eight hours following the injury, to enhance

neurological and functional improvement (Bergman et al 1997:S53; Mitcho & Yanko 1999:61):

- decrease in the extent of injury
- limited complications
- decreased length of stay in hospital
- greater functional gains
- decreased rates of rehospitalisation
- improved survival rates for persons admitted to a specialized unit

However, Bergman et al (1997:S53) point out that in spite of the benefits associated with SCI specialized units, many injured persons are still treated in general hospitals, where they do not benefit from the expertise of highly skilled professionals, and advanced technology as found in specialized units. This may be due to geographic or economic factors.

According to the National SCI Statistical Center in the USA (2001: 2), mortality rates are significantly higher during the first year after injury, particularly for severely injured persons. It is estimated that approximately 30% of quadriplegics die from respiratory problems and pneumonia. In the past, the leading cause of death was renal failure. However, effective urologic management has shifted the causes of death mainly to pneumonia, pulmonary emboli and septicaemia. Clearly, then, the life of a SCI person can be fraught with medical problems. Urinary tract infections and pressure sores are the most common complications and in most cases lead to septicaemia and death especially post discharge.

Due to better management of SCI for those who reach the specialized units, life expectancies for persons with SCI continue to increase. It should be noted that mortality and morbidity are inversely related; as the mortality rate declines, there is an increase in morbidity. Ironically, the provision of life entails financial and societal consequences. In South Africa most of these costs are borne by the State. This becomes a financial burden for the nation. Some people may not be covered by medical schemes, and even those who

are, it is not uncommon for them to be moved to public institutions 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. 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 (Scullion 2000:648-657; Yarkony, Formal & Cawley 1997:S48).

1.2.7 Research on SCI

Much research has been done on coping strategies, experience, learning and readjustment following a spinal cord injury (Glass, Jackson, Dutton, Charliffue & Orritt 1997:320-325). Some studies examined patient factors, such as gender, race and age, associated with psychosocial experiences; others investigated functional status and quality of life, as well as satisfaction with medical rehabilitation (Hampton & Marshal, 2000; Holicky & Charliffue, 1999; Gill, 1999; Manigandum et al, 2000; Chase, Cornille & English, 2004; Tooth, Ottenbacher, Smith, Illig, Linn & Granger, 2004).

Pain is perceived as a threat to SCI persons' function and overall quality of life and a serious problem for SCI patients (Price, Kendall, Amsters & Pershouse 2004:164; Colley & Faul 1997:100). Rehospitalisation, impaired bladder and bowel impairment, and being single or separated have a negative impact on quality of life (Tooth et al 2004:211). Mudzi (2001) describes the problems and informational needs of SCI people regarding pressure care.

Specific physical problems have been studied in South Africa such as sexuality (Sishuba 1992; Walters 2001), urinary complications (Pontier 1988; Coyle 1987); impact of pain (Colley & Faul 1997). Van Niekerk (1995) sampled 22 youth with serious SCI and examined levels of distress and found them to be more distressed than their uninjured counterparts, in a comparison group. Meanwhile McGill (1998) study assessed the bio-

psycho-social outcome of patients to their traumatic SCI. The sample consisted of three groups of black patients with traumatic paraplegia (N=35), matched to a control group (N=75) of able-bodied participants. The groups were at different stages of rehabilitation, with first group at 6 weeks post injury, the second at 6 months and the third group at between 5-6 years. The able bodied (control) group was matched for age, sex and education. The research dealt the stressors, coping mechanisms and outcome variables of SCI. Outcome was assessed by using self-report instruments which examined mood disturbances, life satisfaction, posttraumatic stress symptoms, psychosomatic ailments and sexual satisfaction. Both bivariate and multivariate correlation analyses were performed to investigate correlations and the predictive value of risk factors for negative outcome. Findings of the study suggest that the patients have a relatively poor outcome compared to Western outcome studies. The community group thus reported significantly less life satisfaction and social support and more psychosomatic ailments than the able-bodied control group. Poor outcome was attributed to limited rehabilitation and few community resources.

Carpenter (1994) found that research primarily addressed the needs of specific disciplines such as psychology, sociology, medicine, nursing, occupational and physical therapy. The emphasis was on the observable, quantifiable outcomes of short-term adjustment. (Carpenter 1994:616) notes that there is no link between data for short-term adjustment strategies and data describing the reality of long-term living with a disability.

Kreuter (2000:2) examined spinal cord injury and partner relationships, including divorce, emotional quality of SCI persons' relationships, relationships existing before and relationships established after the injury, able-bodied partners' personality characteristics, and the single SCI person's ability to attract a partner. Kreuter found that partner relationships were not generally affected as much as widely believed. However, there were problems in interpreting the varying results due to culture differences, changes in family life in society in general and the different methodologies used. Holicky and Charlifue (1999:250) report on the impact of spousal support. The results demonstrate that married individuals have less depression, greater life satisfaction and psychological well-being.

In India, Manigandan, Saravan, Gopalan and Bhattacharji (2000:559) assessed the well-being of SCI carers and found that while carers were distressed, they were not significantly depressed. Furthermore, there was a relationship between psychological distress, the educational level of carers and suicidal behaviour of people with SCI. In a study on spouses of SCI persons in China, Chan (2000:764-775) found the most stressful situations reported by the spouses concerned health issues of their injured partners, the family and marital interactions, and the care-giving burden imposed on them.

In the United Kingdom (UK), Oliver, Zarb, Silver, Moore and Salisbury (1988:x) studied the 'disability career' of post-war victims of SCI who described their lives since the injury. In a study of individuals' perception of SCI and its consequences in Canada, Carpenter (1994:614) found that the continuity of "self" was of primary importance to the ongoing experience of disability, and the learning involved was diverse and intensely personal.

Yoshida (1994:98-105) studied the life 'reconstructive process' and institutional impact on the self-concept of individuals who had sustained a spinal cord injury and had been in the community for between one and twenty-two years. The findings highlighted their feelings and concerns about the SCI, omissions in rehabilitation, lack of preparation for the outside world, and lack of attention to sexual concerns and individuality (Yoshida 1994:98-105).

Studies on people living with SCI and individual and family responses to acute SCI found that their main concern was the attitude of the public towards their disability (Thomas & Mulhern 1994; Carpenter 1994:616; Corbet 1980; Sullivan 1990:407-411). In a study in Soweto, South Africa, from an occupational point of view, Kock (1989:3-20) found environmental constraints, which block the potential of people living with SCI to lead independent and productive lives.

Since these studies were all conducted in settings completely different from the rural areas of the Eastern Cape, using mainly quantitative approaches, the results cannot simply be applied to the researcher's situation. The behaviour of disabled people is greatly influenced by their environments, their individual social and physical situations, and by wider aspects of policy and provision, including the type of services available (Trieschmann 1980:191).

In view of this gap in knowledge, the researcher deemed it necessary to conduct the study in the rural communities of the Eastern Cape, as the contexts of other studies are vastly different from where the participants of this study were drawn.

1.2.8 Setting

The setting of the study was a result of politics, economics, and history of South Africa. The Eastern Cape is one of the nine provinces of the Republic of South Africa, towards the East running along the coast of the Indian Ocean. According to the Primary Health Care Report (1997-2000:13-17), the Eastern Cape has the following characteristics:

- 64,4% of the population is rural
- 48,5% unemployment rate (Stats SA & BMR Unisa)
- is one of the poorest provinces with average monthly expenditure for 60-80% of the population less than R 800.00 a month (Stats SA & World Bank)
- serves as a labour reservoir for other wealthier provinces, with men leaving behind women and children whilst they seek employment elsewhere

The setting was chosen for its accessibility to the researcher. The Eastern Cape province is divided into seven district municipalities, one of which is OR Tambo district municipality, with several local municipalities. OR Tambo district municipality is in the extreme east of the Eastern Cape, and had a population of slightly more than one and a half million in 2001. It is an impoverished region formerly designated a homeland for Black South Africans, for thirty years until the demise of apartheid in 1994. Brink and Wood (1998:186) 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. Madjar and Walton (1999:4) emphasise that context plays an important role as experiences are shaped by cultural and social factors as well as by concerns and aspirations.

Researchers need to contextualise phenomena because “reality is actually realities which exist in the form of multiple mental constructions that are socially and experientially based,

local and specific in nature, and dependent for their form and content on the individuals who hold them and on the groups to which those individuals belong” (Lincoln 1992:379).

Although qualitative findings cannot be generalized in the same way as quantitative studies, understanding the meaning of a phenomenon in a particular situation gives insights that can be applied more broadly (Coyler 1996:498).

1.2.9 Statement of the problem

While people who have suffered SCI live longer and many live successful lives as business people and excel in sports, post injury, such as the *Ama-croko-croko*, the paralympics team, little is known about living with SCI in a rural village. Rehabilitation services to SCI are fragmented and there is no coordinated continuity of care after discharge from hospital. Furthermore, rehabilitation concentrates on the physical while the psychological and emotional issues go undetected (Carpenter 1994:615). Stiens et al (1997:S66) refer to physical, social and environmental barriers that the SCI person has to deal with.

This study aimed at finding SCI persons living in the rural and informal settlements in the eastern regions of the Eastern Cape Province, to relate their lived experiences. Moran (2001:232) describes people’s lived experiences as practical encounters with things in their environment. Given that the body is fundamental in constituting a person’s life-world, it is reasonable to assume that the life-world changes when the body changes after SCI (Sadala & Adorno, 2002:286). These changes form the basis for new experiences in interaction with people and things. The new experiences occur against a background of experience with a healthy body, and in the light of ideas, hopes about the future (Kivigne, Gjengedal & Kirkevold 2002:65). According to Trieschmann (1980:19), when persons with SCI are returned to the community they are faced with a range of difficulties. They must learn to live in a world designated for and dominated by able-bodied persons who are not very accepting of those with disabilities.

Oliver and Hassler (1987:114) divide the difficulties encountered into three discrete areas: physical, emotional and practical. *Physical* refers to the maintenance of the remaining bodily functions to their maximum and the restoration of physical health.

Emotional refers to the adjustments that may need to be made in personal and social relationships consequent to living in a wheelchair. They must learn to face people who now communicate that they are different from what they used to be, and perhaps “less” than they used to be. They must also learn to retain some sense of humour in order to cope with the daily frustrations and hard work (Trieschmann 1980:19). *Practical* refers to the constraints on adopting a lifestyle, given that society is not organized to take into account the needs of people in wheelchairs.

1.2.10 Research question

The research question was therefore: What was it like to be a person living with a spinal cord injury?

1.3 RATIONALE FOR THE STUDY

SCI persons acquire their disability suddenly. Unlike the acutely ill with a temporary state of ill health, they never get well; there is no novelty in treating them; they have lost their ‘well’ identity, and they remain disabled. There was no warning therefore they had no prior preparation for what would be a permanent state of affairs. SCI is a low-incidence disease; they could therefore be regarded as a minority group in a society that is obsessed with physical ability. For this reason, the researcher wished to give them an opportunity to tell their stories, how they experience living with SCI. Scullion (2000:667) describes disability as “a life experience which is restrictive, oppressive, and frustrating, and that disability exists at the meeting point, the interface between the person and the environment”. It is hoped that this study will identify their needs, because personal stories can help health care workers consider the impact of their actions.

Thorne (1999:400) cites O’Connor et al (1990) who state that “uncovering meanings embedded in illness phenomena, through qualitative research, nurses begin to take a wider angle of vision with regard to what clients are experiencing and what excellent nursing ought to be”.

Few studies have focused on the experiential world of SCI and more qualitative research is needed to improve our understanding of those aspects of life that are personally meaningful to SCI individuals (Carpenter 1998:99).

The nursing profession recognises that the contribution of nursing in health care is the delivery of humanistic health care, based on personal needs. In addition to care provided in acute settings, the care of persons with long-term disabilities, in institutions and in the community, is the responsibility of the nurse. The community-based health care delivery system is characterized by ensuring continuity of care, among other things. As a nurse educator, the researcher responding to the shift in health care delivery from tertiary to community-based settings, to enable students to learn how to provide support for this group of people. Kim and Kang (2003:155) refer to Treolar (2002) who notes that nurses may believe that they are working to enhance the quality of life experienced by disabled people, but their experiences may not reflect those of the disabled people themselves. The researcher's views in this study concur with Kim and Kang's (2003:154) statement that "a better understanding of the experiences of adolescents living with a physical disorder leads to a more comprehensive view of their lives which, in turn, may help them overcome the difficulties of their disabilities, and allow them to lead a fulfilling life".

The significance of this study for nursing is that "the enterprise of studying meaning in chronic illness will foster the construction of knowledge about real lives and real people – knowledge that is essential if nursing is to effectively provide them with relevant and useful health care. As we listen to the stories of real people, learn how it is from their side of how it feels to be in their bodies, [their] social worlds and life circumstances, we find ourselves making sense of illness and health care in new ways" (Thorne 1999:403).

This study also took up Littlewood's (1989:225) challenge that "whilst the 'whole' person is supposedly emphasized in current nursing perspective, the incorporation of the meaning of the disorder for the patient and their use of metaphorical language to describe their experiences into a systematic understanding has not been seriously considered".

Thorne (1999:397) emphasises that illness [disability] is not experienced as a factual clinical event, but rather as lived, cognitive, emotional, social and political event that is

entered into by thinking, feeling and interpreting beings individually and collectively. Marks (2000:206) states that healthcare providers, educators, even researchers often have attitudes about the disabled that demonstrate a complete lack of awareness regarding the actual disability experience. Marks (2000:206) adds that a disability is in itself neutral, disability is derived from interaction between individuals and the environment.

Morris (1992:161) points out that “this lack of voice, of the representation of our subjective reality, means that it is difficult for the non-disabled to incorporate our reality into their research, their theories, unless it is in terms of the way we feel”.

Re-conceptualisation of rehabilitation so as to capture the experiences of disabled people is consistent with the government policy, which expresses the government’s intention to place the needs of the patients at the centre of the health care system. The researcher is of the opinion that persons living with SCI are at risk, are underserved and not well understood. The purpose of this study was to enhance understanding and with understanding to give better care and create better policy. Further, the findings should help nurses to become more empathic and may also orient them to be more effective in advocacy, strategies, better system and service organization. A base is built upon which clinical wisdom can be constructed, and can also result in generating additional research questions that may eventually, in concert with quantitative approaches, steer the profession toward future directions that reconcile both caring and policy objectives so that nurses can better fulfil the profession’s mandate to the society (Thorne 1999:400-401).

1.4 PURPOSE OF THE STUDY

The researcher identified a need for a greater understanding of the meaning of living with SCI. In accordance with the research question and rationale for the study, the purpose of the study was to examine from the participants’ point of view how SCI persons experience living with the disability, and to describe and interpret their lived experiences in order to gain insight into the meaning of being a person living with SCI in the rural communities of the OR Tambo District Municipality of the Eastern Cape.

Chan, Lee and Lieh-Mak (2000a:505) state that adjustment to dramatic change in functioning, life styles, roles, vocation, family, social relationships is an individualized process that continues throughout life. In the researcher's view, the information supplied by the respondents will enhance understanding of their situation by health professionals, policy makers and significant others, and also enable nurses and other personnel to be more effective in meeting their needs.

1.5 OBJECTIVES OF THE STUDY

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

- identify and document experiences related to living with SCI
- identify and document the respondents' thoughts, feelings and emotions related to living with SCI
- interpret and give meaning to the lived experiences, in order to improve and deepen understanding of what it is like to be a person living with SCI in the Eastern Cape rural communities

1.6 PARADIGMATIC PERSPECTIVE

A paradigm is "a system of ideas embodying one's belief on the nature of reality and how that reality can be known. A paradigm is not necessarily proven or provable, it is just believed, but must be logically coherent. Any process of formal inquiry is guided by a set of 'basic beliefs'" (Bailey 1999:18). The ideas that form the foundation of a research paradigm or model are designed to answer three questions concerning the nature of reality (ontology); how we come to know the world, what the relationship is between the researcher and knowledge (epistemology), and how the inquirer should go about finding the knowledge (methodology). Data collection and analysis have to be grounded in an epistemological position. Methodology is the practical means of how to know; that is, the use of certain methods.

1.6.1 Origin of research paradigms

Meta-scientific reflections on social enquiry resulted in two schools, known as the meta-theories of science, namely positivism and anti-positivism. These schools differ in their ontological and epistemological positions, and as a result use different methodologies.

Auguste Comte (1798-1827) developed the main ideas of positivism between 1826-1829. Positivism is an approach to science based on a belief that social and natural phenomena are similar, a belief in universal laws, and insistence on objectivity and neutrality (Babbie & Mouton, 2001:21). Thus quantitative or positivist research is rooted in a belief that there exists a reality out there (realist ontology), driven by natural laws (objectivist epistemology), that reality can be quantified, and the appropriate way of going about finding the knowledge (methodology) is by surveys, questionnaires, closed ended structured interviews engaging empirical experimental methodology (Mouton 2001:21).

Anti-positivism is based on different ontological and epistemological beliefs, that *realities* exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them (Guba 1990:17). The discovery of knowledge (*epistemology*) is understood as the creation of an interaction between the researcher and the researched. The methods of this paradigm in the search for 'meaning' involve the analysis of descriptions or discourse that people continuously construct, develop and change their everyday interpretations of their world(s), and should therefore be taken into account in any social science research (Babbie & Mouton 2001:28).

Three meta-theoretical paradigms emerged from positivism and antipositivism, which Babbie and Mouton (2001:20) regard as the most influential, namely positivism; phenomenological/interpretivist and critical theory. More importantly, they are linked to three methodological researches in the social sciences. Positivism has experimental, quantitative and hypothesis testing as methodology. Anti-positivism has two meta-theoretical paradigms: (a) phenomenological/interpretivist, with qualitative or naturalistic inquiry, interpretative and interactional as methodology, and (b) critical theory/contructionist

with deconstruction, textual analysis and discourse analysis as methodologies (Terre Blanche & Durrheim 2002:6).

1.6.2 *Paradigm* and its application in the context of this study

Thomas Kuhn (1962) applied *paradigm* to science to describe the way people in society think about the world (Lobiondo-Wood & Haber 2002:127). Kuhn views paradigms as reconstructed logics, and from this perspective they are frameworks for justification of research activities (Atkinson 1995:119). According to Schwandt (2001:183), paradigms include “commitments, beliefs, values and methods”. Field and Morse (1995:243) describe a paradigm as “a collection of logically connected concepts and propositions that provide a theoretical perspective or orientation that frequently guides research approaches to a topic”. Mouton and Marais (1990:146) refer to a paradigm as “primarily a model for conducting normal research”. The researcher “commits him/herself to a specific theory, espouses a given methodology or set of research techniques that are dictated by the paradigm, including the assumptions that the researcher makes” (Mouton & Marais 1990:146-147). According to Neuton and Rubinson (1997:143), a paradigm is “a research perspective that holds views about how research is to be conducted, and has its own assumptions about how the world works and what is important in that world”.

1.6.3 Assumptions

Botes (1995:17) states that no research is value free; therefore the researcher must state his/her assumptions explicitly. Assumptions are basic principles that are taken for granted or considered true even though they have not been scientifically tested (Brink 1999:30; Polit & Hungler 1997:13; Burns & Grove 1997:451). According to Mouton and Marais (1992:192), at different stages of the scientific research process, and for different reasons, the researcher is compelled to make assumptions, justifying theories and methodological strategies that are not tested in the specific study. Assumptions indicate scholars’ insight into their research, their ability to reconcile ontology, epistemology and methodology (Van der Walt 2004:3).

Chin and Kramer (1999:76) state that although “these ‘underlying givens’ are taken to be true and are not intended to be empirically tested for soundness, they can be challenged philosophically. In research studies assumptions are embedded in the philosophical base of the framework of the study design; they influence the development and implementation of the research process. Assumptions in qualitative research take the place of conceptual frameworks in quantitative research.”

Assumptions are designed to answer ontological, epistemological and methodological questions of a particular inquiry. The answers to these questions are derived from the paradigm driving that particular inquiry. They should relate to the implied meta-theoretical point of departure underlying the research. Mouton and Marais (1992:192) emphasise researchers’ responsibility to clearly explicate the meta-theoretical assumptions or commitments, presuppositions, beliefs applicable to their research. Most importantly, researchers should note that if the meta-theoretical and philosophical assumptions are challenged the entire research undertaking is challenged.

The meta-theoretical paradigm for this study, therefore, was the phenomenological interpretive perspective with a qualitative approach. According to Madjar and Walton (1999:viii), interpretive inquiry is based on the idea that “no interpretation is ever complete, no explication of meaning is ever final, and also no insight is beyond challenge”.

1.6.4 Meta-theoretical assumptions

Meta-theoretical assumptions are researchers’ statements on their conception of humans and their society. These views are not theoretically grounded, but must nonetheless be reconcilable with theoretical assumptions. Their origin is philosophical (Mouton & Marais 1992:19). They serve as a framework within which theoretical statements are made (Botes 1995:17). In this study, whose aim was to understand the respondents’ own interpretations of the reality of living with SCI in a specific community, the phenomenological/ interpretive approach was adopted as a meta-theoretical paradigm, thus the meta-theoretical assumptions in the context of this study were consistent with the phenomenological/interpretive perspective (Mouton & Babbie 2001:28-31):

- As human beings we continuously interpret, create, and give meaning to, define, justify, and rationalise our actions.
- People are regarded, first and foremost, as conscious, self-directing symbolic human beings.
- Human beings are engaged in the sense of making sense of their (life)worlds.
- People are knowledgeable about their social world.
- People are continually constructing, developing, and changing the everyday common sense and interpretations of their world.
- The 'world of everyday life' is interpreted to refer to the intersubjective world, which all human beings share.
- The 'world of everyday life' is, first and foremost the object, of our actions and interactions.

There are types of assumptions that relate to the implied meta-theoretical point of departure and these are assumptions relating to epistemology, ontology, and methodology.

1.6.4.1 *Ontological assumptions*

According to Mouton and Marais (1996:124), ontological assumptions include assumptions about human nature, society, the nature of history, the status of mental entities, observation, and material phenomena and causality and intentionality in human action and behaviour.

This study referred to reality as the life experiences of people living with spinal cord injuries in the rural communities in the OR Tambo district municipality in the Eastern Cape.

The researcher subscribed to the following ontological assumptions:

- People's subjective experiences in living with SCI are real and should be taken seriously.
- Reality is dynamic, shaped by social, political, cultural, economic, ethnic and gender values.

- Reality is a lived experience, and is constituted subjectively (Denzin & Lincoln 1994:109).
- Human beings are engaged in the process of making sense of the world; continuously interpreting, creating and given meaning by the language used to describe them (Hughes 1990:116-118).
- Realities exist in the form of multiple mental constructions, socially and experientially based, local and specific, dependent for their form and content on the persons who hold them (Bailey 1997:18).
- Human experience is not closed off inside the human person, it is always world-involvement experience (Valle & King 1978:54).

The researcher envisaged that the meaning of living with SCI that emerged in this study would be influenced by the above reality assumptions.

1.6.4.2 *Theoretical-conceptual assumptions/epistemological commitments*

Assumptions regarding theoretical-conceptual commitments represent commitments to the accuracy or the truth of the theories and laws of the paradigm (Mouton & Marais 1992:147).

According to Flick (2002:43), theoretical assumptions become relevant as preliminary versions of the understanding and the perspective on the object being studied which are reformulated, and above all are further elaborated in the course of the research process. Botes (1995:7) stresses that these statements are testable, theoretically grounded, and yield epistemic pronouncements, which can lead to a better understanding of the research problem. In this study the theoretical assumptions were:

- Knowledge is relative.
- The discovery of knowledge is understood as the creation of an interaction between the researcher and the researched.
- Interpretations of the lived experiences of people living with spinal cord injuries are key to understanding the meaning of being a person living with SCI.

1.6.4.3 Methodological assumptions

Every research tool or procedure is inextricably embedded in commitments to particular versions of the world and to knowing that world (Hughes 1990:11). Botes (1995:7) contends that methodological assumptions offer the foundation for a valid research design, logical and intersubjective acceptability, and, more importantly, reflect views of the nature and structure of science in the discipline. Polit and Hungler (1997:13) describe methodological assumptions as “the way knowledge is obtained”. According to Mouton (1996:124), methodological assumptions are about “the nature of the research process and the most appropriate methods to be used, about the relative worth of quantitative and qualitative methods about interpretation versus exploration and logical generalization. Therefore research instruments and methods cannot be divorced from a perspective; they operate within in a given set of assumptions about the nature of reality, nature of human being and the relationship between the two and how they may be known.”

The methodological assumptions for the study were:

- Interviews will be best for interaction and to obtain narrative descriptions of living with a spinal cord injury.
- During the interaction between the researcher and the participant the subjective meaning of living with a spinal cord injury will be uncovered.
- Only an interactive process between researcher and participant can obtain information on which to base an interpretation.

1.7 RESEARCH DESIGN AND METHODOLOGY

A blueprint for conducting the research is introduced in this section, and is discussed fully in chapter 4.

1.7.1 Research design

The researcher chose a phenomenological, qualitative research design, which was descriptive, interpretive and contextual. Phenomenological research seeks to describe rather than explain and starts from a perspective free from hypotheses. The qualitative

approach was selected because rich descriptive data, not available through quantitative studies, were desired to document experiences and realities in living with SCI. Qualitative research aims to find out about people and approaches to collect a rich, in-depth picture of their perceptions and experiences of the phenomenon (Polit & Hungler 1997:20).

1.7.2 Population and sample

All people with traumatic SCI from the OR Tambo municipal district, who met the criteria, were eligible to participate. In this study, the sample consisted of ten Black males living with SCI, who were interviewed in their homes or in hospital, where they had been re-admitted. That the sample was males only was not intended, but depicted the demographics of people living with a traumatic SCI in the area.

1.7.3 Data-collection methods

The researcher collected data through face-to-face in-depth phenomenological interviews, and field notes. Data collection continued until data saturation was reached. The interviews lasted between 20 and 45 minutes.

1.7.4 Data analysis

Data analysis was done according to Heideggerian hermeneutic phenomenology.

1.8 TRUSTWORTHINESS

Trustworthiness was ensured through reliability and validity (see chapter 4).

1.9 ETHICAL CONSIDERATIONS

Ethical considerations were implemented to prevent ethical dilemmas. The researcher obtained permission to conduct the study from the Provincial Department of Health Ethical Committee and to use people as the main source of data. The researcher also observed the universal ethical principles adopted for the conduct of research with human

participants. The researcher explained the nature and purpose of the study and asked the respondents to consent to participate in the research (Lobiondo-Wood & Haber 2002:272). This consent contained all the rights that participants are entitled to, including confidentiality, anonymity, fair treatment, to withdraw even after the initial consent.

1.10 LIMITATIONS OF THE STUDY

Acknowledging limitations helps researchers and readers to appreciate what constraints were imposed on the study (Vithal & Jansen 2002:35). This study was limited to a small region of the Eastern Cape Province. See chapter 6 for complete limitations as identified by the researcher in this study.

1.11 OPERATIONAL DEFINITIONS

The following terms are used in this study as defined below:

- **Lived experience**

Wehmeier (2001:693) defines *live* as “to be alive and to spend your life in a particular way”.

Rooney (2001:406) defines *experience* as “involvement in something over time, active involvement in an activity or exposure to events or people over a period of time, leading to an increase in knowledge and skill’.

Wehmeier (2001:406) defines *experience* as “events or activities that have happened that influence thinking and behaviour, to have and be aware of a particular emotion or physical feeling”.

Boyd (1993:85) states that *experience* refers to *living* through a situation, event, or circumstances in time, which can only be known reflectively and can be recalled.

The South African Concise Oxford Dictionary (2003:406) defines *experience* as an event or occurrence, which leaves an impression on one; as a verb to encounter or undergo an event or occurrence leading to a feeling, an emotion.

Lived experience in this study is the life-world as it is lived, felt, undergone, made sense of, and accomplished by people living with SCI (Schwandt 2001:84).

- **Spinal cord injury (SCI)**

The *South African Concise Oxford Dictionary* (2003:133) defines spinal cord injury as an injury to the cylindrical bundle of nerve fibres, which is enclosed in the spine and connected to the brain, with which it forms the central nervous system.

- **Community**

Community: A group of people living together in one place, especially one practising community ownership; a rural community (*South African Concise Oxford Dictionary* 2003: 89).

- **Environment**

Someone's environment is a combination of the surroundings and the conditions that they live and work (*South African Concise Oxford Dictionary* 2003:386).

- **Coping**

According to Smeltzer and Bare (2004:74), *coping* consists of "the cognitive and behavioural efforts made to manage the specific external or internal demands that tax a person's resources. *Coping* can be emotionally focused or problem focused."

Coping is a problem-solving process that draws on cognition, judgement, memory, and defence mechanisms. *Coping* is an adaptation strategy (Thelan, Urden, Lough & Stacy 1998:78).

Frydenberg (1997:25) describes *coping* as made up the responses (thoughts, feelings and actions) that an individual uses to deal with problematic situations that are encountered in everyday life and in particular circumstances.

For the purpose of this study, *coping* refers to the attempts people living with SCI to reduce stress while adapting to their changed lives.

- **Family**

Rooney (2001:516) defines *family* as “a group of people who are closely related by birth, marriage or adoption”.

In this study, *family* refers to close relatives and significant others in the life of the people living with an SCI.

- **Attitude**

Louw and Edwards (1997:750) describe *attitude* as “a strong belief or feeling toward a person’s object, idea or event and consists of three parts: cognitive, (thoughts or beliefs) affective (evaluations or emotions) and connative (motives or intentions)”.

In this study, *attitude* refers to the thoughts or beliefs, evaluations or emotions and motives that the people living with the SCI experience.

- **Society**

Rooney (2001:1375) defines *society* as “the sum of social relationships among groups of humans”.

For the purpose of this study, *society* refers to all the people with whom persons living with SCI come into contact.

1.12 OUTLINE OF THE STUDY

This chapter discussed the background to, motivation for and purpose and objectives of the study, and defined key terms.

Chapter 2 discusses the literature review on rehabilitation and adjustment to SCI undertaken for the study.

Chapter 3 presents the philosophical framework for the study.

Chapter 4 discusses the research design and methodology, including data collection and analysis, trustworthiness and ethical considerations.

Chapter 5 discusses the findings with reference to the literature review.

Chapter 6 presents the framework and guidelines

Chapter 7 discusses the conclusions and limitations of the study and makes recommendations for practice and further research.

1.13 CONCLUSION

This chapter outlined the background to and purpose of the study, the problem statement, the research design and methodology and defined key terms. Chapter 2 discusses the literature review undertaken for the study.

Chapter 2

Literature review

2.1 INTRODUCTION

Chapter 1 stated the problem, significance, purpose and objectives of the study. The literature referred to in outlining the background and problem statement was concerned mainly with SCI itself and its effects on the victim.

This chapter discusses the literature review conducted on SCI, in terms of the individual's rehabilitation and adjustment to SCI. In this instance, rehabilitation refers to the enablement of independent living or optimal functioning of the SCI persons in their own environments, and adjustment means adapting to a new condition (Long, Kneafsey, Ryan & Berry 2002:71). The adjustment process is catalysed by rehabilitation.

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.

2.2 REHABILITATION OF SCI PERSONS

Price, Makintubee, Herndon and Istre (1994:37), Stiens, Bergman and Formal (1997:S65) and others maintain that few injuries result in more profound and long-term disability than the traumatic SCI. Sjolund (2002:252) states that many general physicians might think that the first shock striking the SCI victims is due to trauma, but the greatest shock comes from the lost bodily identity when they suddenly realize that they have lost their ambulatory capacity along with many other important bodily functions. The patients perceive these changes, and experience and react at the personal level. Their impressions, beliefs, predictions and response to this predicament drive the adjustment process as catalysed by rehabilitation (Stiens et al 1997:S65). The end goal of the rehabilitation process is to enable the fullest range of activities and active participation in all aspects of human life,

maximize independence and prevent complications (Sjolund 2002:251; Cawley et al 1997:S73). Inman (1999:25) stresses the effectiveness of rehabilitation, as the improvement in outcome from SCI occurred after the development of specialist rehabilitation programmes. The SCI patient will 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 will continue, and many will have disappointing levels of neurological recovery (Formal, Cawley & Stiens 1997:S59). In the RSA, the average stay with initial hospitalisation is approximately four months for paraplegics and six months for quadriplegics. However, in the USA, SCI persons are expected to spend fifteen days on average in the acute care unit and forty-four days in the rehabilitation unit (Christopher Reeve Organisation 2003).

2.2.1 Post-acute SCI rehabilitation

In the early rehabilitation, the focus is on vital functions, providing adequate respiratory care, thrombosis and pressure sore prophylaxis as well as an adequate bowel and urinary bladder management, and maintaining adequate nutrition as the SCI patient may develop a severe catabolic state and as a result a negative nitrogen balance predisposes the patient to sepsis and other complications (Mitcho & Yanko 1999:67). Simultaneously, specially trained staff provide crisis psychotherapy, much needed by the injured person to be able to gradually reflect on his or her situation. Also crucial is an early contact with an independent SCI person. Ideally, this should be achieved within the first week, as the newly injured person usually considers this extremely valuable (Sjolund 2002:251). Mitcho and Yanko (1999:60) emphasise the importance of building a trusting relationship with patient/family, excellent clinical skills and empathy to meet the goal of acute care management, which “lays the groundwork for achievement of the best possible quality of life and well-being”.

An important part of the physical rehabilitation programme is to enable the patient to resume upright posture, a process that may be slowed down by the lack of stability of the vertebral fractures, which is usually treated by surgery. Orthostatic reactions to insufficient autonomic control pose another problem, and may require treatment with *alpha-adrenergic* medication. Prophylaxis and treatment of contractures are vital. When the upright position has been regained, the training of equilibrium and muscle strength becomes important, as does fitness training. The next step is to train in transferring from bed to chair and to practise wheelchair skills both in manual chair and for high injuries in an electric chair. Then comes the resumption of activities of daily living, focusing on personal hygiene, dressing and other aspects of personal care, including adjusting to the most efficient way of regular urinary bladder emptying.

In the later stages of post-acute rehabilitation, counselling on relations, sexual activity and fertility is important. At the same time adjustment of living quarters, planning for future education and resuming work are important issues to bring up and support. Usually, persons with SCI maintain annual or biannual contact with the rehabilitation team (Sjolund 2002:251).

According to Stover (1995), rehabilitation for SCI persons developed in three phases, namely building, idealism and practical realism.

2.2.2 Rehabilitation phases

Stover (1995:175-182) found that rehabilitation outcomes were increasingly driven by cost and professionals' ideologies and that these were often not related to the everyday lives of the individuals concerned. According to Stover (1995:175), SCI rehabilitation went through three major phases: building, idealism and practical realism.

- *Building*. A comprehensive SCI rehabilitation programme, utilizing a team approach, had to be built up in the 1940s, 1950s, and 1960s because prior to this period SCI persons were not expected to live long.

- *Idealism.* As the team concept grew and was accepted, the 1970s and 1980s were a time of idealism because there were sufficient financial and other resources to develop and test concepts and programmes.
- *Practical realism.* This phase was the result of national concern over spiralling medical costs. The length of initial stay following an SCI decreased markedly, due mainly to the increased efficiency of the rehabilitation team. In spite of the increased efficiency, however, most health care professionals working with persons with SCI felt that the trend to decrease inpatient hospital time was becoming detrimental to the time needed for rehabilitation, including adjustment, education and preparations for return to the community (Stover 1995:175-178).

2.2.3 Rehabilitation interventions

The collective secondary effects of spinal cord trauma produce a unique state of disablement for the person with SCI. According to Stiens et al (1997:S65), the World Health Organization (WHO) has provided terminology for disablement as related to three domains: organ (impairment), person (disability), and social (handicap). Thus, the interdisciplinary team and the patient must integrate data from patient experience and clinical parameters to derive a unique plan in each case and to target specific needs for rehabilitation. Rehabilitation interventions to promote adaptation should restore self-directed behaviour; engaging the patient in independent thought and problem solving restores a sense of power. The learning process achieves adaptation of the unique SCI individual. Through experimentation, personal solutions are derived for negotiating barriers in individuals' own environment. The interdisciplinary team enhances this process as patient and family consultants. Specific education offered to the family and patient serves as a support system on the challenges of adjustment, and the process of SCI rehabilitation further increases the effectiveness of this education (Stiens et al 1997:S66).

2.2.4 The nursing role in SCI rehabilitation

The nurse is one of the members of the multidisciplinary team. In a study in the USA on the meaning, process, and consequences of nurse caring from the perspective of persons

with SCI, Lucke (1998:253-264) found that a process of knowledge acquisition and decision making, facilitated by nurses and therapists in special caring with the persons with SCI, resulted in outcomes of well-being, self-care, autonomy in decision making, independence, and hope. All of this contributed to the SCI persons' reintegration of self before discharge from inpatient rehabilitation.

With regard to nurses' and patients' perceptions of nurses' role in SCI rehabilitation, Pellatt (2003:292-299) found that the nurses' role was not clearly identified. The patients valued the nursing contribution as a means of emotional and physical support, but did not necessarily see nursing input as rehabilitation. The nurses, however, saw their role as multifaceted but had difficulty in crossing over from an acute care to a rehabilitation philosophy. Johnson (1995) emphasises the important contribution nurses can make, by virtue of being with clients 24 hours every day. Patients spend only a small part of their waking day in therapeutically useful activities. Nursing staff therefore provide a consistent approach, by being there 24 hours, help the patients to learn optimally, work on achieving short-term goals and focus on their long-term objectives. Nurses can "close the circle", ensuring that rehabilitation is a continuous process optimising the patients' stay and enhancing the contributions of the multidisciplinary team (Johnson 1995:113-114). Nolan and Nolan (1999:959) refer to the nurse's role in rehabilitation as an "unfulfilled potential". With regard to the nurse's contribution in the multi-professional rehabilitation team, Long, Kneafsey, Ryan and Berry (2002) identify six interlinked roles for the nurse: assessment, coordination and communication, technical and physical care, therapy integration and therapy carry-on emotional support, and involving the family. Of particular significance is the creation of a supportive environment for rehabilitation (Long et al 2002:70). Long et al (2002:76) emphasise the key elements of the nurse's contribution in a rehabilitative setting as aiming at maximizing client choice and autonomy and enabling independent living or optimal functioning within the client's own environment

Seeing the nurse's role in rehabilitation as confined to a hospital setting, focusing on physical care with the primary aim of discharging back into the community, does not close the circle, as the patients' needs do not disappear at the hospital exit door (Nolan & Nolan 1998:102).

Nurses have a rehabilitative role, especially with the concept of community-based nursing education in place in South Africa. Accordingly, it is important that the needs of this particular group of clients are met hence the focus of this study was to learn what it is like to live with an SCI in the rural communities of the Eastern Cape.

2.2.5 Rehabilitation approaches and models

The predominant approach, also referred to as the restorative, rehabilitative, or medical model of intervention, that underpins health care for people with SCI is rehabilitation, which aims at helping individuals to return to optimal effectiveness in daily living (Richardson 1997:1270). According to the *medical model*, disability is caused by disease or trauma. In this study, a fractured spine disables the person. Disability, here, is perceived as a falling away from normality. The role of the disabled individuals is to gratefully and passively accept the care imposed on them by the experts (health professionals). Their role is to shift the patients' functioning towards what is normal (Goodall 1995:324). Traditionally, rehabilitation for the SCI person is seen as the teaching of skills in order to achieve the highest possible level of independence. Success in activities of daily living, such as self-care, transfers and other physical skills, is evidence of good rehabilitation.

Hanson (1994:13) and Nolan and Nolan (1998:958) point out the limitations of traditional models, underpinned by medical principles of cure, because they exclude subjective experiences. According to Richardson (1997:1270), they reflect the personal tragedy model of disability. Hammell (1992:318) criticises the traditional view of rehabilitation for its potentially "deleterious" consequences, namely that it

- could lead to a view that those with higher levels of injury have less potential than those with lower level injury
- ignores the value of satisfying relationship and meaningful interaction with the environment

Moreover, Hammell (1992:318) stresses that it is not sufficient to simply teach people to get out of bed, they need a reason for doing so.

According to Richardson (1997:1271) and Hanson (1994:13), the *social model* develops nursing interventions focused on the social dimensions of recovery. Burton (2000:301) points out that such developments must take account of how patients themselves experience recovery, rather than professional interpretations of holism alone. There is a danger that without sufficient direct information from the patients, health professionals might assume the authority to decide the fates of underprivileged people (Carpenter 1994:615). From the social model perspective, disability is brought about by the established environment, constructed primarily for the able-bodied majority, as well as attitudes of others towards those with physical impairments. Goodall (1992:24) states that professionals, including nurses, disable certain of their clients by patronizing attitudes, and refusing to listen to the real experts (disabled people). Barnitt and Pomeroy (1995:89), however, maintain that rehabilitative workers value the concept of holism because they genuinely desire to find ways of working with people who are unlikely to benefit from the biomedical approaches, and this includes treating patients as autonomous and responsible people. Pellat (2003:297) refers to Lucke's (1999) findings that nurses perceived as caring were those who enabled participants to take charge of their care by supporting them in their move towards independence. Uncaring nurses were those who demanded that participants do as they were told. Patients reported feeling helpless, powerless and vulnerable when entering rehabilitation.

Nolan and Nolan (1998) maintain that the nurse's contribution must be considered in the context of the part played by other members of the multidisciplinary team. They (1998:101) caution, however, "much as effective team working seems important, as the team grows in number so does the potential for 'comprehensive fragmentation'". Thus nurses have a responsibility to coordinate and integrate multiple perspectives in developing and executing "an individualized patient and family-centred plan" (Nolan & Nolan 1998:102).

2.2.6 Rehabilitation outcomes

Many theories predict potential physical abilities after SCI, yet very little is known about the actual numbers who achieve this theoretical level of independence (Schonherr, Groothoff, Mulder & Heisma 2000:185). Schonherr et al (2000:185) found that prediction of functional

outcome after SCI was most successful if the expectations of the team and the patients were combined.

With regard to sexuality and sexual functioning in SCI, Kendall, Fronek, Booth, Miller and Geraghty (2003:50) state that rehabilitation that successfully addresses sexuality issues must also encompass a range of factors including “alterations to physical functioning, body image, and self-esteem, social and familial roles and community access, integration and participation”. Rehabilitation outcomes of well being, self-care, independence, autonomy in decision making, and hope can be achieved through feelings of wholeness, humanness and dignity, that emerge in caring relationships with members of the health care team (Lucke 1999:263).

2.3 ADJUSTMENT TO SCI

According to Rolland (1999:247), adjustment entails the long haul of day-to-day living with a SCI, and coming to terms with losses and limitations. Adjustment includes a multitude of spontaneous and applied processes that enable a person to achieve optimal health, personal role performance and environmental integration in spite of disablement (Stiens et al 1997:S65). Adjustment is often viewed as an outcome of coping (Loy, Dattilo & Kleiber 2003:233). Loy et al (2003:233) refer to Shontz’s (1975) view that adjustment is a function of the congruence between the subjective perceptions of the individual with a disability and the external environment. Livneh and Antonak (1997:22) state that in adjustment, the “individual reaches a state of cognitive reorganization and reorientation toward self and the external environment typified by the integration of the functional limitations associated with the condition into his/her self-concept”.

Spinal trauma is regarded as one of the most devastating injuries an individual could experience. The sudden alteration from activity to often total immobility is unique to such trauma, and makes considerable demands on the individual and relatives (Glass 1994:468.). Adjustment to such an event is immensely complex. Glass, Jackson, Dutton, Charlifue and Orrit (1997:320) concede that although assessment of an individual’s level of functional independence has been accomplished during inpatient rehabilitation, functional ability in an institutional setting may not equate with an ability to manage in the community.

Moreover, definitions of adjustment are open to interpretation (Glass 1994:467). 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 (1980:22) contends that psychological adjustment, rather than intellectual capacity or completeness of injury, is the critical factor in determining the rehabilitation process.

Stiens et al (1997:S65) 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, assertiveness, 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 the adjustment cycle faster with better outcomes and fewer recurrent problems (Kendall & Buys 1998:18).

2.4 THEORIES ON ADJUSTMENT

It was initially assumed that a SCI itself produced not only major physical consequences but also grave psychological consequences, which made these people inherently ‘different’ from non-disabled individuals. Thus earlier research examined the psychological characteristics of those with SCI in order to document these differences (Trieckmann 1992:58). However towards the end of the twentieth century, it became clear that people with physical disabilities are no different from non-disabled people except for the presence of a physical impairment

Theories on adjustment to SCI fall into three categories, namely psychological, personality and sociological. It should be noted that people living with SCI resent these 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” (Trieckman 1980:xii).

2.4.1 Psychological theories

Initial efforts to characterise adjustment include topologies of various reactions to injury and models of the sequential process (Stiens et al 1997:S66). Examples are the “crisis period” and “stage” models.

2.4.1.1 *Crisis and denial*

According to Hammell (1992), a traumatic injury to the spinal cord presents a sudden, overwhelming threat to the individual's safety and constitutes a crisis event. At this stage, crisis intervention is directed to survival of the injury. However, the person may react in various ways. Some of the responses to the crisis are short-term unreality due to anaesthesia, muscle tension, anxiety and depression, problems with reasoning, judgement and concentration; there may even be shame and guilty (Hammell 1992:318). These responses to the crisis may be exacerbated by the environment and medical interventions to manage it. The patient is said to deny the problem immediately post-trauma in order to cope with it. Hammell (1992:318) cites Horn's (1989) finding that factors like medication, pain, total immobilisation, and enforced bed rest might keep reality at bay. This phase may be passed as a dream like state in which adaptation cannot begin; neither can new learning take place during this period.

2.4.1.2 *Stage models of psychosocial adjustment*

According to stage theory, adjustment takes place in stages or sequences such as denial, depression with internal or external hostility, reaction against independence and reconstitution of pre-traumatic personality.

Gunther (1968) identifies three stages of adjustment, namely *shock*, *partial recognition* and *initial stabilisation*. Shock may last for days and is characterised by slow thought processes, confusion, flat affect, and reduced responsiveness to the magnitude of the trauma. Partial recognition may last for days or weeks as the person becomes more responsive to the environment, but continues to avoid the recognition of feelings about the physiologic changes that have occurred. Finally, initial stabilisation may last for months or

years and is characterised by a shallow awareness of the existence of the injury and superficial acceptance (Sullivan 1990:408).

Dunn (1969) identifies three phases of adjustment to SCI during hospitalisation in the rehabilitation setting: *avoidance*, *transition* and *life integration*. The first phase is characterised by a rapid rate of physical recovery with an avoidance of recognition of the permanence of the disability. The transitional phase consists of the effects of the injury. The last phase is recognised by life integration of the style around the disability (Sullivan 1990:408).

Kerr and Thompson's (1972) three-stage adjustment process consists of *shock*, *fear and anxiety* followed by *grief and mourning*, and lastly *aggression and rebellion*, which is a necessary requisite for the final outcome of maturity (Sullivan 1990:408).

Weller and Miller (1977) parallel the stages of adjustment to SCI to Kubler-Ross's description of impending death and mourning. The emotional reactions consist of *shock*, *denial*, *anger*, and *depression* (Sullivan 1990:408). Bracken and Shephard (1980) delineate the following stages: denial, rage and anger, bargaining, depression and, eventually, acceptance.

However, Tucker (1987), a person living with a SCI, questions whether the mourning process in disability is the same as or different from mourning after an actual death. She identifies the mourning process in adjustment to SCI as consisting of *shock*, *denial*, *anger*, *guilt*, *depression*, *sadness* and *adaptation*. According to Tucker, the phases of adaptation are *changing and dynamic*. Some people experience them sequentially, some phases may be omitted, and most often, people *move back and forth* among them as new experiences are presented (Sullivan 1990:408). This disputes the linear progression suggested by other stage theorists.

2.4.2 Personality theories on adjustment

Personality theories take cognisance of individual differences, the subjective experience of people with acquired disabilities, and their personalities, referring specifically to the locus of control, and crisis theory.

2.4.2.1 *Locus of control*

Hancock, Craig, Tennant and Chang (1993:451) define locus of control as “the extent to which the individual perceives outcomes to be contingent upon his/her behaviour. Locus of control has two dimensions: external and internal. An external person believes that he/she has little control over his/her fate and fails to perceive a cause and effect relationship between his/her behaviour and outcomes. Outcome is seen as due to luck, chance, fate, or powerful others. An internal person believes that his/her behaviour has an effect on outcomes.”

Internal versus external control response to SCI depends on pre-injury personality type. Those with external locus of control adjust poorly compared to those with internal locus of control. Regarding the relationship between locus of control expectancy and adjustment to traumatic SCI, Mazulla (1984) found that individuals who exhibit an internal locus of control are more able to adjust to the onset of SCI, irrespective of the time since onset or level of disability (Hammell 1992:321). According to Triechmann (1980:62), “even though a person with quadriplegia may in fact have less control over his immediate circumstances, this does not necessarily change the generalised expectancy of control over the rewards in life nor satisfaction with life”.

2.4.2.2 *Crisis theory*

People respond differently to being given negative information or experiencing trauma. Glass (1994:469) refers to Moore’s (1982) crisis theory, which describes a number of factors that influence adjustment as: illness related factors, background, and personal factors and environmental factors. If the equilibrium between these factors is breached, the individual fails to resolve any conflict.

2.4.3 Sociological theory

Psychological approaches concentrate on the individual while sociological theory examines the adjustment to disability in the broad context of each individual's social environment. Successful outcome relates not only to the individuals' physical abilities, but also to their unique physical and social environment (Hammell 1992:322). According to Oliver, Zarb, Moore and Salisbury (1988:11), the process of social adjustment arises between individuals and their physical and social environment and, more importantly, from the meanings which these interactions have for both the individuals and their families.

Trieschmann (1980), and Stiens et al (1997) add other compounding factors in social adjustment, including age at onset of injury, gender, academic background, philosophical and religious beliefs, family structure, employment status, previous losses and coping abilities, and the symbolic meaning SCI has for the individual. In addition, medical complications, strength, coordination, pain and degree of impairment also need to be considered. Environmental variables include income, transportation, as well as architectural and geographic barriers (Barton 1993:238). Gill (1999:4) points out that adjustment can be negatively affected by limited social support, a sense of hopelessness, low self-worth, a fragmented family system, and nonreligious or non-spiritual beliefs that lead to poor coping.

2.5 CRITICISM OF STAGE MODELS

Kendall and Buys (1998:16) state that although evidence supports a general trend towards acceptance of disability over time, stage models have negative implications for the rehabilitative process. For instance, conceptualising adjustment as a series of unavoidable stages implies passivity on the part of individuals with disabilities and the rehabilitation workers, who could thus be expected not to implement psychosocial interventions, while waiting for time to heal their clients. Moreover, stage models of adjustment are seen to normalize responses such as denial and distress, which may lead rehabilitation workers to even encourage such responses (Kendall & Buys 1998:17). Hammell (1992) is critical of the assumption that an individual who does not proceed through the prescribed phases must, by default, be abnormal.

Kendall and Buys (1998:17) cite Dovey and Grafan (1987) who refer to the stage model as a form of social oppression, because it can encourage people living with disabilities to accept fewer alternatives and less personal control of their situation than people without disabilities.

Yoshida (1993:218) maintains that stage models of adjustment do not adequately match the subjective experiences of people with acquired disabilities. Furthermore, Hammell (1992:319) found that experienced professionals have been “shown to exaggerate the distress of their SCI patients”. An alternative approach to conceptualising adjustment is the recurrent model, an integrated model in which adjustment is viewed as an ongoing cycle.

2.6 AN INTEGRATED MODEL OF PSYCHOSOCIAL ADJUSTMENT

The limitations of stage models led to the recognition of the ongoing “tragedy” and the inappropriateness of “time-bound” definitions of grief process in such circumstances. In the integrated approach the recurrent model is used as a framework in which adjustment is viewed as a gradual process of learning to tolerate an almost intolerable set of circumstances (Kendall & Buys 1998:17). Adjustment therefore becomes a continuous life transition rather than a time-limited process. Cognitive theories of psychosocial well-being are based on the notion of schemas, which are fundamental beliefs and assumptions about self, others and how the environment works. The schemas filter and interpret people’s experiences especially in times of stress.

Following an unexpected shift in life circumstances as a result of disability, the usefulness of existing schemas for understanding the world are likely to be challenged. By necessity, however, individuals will persist with these schemas even though they no longer explain the environment adequately, thus distorting reality or appearing to be in denial (Kendall & Buys 1998:17). Individuals may initially be overwhelmed by their inability to experience leading to symptoms such as depression. However, as more information about the new environment is gathered and integrated, new schemas can be developed. Schemas can be developed incrementally and revised, modified or completely restructured (Kendall & Buys 1998:17, citing Newsome & Kendall 1996).

Taylor (1983:1161) adds that the modification of schemas is influenced by three main themes, namely the search for meaning in the disability and subsequent living with a disability; the need for a sense of mastery of the whole situation, and efforts to protect and enhance one's post-disability identity. The recurrent process is complicated further by the fact that the themes develop at different speeds and are sensitive to experiences that the individual is going through. Thus the process of adjustment is likely to occur in an iterative manner as different aspects of the new environment are encountered, and it is an individual process that continues as it is influenced by the particular circumstances or experiences of the person. The recurrent model advocated in the integrated approach supports Tucker's (1987) explanation that the phases of adaptation are changing and dynamic and people move back and forth among them as new experiences are presented (Sullivan 1990:408). Yoshida (1993:228) found that following a permanent disability, individuals alternate between periods when they acknowledge only their former 'pre-disability' identity at one extreme and only their new 'disability' identity at the other extreme. The swing from 'pre-disability' identity to 'disability' identity is likely to be prompted by the disappointment and failure that accompanies the 'pre-disability' identity. Although the person who existed prior to the injury continues to exist, such traumatic loss transforms individuals in an irreversible manner, meaning that the former self cannot be fully recaptured (Kendall & Buys 1998:17). At the other 'disability' extreme, individuals tend to see themselves only in negative terms, leading to diminished self-worth, self-recrimination and severe depression (Charmaz 1983:1169).

The recurrent model concurs with Carpenter's (1994) expanded model of rehabilitation, which acknowledges that the process of adjustment occurs over a period of many years.

2.7 DEMOGRAPHIC VARIABLES AND SCI ADJUSTMENT

Age and socio-economic status are important factors in adjusting to SCI.

2.7.1 Age

Age below twenty is associated with better adjustment than later onset (Triechmann 1980:99). Triechmann adds that between 20 and 35 people establish their identity and

create a role for themselves. In this context therefore those injured before 20 may not have begun or gotten very far into this process, hence the difference is more likely due to their social psychological stage of adulthood. At the same time, however, in the twenties and thirties more readjustment may be required, as their “inner strength” becomes a critical variable (Trieckmann 1980:100). Beyond age forty, there are “those who ‘give up’ and those who still have important items on their agenda” (Trieckmann 1980:100). This may be related to reduced social networks and reduction in physiological activities (Kennedy et al 2003).

2.7.2 Socio-economic status

People’s socio-economic status has an impact on their reaction to SCI. It plays a role in shaping the person’s personality life style before the injury and correlates with environmental resources available to them, as they face the world as disabled persons.

Whalley Hammell (1992:322) states that all the variables involved make it impossible to identify a course of adjustment that is predictable, solitary and uniform. However, Chan, Lee and Lieh-Mak (2000b:688) contend that the socio-psychological perspective alerts people to adopt a broader interpretation of adjustment, and emphasize that interpersonal support and re-socialization are important signposts in adjustment to SCI.

Hammell (1992: 321) refers to Starks’ (1980) description of adjustment to SCI in terms of Maslow’s hierarchy of needs.

Table 2.1 Adjustment to SCI in terms of needs

Maslow’s hierarchy of needs	Adjustment to SCI
Self-actualisation	Lack of spontaneity in life, boredom, and dissatisfaction with meaning and purpose in life
Self-esteem	Frustration with architectural barriers, discomfort in asking for help and dissatisfaction with education or occupation
Love and belonging	Sexual love adjustment, limitations in social activities, and limitations in touching
Security	Loss of mobility, transportation difficulties, financial insecurity, insecurity concerning long-term care
Physiological needs	Muscle spasticity, soft tissue damage (pressure sores, paralysis, loss of sensation and autonomic hyper reflexia)

Source: Hammell (1992:321)

2.8 RESEARCH ON ADJUSTMENT OUTCOMES

There is a growing base of research investigating how people with SCI cope with and adjust to their injury. Three major factors associated with the adjustment outcomes of persons with SCI have been identified, namely

- *coping strategies* (Bulman & Wortman 1977; Frank, Umlauf, Wonderlich, Ashkanazi, Buckelew, & Elliot 1987b; Moore, Bombardier, Brown & Paterson 1994; Sholomskas, Stiel & Plummer 1990)
- *attributional styles* (Frank et al 1987; Moore et al 1990; Burkelew, Frank, Elliot, Chesney & Hewett 1991)
- *perceived social support* (Kalimu & Vuori 1993; Schultz & Decker 1985)

These approaches are based on Lazarus and Folkman's (1984) theoretical framework that focuses on the transactional nature of stress and emphasizes cognitive appraisal and coping. Lazarus and Folkman (1984) describe two levels of stress appraisal (primary or secondary) and subsequent coping as either problem-focused coping, the function of which is to change the 'troubled person environment relationship' aiming at affecting the cause of the problem; or emotion-focused coping, and its function is to change either a) the way the stressful relationship with the environment is attended to (as in vigilance or avoidance or b) the relational meaning of what is happening, thus, emotional coping aims at treatment of the harm (Lazarus 1993:238). In addition, a person's attributional style, or sense of control, may play a crucial role in the appraisal of a stressful event and of possible outcomes.

Cross-sectional single assessment designs and multi-assessment follow up have been used to investigate the association between coping and adjustment (Bulman & Wortman 1977; Schultz & Decker 1985, Buckelew, Baumstark Frank, & Hewett 1990; Frank et al 1987; Sholomskas, Stiel & Plummer 1990; Moore et al 1994; Hanson, Buckelew, Hewett & O'Neal 1993).

In a study to assess the relationship between their "attributions of causality for their accidents and ability to cope with their severe misfortune" within the first year of being injured, Bulman and Wortman (1977:351) specifically examined the area of self-blame for

the injury, perceived avoidability, and blame attributed to external factors. Staff rated coping on a 16-point scale, ranging from coping poorly to very well.

The findings showed a relationship between victims' tendency to self-blame and others' evaluations of them as "good copers". Despite the fact that most of the accidents seemed to have occurred by chance, victims who blamed themselves for the accident were the ones most likely to receive higher coping ratings from a nurse and a social worker. Those who blamed 'others' for the accident and saw the accident as avoidable were more likely to be rated as coping "poorly". No clear or specific definition of coping was provided to the staff. The staff agreed that individuals were coping well if they "had accepted the reality of their injury ... were attempting to deal positively with the paralysis ... had a positive attitude toward physical therapy ... were motivated to work toward improvement of their physical abilities, and reflected a desire to be physically independent" (Bulman & Wortman 1977:355).

Other studies on the relationship between self-blame and adjustment yielded mixed results. Sholomskas, Stiel and Plummer (1990) replicated Bulman and Wortman's (1977) study with a similar sample, using comparable procedures, measures, and analysis, but did not replicate the relationship between self-blame and effective coping. The relationship between other-blame and poorer coping, however, did replicate. A significant finding in their study was the identification of alcohol use prior to the accident as the best predictor of self-blame.

Schultz and Decker (1985) found only modest correlations between self-blame and three measures of adjustment (depression, life satisfaction, and psychological well-being). Yet, Burkelew, Baumstark, Frank and Hewett (1990) found self-blame significantly correlated with psychological distress even after controlling for age, time since injury and level of injury.

In their study of participants whose injuries had occurred approximately eleven years prior to the investigation, Heinemann, Bulka and Smetak (1988) found self-blame unrelated to acceptance of disability. However, when the participants were asked to describe the coping strategies they used to deal with their quadriplegia, the responses were categorized into

four different coping processes: direct action; emotional regulation; cognitive regulation, and maladaptive actions. Furthermore, the findings revealed more disability acceptance with people who were injured for a longer period, and did not use maladaptive coping processes like drinking.

Some studies assessed a broad range of coping strategies used by the SCI population. Frank et al (1987b) studied and measured the choice of coping strategies, health care beliefs, and psychosocial distress with the ways of coping (WOC) scale (consisting of seven variables: problem focused, wishful thinking, mixed coping, minimize threat, seek social support and self-blame) and the multidimensional health locus of control (MHLC) (with three variables: internal, powerful others, and chance). The mean time since injury was 43,58 months, and mean age 30,51 years. Using cluster analytic techniques, Frank et al (1987b) identified two subgroups. Participants in one cluster relied heavily on a variety of coping strategies, utilized more wishful thinking, mixed coping, growth coping and self-blame. The cluster had higher external health attributes and reported more psychological distress and depression, and indicated that their coping was not effective. The results for the first cluster were similar to earlier research that using more coping methods was related to increased distress and poor health (Frank et al 1987b:730). Subjects in the second cluster emphasized internal health locus of control attributes; reported less psychological distress, and relied less on all coping strategies. Regarding the concept of perceived control, Frank et al (1987b) found that the second group relied heavily on internal attributions of control while the other group attributed control of health to chance. Since these findings were similar to other research findings, Frank et al (1987:730) concluded that an important aspect of emotional recovery is moving the injured person toward a belief in internal resources.

Burkelew et al (1990) compared the coping strategies used during in-patient rehabilitation over a two-year period. The participants were divided into three groups based on the symptom checklist (SCL-90-R) for psychological distress scores. The participants completed the WOC questionnaire, along with the MHLC scale. The findings revealed that the patients who reported the most psychological distress were those who used more wish fulfilment, emotional expression, self-blame, and threat minimization, but not cognitive restructuring or information seeking strategies. In addition, the self-blame coping strategy

significantly correlated with psychological distress, thus supporting Bulman and Wortman's (1977) findings regarding self-blame and poor coping.

Hanson, Burkelew, Hewett 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, using Burkelew et al's (1990) findings as a baseline. The findings indicated that the relationship between specific coping strategies and adjustment changes over time. For example, patients who reported higher levels of self-blame during acute rehabilitation reported more psychological distress. Five to six years later, the importance of self-blame to psychological distress had diminished. Moreover, at five years the cognitive restructuring positively correlated with acceptance of disability. Hanson et al (1993) found an increase in cognitive restructuring over time, with participants reporting that, in addition to information seeking and threat minimization, they used cognitive restructuring more frequently, at the five-year follow-up than during acute rehabilitation. Self-blame as a coping strategy thus appeared to be used in the early days of SCI.

Chan et al (2000b) investigated the pattern of coping in persons with SCI in the context of Chinese culture, using scales to measure locus of control; participants' perception of social support, and the coping styles tackling emotion- and problem-focused aspects. The participants' spinal injuries had a mean time of 13,27 years. The results showed three statistically relevant clusters of coping patterns. Cluster 1 had high scores in external locus of control, perceived a lower level of social support from family and friends and tended to a narrow range of strategies. Cluster 2 endorsed a higher internal control and adopted more balanced coping strategies. They also perceived more social support from family and friends. Cluster 3 had scores in coping strategies in the mid-range between 1 and 2 and tended to be more problem-focused and perceived a high level of support. The findings are consistent with Western-based studies that the number of coping strategies adopted and their attributional styles lead to different clustering. Chan et al add the use of social support as another coping variable. Inadequate support may influence coping behaviour adversely by causing these persons to appraise a situation as more stressful and have high depression scores. Social support perceived as adequate may function as a coping resource (Chan et al 2000a:505). These findings in relation to social support in the SCI

population are also consistent with Elliot, Herrick, Witty, Godshall and Spruel's (1992) study.

2.9 SOCIAL SUPPORT AND SCI

Elliot, Herrick, Witty, Godshall and Spruel (1992) found "interesting" relationships between specific types of social support and depressive behaviours among people with SCI. Specifically, reassurance of worth and social integration support were associated with lower levels of depression. No interactions between specific types of social relationships and time passage were observed, suggesting that the relation of the different types of support to depression was not moderated by time since injury. The participants' injuries had been sustained 1 month to 490 months prior to time of data collection. A theoretical model of social support was incorporated. According to Weiss (1974), relationships that comprise social support systems can be categorised into the essential functions they perform. Those that provide a sense of closeness and security are classified as *attachment* relationships; those providing a sense of belonging exemplified in friendships, as *social integration*; those providing informed advice (as from professionals), as *guidance*; those acknowledging and reinforcing a person's worth, as *reassurance*; those offering tangible assistance as from family, as *reliable alliance*, and those giving a sense of responsibility, such as often derived from caring for one's children, as *opportunity for nurturance* (Elliot et al 1992:40).

Glass (1994:474) 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 the likelihood of hallucinations.

Support from others that is social support in general, is crucial. Perceived social support is an important component of quality of life, coping, and positive long-term adjustment (Anson, Stanwick & Krause 1993; Clayton, Robert & Chubon 1994; Cobb 1976). Social support serves two important functions (Holicky & Charlifue 1999:250). The first is a positive effect on health and well being, while the second is a stress reducing, buffering function that leaves individuals receiving such support less susceptible to the negative

effects of stress. McCall and Rosenthal (1994:262) state that social support can provide a variety of positive effects such as: instrumental help (physical assistance as in helping with transfers, meal preparation, bowel or bladder, or any other variety of activities of daily living), and emotional support. McColl and Skinner (1995:25) explain that emotional support reduces anxiety through empathic interaction, changes in attitude toward disability, provides emotional release and thus buffer against stress and perceived threats.

Holicky and Charlifue (1999:250) report that those who are satisfied with the level of social support they receive, display greater overall psychosocial adjustment, as well as less overall functional disability.

2.10 QUALITY OF LIFE AND SCI

Spinal cord injury is a chronic condition. Assessing the quality of life of people living with a chronic illness is the main interest of clinicians seeking to determine whether the interventions are successful, and measuring success according to aspects of life that they give weight to and using scales determined by professionals rather than the ill person (Wellard 1998:51). There are many aspects to successfully adapting to and coping with SCI and maintaining ongoing quality of life in the face of the resulting long-term disability. As medical care improves and the life expectancy of SCI persons increases, it is important to identify and examine those factors that contribute to this longer life expectancy, but also those that enhance its quality (Holicky & Charlifue 1999:250).

Some studies have attempted to examine the longitudinal process of adjustment to SCI, and other disabilities, by including some measures of perceived quality of life. Ferrans and Powers (1992:29) define quality of life as “a person’s sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her”

Quality is seen as synonymous with satisfaction, and life satisfaction is considered to embody an assessment of life as a whole based on how well personal goals match with personal achievement (Glass, Krishman & Bingley 1997:321, citing Calman 1987). Thus quality of life is something relative which individuals measure in relation to their needs. An

attainment of an acceptable quality of life may thus be seen as the ultimate goal of rehabilitation (Ferrans & Powers 1992:29).

In a study in Sweden on persons aged 18 to 75 years who had sustained a complete, irreversible traumatic SCI and been injured for not more than five years, Stenman (1994:417) found the concept of quality of life to be a “keynote in an individual’s life”, which is influenced by several factors including psychological and physical conditions as well as relations to other people and society. The participants were interviewed at intervals from 0.5 to 5 years, on six occasions. The results over time showed, out of a total of 17, that:

- Five remained stable throughout (3 paraplegia and 2 tetraplegia) and were regarded as “*good coping*”. Four had returned to work.
- The second group of six was considered as “*good coping after initially low QOL*”. At 3 to 5 years’ post injury they had stabilized. These were fairly young men and four had returned to work. Five had tetraplegia, two had moderate pain and one had bowel problems.
- Two men, considered as “*unstable, fairly coping*”, reported different values of QOL at different times. They reported pain and other problems and both were ADL dependent.
- The four persons designated “*unsatisfactory coping*”, reported no improvement in QOL. They were older men with a mean age of 43 years at the time of the accident. Two had tetraplegia. Two had very severe pain below the injured level, and the other two had moderate pain.
- All the subjects reported the negative factors associated with SCI as being dependent, having problems with bladder pain, not being able to do things at once, being unable to walk, use stairs, dance, cycle, be out in the countryside, ski and fish. One suffered from spasticity.

The results endorse the contention that age at the time of injury does influence adjustment to SCI; the younger the individual at the time of injury, the better the adjustment, and conversely, the older the individual at time of injury, the less successful in adapting. Triechman (1980:100) found those who “give up” are over 40 years old. The level of injury is not a determinant of coping with SCI, as more participants with tetraplegia were identified as good copers. But pain is an issue, with the group designated as “unsatisfactory coping” suffering moderate to severe pain. Price, Kendall, Amsters and Pershouse (2004) identify pain as a threat to quality of life, as well as changes in skin integrity and general medical problems. Furthermore, emotional and social factors such as finance, employment, and accommodation are most frequently perceived to have a positive influence on quality of life, whilst physical, emotional and social issues such as stress, family difficulties, loss of strength, pain and joint stiffness are the main causes of negative change in the life of SCI persons.

Bach and McDaniel (1993:364-374) refer to Carlson’s (1979) finding that for paraplegic and quadriplegic adults, life satisfaction is related to family relationships, intimacy, presentation of self and stress management. Individuals with high levels of satisfaction report higher levels of perceived control, greater social support, higher income, and more education than those reporting lower levels of satisfaction (Schultz & Decker 1985; Clayton & Chubon 1994).

2.11 MARITAL/PARTNER RELATIONSHIPS AND SCI

Family, specifically spouses, are usually the primary carers; in other words, the sources of social support. For a number of SCI survivors marriage nevertheless often seems to be out of reach, due largely to the typically young age when the injuries occur, and thus limiting the opportunities of attracting partners, and also marriages that end following the injury. Thus many SCI survivors do not report having abundant social support (Holicky & Charlifue 1999:250). Spouses provide 80 to 90% of long-term care, and may be the only important element in successful rehabilitation and long-term home care (Gaynor 1990:209). Among married couples, both disabled and non-disabled partners report better health, with men deriving more positive benefits than women (Holicky & Charlifue 1999:251). In

addition, levels of depression are also lower for both men and women who are married (Holicky & Charlifue 1999:251).

Having a spouse does not in and of itself guarantee positive coping (Holicky & Charlifue 1999:251). Their relationship and the rules by which they lived prior to the accident influence the type of role assumed in the relationship, the type of care provided and the outcomes experienced. Hence a good marital relationship is an important factor affecting the psychosocial outcomes of persons with SCI and their spouses. McGowan and Roth (1987:359) found that married couples tend to have more relationship problems when the disabled partner's level of functional independence is low. In this regard, Kreuter (2000:27) refers to the issue of care giving and thus changes in balance of power in the marriage and the family's dynamics, which potentially place the relationship at risk. Chan et al (2000b:688) state that persons with SCI in distressed marriages are affected to the extent that they tend to engage in fewer activities, spend considerable time in solitary and disengaged behaviour.

Patients married after the injury tend to be more satisfied with their social lives, general health, emotional adjustment, and sense of control over their lives than those married before the injury (Chan et al 2000b:688; Crewe & Krause 1988, 1991). For those not involved in intimate relationships at the time of injury, opportunities for developing intimate relationships may be hampered by lack of peer acceptance in the community as well as lack of confidence (Kreuter 2000:27). McNett (1987) maintains that while spousal support is positively related to coping effectiveness, unmarried subjects cope more effectively and perceive events as less threatening than married subjects.

2.11.1 Suicide and SCI

The overall suicide risk is higher after SCI than that observed for the general population. After the injury, however, the risk decreases with time, this indicates that a successful adjustment process may take many years. The risk of suicide is about four times the standard age-adjusted suicide rate of the general population (Charlifue & Gerhart 1991:489).

Seventy five percent (75%) of suicide deaths occur within 4 years of injury. The *pre-injury* demographic predictors include previous attempts, age at injury (suicide risk increased with age), depression, sense of hopelessness, guilt, alcohol abuse, anger, Caucasian, and a history of family fragmentation. *Post-injury predictors* are despondency, alcohol abuse, and apathy, expression of shame, tension, weight loss, anger, and destructive behaviour (De Vivo, Black, Richards, & Stover 1991:622).

2.11.2 Depression and SCI

Depression designates a sad affect as well as a primary or secondary depressive disorder. Stiens et al (1997:S67) state that standard depression inventories may be confounded by the physical sequelae of SCI itself and contribute to falsely increased prevalence rates in SCI populations. Moreover, depression has not been substantiated as a necessary stage of required mourning and adjustment to SCI, yet staff may overestimate the frequency and intensity of negative mood state and disregard the patient's optimism (Stiens et al 1997:S67).

Triechmann (1980:52) found that two to three weeks after admission was the most depressive period and the period just before discharge was also characterised by significant depressive and elative reactions.

Stiens et al (1997) maintain that depression may occur as a result of individuals' perceived handicap, it correlates less with impairment and disability measures. Perceived handicap is a significant predictor of depression at two years after injury. Handicap is "the disadvantage resulting from a given person's impairments or disabilities which limits the fulfilment of roles within that person's social or cultural system that would be considered normal for a person of his or her age and gender" (Stiens et al 1997:S67).

It is difficult to fully "dramatize" the unique human-environment interaction for a patient in the acute setting environment, because this requires providing specific information regarding the process of adjustment, and prognosis, including the modified functional outcome, emotional responses, and potential for social relationships and employment (Stiens et al 1997:S67).

2.11.3 Personality traits: variability in adjustment

Antonovsky's (1987) sense of coherence is a set of personality traits that holds promise for explaining the variability in adjustment (Antonovsky 1993:725). Individuals with a strong sense of coherence are able to manage the tension associated with stressors more successfully. Antonovsky (1993:725) maintains that factors such as money, religious faith, family, and social support, as generalized resistance resources, provide individuals with life experiences that are characterized by consistency, an underload-overload balance of stimuli, and participation in determining outcomes. These kinds of life experiences lead individuals to believe that they can derive order and sense out of chaos. This belief about world coherence is the global orientation that the world is comprehensible, manageable, and meaningful (Lustig 2005:147). With regard to the relationship between sense of coherence and adjustment with individuals with disabilities, Schnyder, Buchi, Sensky and Klaghofer (1999:296-302) found no relationship between sense of coherence and functional impairment, but significant correlations between sense of coherence and adjustment with individuals who had experienced a life-threatening accident. Lustig (2005:148) refers to O'Carroll, Ayling, O'Reilly and North (2003) finding that a strong sense of coherence was associated with better self-reported quality of life in a group of individuals with SCI. In a study on the relationship between changes in perceived sense of coherence and adjustment, Lustig (2005) found that two thirds of the participants thought their sense of coherence weakened post injury. The results indicated that a person with a weakened post injury sense of coherence was positively associated with non-adaptive aspects of adjustment (i.e., shock, anxiety, depression, internal anger, and external hostility) and negatively associated with adaptive adjustment (i.e., denial, adjustment, and acknowledgement). In other words, a perceived weakened sense of coherence was associated with problematic adjustment post-injury whereas a perceived strengthened sense of coherence was associated with adaptive adjustment (Lustig 2005:152-153).

2.12 SUMMARY OF LITERATURE REVIEWED CONCLUSION

This chapter discussed the literature review undertaken for the study. The literature reviewed was divided into two main components, namely rehabilitation of spinal injured persons and adjustment to a spinal injury. Subjective assessments of aspects of SCI

rehabilitation focus on stage theories of adjustment. Stage theories represent the process of coming to terms with losses associated with injury as clinical depression involving stages through which individuals move sequentially in order to achieve effective adjustment. Regarding the psychological adjustment of individuals with SCI, factors related to adjustment include internal locus of control, coping strategies, personality traits, social support, attribution of responsibility, and purpose in life. Psychological adjustment is critical in determining the rehabilitation process. The literature review found a positive relationship between perceived social support, employment status, age at onset of disability, marital status, and educational attainment and positive adjustment.

The difficulties facing people living with SCI fall into three distinct areas: physical, emotional and practical. There is no simple relationship between severity of disability and degree of psychological impairment. Individuals who predominantly adopt problem-focused coping strategies experience less psychological distress, compared to those who employ emotion-focused coping strategies, such as blaming others; feeling that the accident was avoidable, particularly immediately following the accident, and feeling that external forces determine what happens. Physical symptoms, such as pressure sores, pain, and urinary tract infection, and family dynamics are sources of stress. Higher levels of well being are associated with adequate social support, perceived high levels of control, high income and more education.

Chapter 3 presents the methodological framework of the study.

Chapter 3

Methodological framework

3.1 INTRODUCTION

This chapter deals with the methodological framework of the study. The researcher wished to describe and understand the nature of existence of people living with an SCI, from their accounts of lived experience. Experience is people's perception of their presence in the world. Perceptions present people with evidence of the world – not as it is thought, but as it is lived (Morse & Field 1995:152). This put the study in an interpretive framework. The analysis of particular existential facts proceeds from an interpretation of the relevance it has to existence (Walters 1994:609). Thus the methodology of this study, which implies the epistemology and ontology, was founded on the qualitative paradigm. Terre Blanche and Durrheim (2004:481) describe a paradigm as “an all encompassing system of practice and thinking, which defines for researchers the nature of their enquiry, i.e., those things that can be taken for granted about the social world they are studying and the correct ways of going about studying it”.

There are two methodological paradigms in social research, namely qualitative and quantitative. The quantitative paradigm emanates from Comte's (1798-1857) positivist meta-theory. Comte held that society is similar to the human body, therefore social sciences are sufficiently similar to bio-medical sciences, and thus equated the aims of social and medical research, i.e., to heal the social 'diseases', the similarity is found in the sense that, in medical practice treatment is based on accurate diagnosis of the problem and similarly diseases of the society can only be cured once their causes have been diagnosed (Bilton 1992:550).

Conversely, the qualitative research paradigm is a generic approach that takes its departure point as the insider, “emic” perspective on social action, as opposed to quantitative research, which is primarily studied from the researcher's perspective (Farley 2003:159). The primary goal of qualitative studies is describing and understanding (Babbie

& Mouton 2001:53). The researcher used a qualitative approach, as the purpose of this study was to explore and describe the subjective experiences of the participants.

Hardiman (1993:1024) cites Melia (1992) who emphasizes that qualitative methodologies favour understanding rather than predicting behaviour. This understanding is described as *verstehen*, understanding by means of empathy, intuition or imagination, as opposed to knowledge from without, by means of observation or calculation. Quantitative studies though useful, may limit people's expressions of issues and concerns that are not identified by the instrument (Jamerson, Scheibmeir, Bott, Crichton, Hinton & Cobb 1996:468).

Qualitative research represents a diverse set of techniques and philosophies that underpin research practice in human sciences. A qualitative approach may be adopted if it is in keeping with the research questions being asked (Maggs-Rapport 2001:375).

3.2 QUALITATIVE RESEARCH

Qualitative research is concerned with understanding life from the perspective of the participants in the setting under study; life-world structures are viewed from different disciplinary perspectives, which have developed partly from epistemological underpinnings and give rise to distinct methodologies (Morse & Field 1995:22). Atkins (1995:120) nevertheless maintains that even those who advocate a paradigm view clearly distinguish between alternative approaches to qualitative research. Despite some broad similarities, each of these perspectives represents a distinct approach to all components of the research process, including question identification, definition of data sources, data-collection methods, analytic procedures, and application of findings (Thorne 1991:179). The differences and similarities in three commonly used qualitative approaches are presented below, namely ethnography, grounded theory, and phenomenology.

3.2.1 Ethnography

Ethnography has its roots in social anthropology, and is a direct description of a culture or a subculture. It is the oldest qualitative method and can be identified in ancient Greek and Roman writings (Alistair 2003:160). Ethnography is also a means of gaining access to the

health beliefs and practices of a culture as it allows the researcher to view the phenomena in the context in which they occur (Morse & Field 1995:26). Ethnography, always informed by the concept of culture, is a generalized approach to developing concepts and understanding human behaviour from the insider's point of view (Polit & Beck 2004:47). The ethnographer needs to spend sufficient "everyday" time in the setting where participants carry out their daily tasks (Henning, van Rensburg & Smit 2004: 43). Multiple forms of data gathering are used in ethnographic studies, including participant observation, interviews, field notes, which may be supplemented by records, life histories and other techniques (Morse & Field 1995:26; Polit & Beck 2004:47).

3.2.2 Grounded theory

Whilst ethnography focuses on cultural beliefs and values, grounded theory is process oriented and allows for change over time, describing stages and phases inherent in a particular experience (Polit & Beck 2004: 28). According to Morse and Field (1995:27), grounded theory was developed to address issues raised in sociology about the understanding of human behaviour based on the quantitative paradigm and thus average behaviour through statistics. The theoretical base for grounded theory is symbolic interactionism, which stresses that human behaviour is developed through interaction with others through processes of negotiation. Hence, the primary purpose of grounded theory is to generate explanatory theories of human behaviour.

Artinian (1998:5) says grounded theory provides a way to "transcend experience", to move it from a description of what is happening to understanding the process by which it happens. Furthermore, grounded theory provides categories for 'knowledgeable' people to use in understanding their own worlds (Artinian 1998:5). Data collection, sampling and analysis all occur simultaneously as the study progresses, and sampling and further data collection are based on emerging theory. Data collection is through unstructured interviews, observation. Data analysis includes constant comparison in which all pieces of data are compared with other data. Henning et al (2004:3) describe grounded theory as "a good qualitative inquiry that is not theory-driven, but data driven", not a methodology.

3.2.3 Phenomenology

Phenomenology, the qualitative approach adopted for this study, has its roots in the philosophical examination of being, and is essentially the study of lived experience. It is concerned with how an event is experienced and understood by certain individuals (Clarke 1998; Forsberg, Backman & Moller 2000:328). The life-worlds of the individuals under study are the primary source of data, but literature, poetry or art may also be used to gain an understanding of the essence of a phenomenon. With its focus on the subjects' experience, phenomenology provides an approach for viewing people as having their own rationality for explaining their meanings and behaviours. Phenomenology is partly about "what is being" or "how we know" (Alistair 2003:160). In phenomenological research, the interview is considered the foremost method of gathering data.

According to Kvigne, Gjengedal and Kirkevold (2002:62), phenomenology was developed as a critique of and alternative to the traditional objectivist ideology of modern science in which scientific objectivity is conceptualised as depictions of the material world, existing independently of humans. The researcher chose phenomenology for this study because of its appropriateness.

3.3 PHENOMENOLOGY: THE PHILOSOPHICAL STANCE OF THE STUDY

The researcher examined the origin of phenomenology, its philosophical roots and how it evolved through the ages, and concentrated on Husserl (1859-1938) and Heidegger (1889-1976).

3.3.1 Origin of the term "phenomenology"

Immanuel Kant first used the term "phenomenology" in 1764, in a scientific context, when he described the concepts "phenomena" and "noumena" in a complicated fashion (Cohen 1987:258). Phenomenology for Kant is "that branch of science which deals with things in their manner of appearing to us, for example relative motion, or colour, properties which are dependent on the human observer" (Moran 2000:7). According to Kant, knowledge comes from "experience given in time and space, but it should be noted that he did not

have in mind what phenomenologists call 'lived space or lived time', but rather the mathematical space and time of Newtonian mechanics" (Benner 1994:13). Hegel (1770-1831) criticised Kant for failing to develop a conception of mind other than as consciousness, felt the Kantian philosophy remained only phenomenology of mind (not a philosophy) (Moran 2000:7). In 1894, Ernst Mach, a physicist, proposed a "general physical phenomenology" which would describe people's experiences of physics as a basis for a physical theory that would for instance describe electricity in terms of the sum of experiences we have of it. Husserl later acknowledged Mach as a forerunner of phenomenology (Moran 2000:7).

3.3.2 Philosophical roots of phenomenology

Phenomenology has its roots in both applied philosophy and psychology. As a philosophy it is rooted in the phenomenological movement of the 19th and 20th centuries (Rose, Beeby & Parker 1995:1124). Phenomenology, founded by Edmund Husserl, is a philosophical approach that tries to make a radical departure from the Cartesian dualism (Benner 1994:13).

Spielberg (1960), (Cohen 1987:31-32), divides the history of the phenomenological movement into three phases:

- *The preparatory phase.* Franz Brentano (1838-1917), philosopher and psychologist proposed a kind of philosophical psychology, a form of descriptive psychology, which would concentrate on illuminating the inner 'self-aware' acts of cognition without appealing to causal or genetic explanation. The domain of the mental was to be described in terms of intentionality, the grasp of inner mental life as inner perception (Moran 2000:8).

Carl Stumpf (1848-1936) demonstrated scientific rigour in phenomenology.

- *The German phase,* dominated by Husserl (1859-1938) and Heidegger (1889-1976). Husserl developed a descriptive psychology as an early form of phenomenology. In 1911, he openly criticised forms of naturalism, historicism, and psychologism, and

subsequently announced the birth of the new science, phenomenology. Husserl influenced Heidegger, Gadamer, Arendt, Levinas, Merleau Ponty, Riccour and Derrida and others.

- *The French phase.* In France, Merleau Ponty (1908-1961) and Sartre (1905-1980) developed phenomenology further. Merleau Ponty developed Husserl's thinking and described phenomenology as a rigorous science and also a philosophy that sees people in a world that already exists before any reflection.

3.3.3 The phenomenological movement

According to Morse (1994:137), Spielberg (1982) used the term "movement", in his history of phenomenological history, to show that it is a philosophy that has changed over time, both across different philosophies and within each philosopher. Even Husserl's philosophy was also distinctively different across time (Cohen 1987:259). His project was to develop a philosophy based on the assumption that all knowledge, including scientific knowledge, is grounded in the everyday world, which he called the "life-world, or lived experience", a concept found posthumously in his unpublished works (Kvigne et al 2000:62; Cohen & Omery 1994:139). Husserl claimed that the life-world is not readily accessible because it constitutes what is taken for granted or those things that are common sense (Koch 1995:828). He introduced the idea "of going back to the things themselves" to underscore that in order to understand, a phenomenon, we must take as a point of departure how it appears to us in our life-world (Kvigne et al 2000:62). Kohak (1978) (Koch 1995:828) states that "to know means to see". Thus a researcher using Husserl's approach always asks about the meaning of human experiences.

3.4 HUSSERLIAN PHENOMENOLOGY

Husserlian phenomenology retains elements of objectivism and accepts the traditional positivistic view of truth. Husserl defines phenomenology as "the descriptive science of the essences and actions of consciousness" (Sadala & Adorno 2002:285). Although his philosophy changed over time, Husserl's four constants are ideal of rigorous science; philosophic radicalism; ethos of radical autonomy, and respect for wonders (Cohen &

Omery 1994:138). Husserlian phenomenology emphasizes the ideal of rigorous science and philosophic radicalism.

- (a) The ideal of rigorous science. Back to the things themselves, when Husserl asks, “What, then, are things? What sort of experience is it to which we must return?” (Yegdish 2000:36).
- (b) Philosophic radicalism. According to Husserl, phenomenology was originally intended as “a radical beginning, a return to philosophical questioning”, and a way to see the world anew as it is, without the influence of culture, insisting on prereflective experience (Caelli 2000:370).

In Husserl’s tradition the ‘eidetic’ phenomenology is epistemological and emphasizes a return to reflective intuition to describe and clarify experience as it is lived and constituted in consciousness (Ray 1994:118). Husserl’s phenomenology is based on the belief that there are essential structures to human experience (Draucker 1999:361). He was primarily concerned with fundamental epistemological problems, and his phenomenological philosophy is that of theory of experience and not a scientific method (Kvigne et al 2000:62).

3.4.1 Concepts associated with Husserlian philosophy

The following concepts are associated with Husserl’s philosophy: intentionality, bracketing, phenomenological reduction, eidetic variation, intuition of essences through descriptive analysis, description and inter-subjective dialogue

- **Intentionality**

Intentionality ‘encapsulates’ Husserl’s radical departure from positivistic assumptions of objectification (Yegdish 2000:31). “The core of phenomenology is the *intentionality of consciousness*” understood as the direction of consciousness towards understanding the world (Sadala & Adorno 2002:283). Furthermore, through the intentionality of consciousness, all actions, gestures, habits and human actions have a meaning.

Intentionality eliminates the subject-object divide in objectively revealing the world for all through consciousness. By studying consciousness, the researcher is able to explore the nature of how a person participates in the life-world (Moyle & Clinton 1997:122). Thus, the researcher's task is to "analyse the intentional experiences of consciousness in order to perceive how the meaning of a phenomenon is given meaning and to arrive at its essence" (Sadala & Adorno 2002:283).

- **Bracketing**

Bracketing means suspension of all ontological commitments regarding the existence of a world independent of the mind. It does not bracket the actual existence of the world, only puts it in abeyance. The essential acts of consciousness are transformed into the subject of rigorous science – the *eidōs* or essence (Yedgich 2000:31). Bracketing is linked to the notion that consciousness is intentional. Yedgich (2000:37) refers further to what he calls a "phenomenological paradox" as Husserl (1960:157) believes surrendering the everyday world through bracketing so that we lose nothing and gain the "Whole of Absolute Being" because "we put out of action the entire ontological commitment that belongs to the essence of the natural attitude, we place in brackets whatever it includes with respect to being". By bracketing we allow for pure description, allowing the phenomenon to be seen "precisely" as it presents itself (Dahlberg, Drew & Nystroom (2001:92). According to Walters (1995:792), bracketing is modelled on the mathematical strategy of placing in brackets that part of a mathematical equation to be treated differently from the remainder of the equation.

- **Phenomenological reduction (Husserl's eidetic reduction/ epoche)**

Phenomenological reduction is the fundamental resource that ensures a reliable description of a phenomenon. This reduction highlights the intentional character of consciousness turned towards the world, once it brackets the reality conceived by common sense and "cleanses" the phenomenon of everything that is "unessential" (Sadala & Adorno 2002:283). Dahlberg et al (2001:92) refer to Giorgi (1992) who says of phenomenological reduction, that when the phenomenologist has "freed himself from theoretical, and empirical fastenings" he can go "to the thing".

Nurse researchers understand phenomenological reduction as concentrating on the phenomenon, becoming absorbed in it, and through bracketing, seeing it for the first time (Rose, Beeby & Parker 1995:1124). This leads to identification with the essence of the phenomenon, and is achieved through “reflective thoughtfulness about what is important in the taken for granted and seemingly trivial aspects” of the phenomenon (Rose et al 1995:1124). This is known as reduction because it leads back to the source of meaning of the experience. The purpose of reduction is to prepare for analysis.

- **Eidetic variation**

Eidetic variation is a technique that Husserl created to keep only the essence of the phenomenon under study. Thus, when investigating a phenomenon, a researcher starts from the experiences lived by the participants and then unveils the essence of the phenomenon by applying the principle of intentionality, also referred to as *free variation*. According to Rose et al (1995:1124), this means that the imagination freely associates the experience with those of self and others, and imagines the appearance of the phenomenon in a variety of contexts. In this way the meaning of the phenomenon is determined.

- **Intuition of essences through descriptive analysis**

Intuition is a means of attaining “indubitable knowledge itself” and rigorous science a means of attaining such knowledge (Yegdish 2000:31). *Intuiting* is an inductive process involving bracketing, reduction, free variation and transforming (Rose et al 1995:1125). The researcher looks at the phenomenon afresh without layering it with what he/she has bracketed out (Brink & Wood 1998:341). Through intuition the researcher comes to understand the phenomenon as described by the participants. The researcher must be totally immersed in and reflect on the phenomenon. Intuition and reflection are important in the data analysis process to help open up “the meaning of experience as discourse” (Polit & Hungler 1999:575). According to Husserl and Gibson (1962) (cited in (Porter 1998:21), researchers must strive “to describe faithfully what we really see from our point of view and after the most earnest consideration”.

- **Description**

Description, also known as “transforming”, is the analytical process in phenomenology. It involves exploring the meaning as it unfolds for the participants, and articulating meanings as they emerge in the phenomenon. The transmission to writing may include full descriptions of cases and description of thematic analysis (Rose et al 1995:1125). Dahlberg et al (2001:920) add that in description one sets aside theories as explanations of the phenomenon. The aim is to be as open as possible to the phenomenon in question. For Husserl, “pure” consciousness is the key and necessary factor for phenomenological analysis.

- **Inter-subjective dialogue**

Husserl and Gibson (1962) (cited in Porter 1998:21) maintain that in order to fully develop a phenomenon, two “formations in the constituting of the Thing” are needed: the first formation is reflection, bracketing, and intuiting by the researcher and the second is “the inter-subjective identical thing” to discuss phenomena and “counter cases”.

3.5 BRACKETING IN QUALITATIVE RESEARCH

The process of “bracketing” is used to retain an element of objectivity and involves researchers’ deliberate examination of their own beliefs about the phenomenon and their temporary suspension of those beliefs (Koch & Harrington 1998:884). Researchers engage in this process by attempting, as far as possible, to be free from bias, working to recognize bias and ‘control’ it. The use of bracketing defends the validity and objectivity of interpretation against the researcher’s self-interest, and that bracketing is achieved through the process of phenomenological reduction (Koch 1995:829). Gibbins and Thomson (2001:305) are of the opinion that bracketing attempts to make researchers’ bias explicit, rather than eliminate it. They add that it is realistic to recognise that researchers can only write about their bias as honestly as possible, clearly identifying their presuppositions so that consumers of research can make their own judgement about how the research has been influenced by the bias (Gibbins & Thomson 2001:305). To see lived experiences one must suspend and lay aside what one thinks and already knows about it. Bracketing

enables inductive development of concepts (Gift 1997:83). Bracketing enables researchers to intuit from the data. Beck (1994:500) refers to Swanson-Kauffman and Schonward's (1988) description of bracketing as a "tool researchers use to meet the 'ethical dictum' of phenomenology". Yegdish (2000:32), however, maintains that bracketing or epoche occurs in nursing in the natural attitude, in order to remain faithful to their subjects' experiences, *not* to phenomena or the things themselves whereas Husserl insists on bracketing the natural attitude. What this means is that although nurse phenomenologists claim to follow Husserl's quest of returning to things themselves, they focus on people's experiences as phenomena existing in themselves (Yegdish 2000:32). Husserl's notion of "letting the facts speak for themselves" is congruent with the notion of objective truth, suggesting that people's experiences can be analysed with the same certainty as physical phenomena, and this is possible by identifying the "facts" of the situation by Husserlian reduction (Walters 1995:795).

Husserl's inquiry is committed to describing the essential structure of the lived experience, thus the essence of a thing, without preconceptions and prejudices. The transcendental subjective process is achieved by seeking to attain the genuine and true form of things themselves (Ray 1994:119). Researchers using Husserl's phenomenology seek answers to questions about the world and the objects within it, rather than the nature of existence or Being (Mackey 2005:181). Ray (1994:119) cites Stapleton's (1983) view that what is important about Husserl's phenomenology is the claim that consciousness is a "realm of absolute being" where the starting point for philosophical reflection is not theory or history, but "a description of the presence of man in the world, and the presence of the world for man". According to Walters (1995:792), for Husserl, phenomenological research means presenting a systematic view of mental content and assumes that this is possible if symbols representing the world are manipulated in the mind, and these manipulations permit the external world to be brought into consciousness by cognitive process.

3.6 REACTION TO HUSSERL'S PHILOSOPHY

Subsequent philosophers' perspectives are always compared to Husserl's, in order to examine how they have developed and modified his thinking, and how they differ. For example, Merleau Ponty's existential philosophy is interested in "historical persons" in as

much as they engage with and live in the world. Ponty sees the individual as the body itself, at a place and time, acting in the world in which it lives. The body itself is the *perceiving subject*, whereas Husserl refers to an impersonal transcendental self, which is intentionally correlated to the world (Sadala & Adorno 2002: 286; Yegdish 2000:29).

Martin Heidegger (1889-1976), a contemporary of Husserl's, is discussed next, and the tensions between Husserlian and Heideggerian approaches highlighted.

3.7 HEIDEGGER'S ONTOLOGICAL PHENOMENOLOGY

Like Husserl, Heidegger sought to redefine the mission of philosophy through phenomenology (Cohen & Omery 1994:137). He criticized the way Husserl had constituted phenomenology, especially by emphasizing description rather than understanding (*verstehen*) as its basis. Heidegger thereby dissociated himself from the eidetic and the transcendental approaches (Cohen & Omery 1994:141). Heidegger sought to answer the question of the meaning of Being. According to Omery and Cohen (1994:141), Heidegger saw the task of phenomenology as destruction, looking past the normal, everyday meanings of life to see the larger meaning in Being. Being or *Sein* is interpreted as the "presence in the world" through which the truth is self-determined, as opposed to being, or "being there" (*Dasein*) which signifies how people (beings) comprehend this presence. Being is the ground of all beings; all persons (beings) need Being (Cohen & Omery 1994:140). Heidegger's phenomenology does not accept the object-subject dichotomy and, most importantly, does not accept the notion of "letting the facts speak for themselves" or of knowledge independent of interpretation (Walters 1995:795).

Heidegger rejected the notion that people observe subjects separated from the world of objects about which they try to get knowledge (Draucker 1999:361). According to him, people are beings inseparable from an existing world. He further contradicts Husserl's role of consciousness that by studying consciousness the researcher is able to explore the nature of how a person participates in the life-world. Heidegger maintains that much of what people do does not involve consciousness or awareness, but rather everyday skilful coping (Draucker 1999:361).

Heidegger maintained that getting to know and describe the experience of individuals was not enough. Instead he stressed the importance of knowing how respondents come to experience phenomena the way they do. Heidegger extended Husserl's philosophy to examine its ontological status, and for Heidegger, phenomenology is only possible as ontology (Walters 1994:609).

Bracketing is the indispensable starting point of Husserl's phenomenology, hence a key distinction between Heideggerian and Husserlian philosophy is Heidegger's position that presuppositions cannot be suspended because they "constitute the possibility of intelligibility or meaning" (Ray 1994:120). Heidegger challenged Husserl's construction of phenomenology as a purely descriptive philosophy, considering description without interpretation to be impossible. Heidegger maintained that phenomenological understanding requires recognizing one's own pre-understanding and interpretive functions. Heidegger introduced interpretation as both a concept and method of phenomenology, and referred to phenomenology, which seeks to uncover understanding of the meaning of Being, as "hermeneutic" and an interpretive process (Mackey 2005:181). Interpretive researchers, or Heideggerian phenomenologists, see bracketing as a misnomer for reflexive processes occurring in interpretive research, and reject that individuals can step outside of their unique viewpoints (Dahlberg et al 2001:92).

Husserl and Heidegger involve divergent ontological and epistemological assumptions. Consequently, the term "phenomenological" is less useful in epistemological and methodological debates unless the specific meanings and assumptions of the term in that context are made explicit (Lowenberg 1993:64). Heidegger's philosophic concerns were ontological aimed at an understanding of 'Being' itself. People and Being are interdependent; they subsist together.

Heidegger believed people are in and of the world. Heidegger refers to this situatedness in the world as *dasein*, which can be translated as "being there" in the world, a specific way of being in the world, the way people comprehend this presence in the world (Moran 2000: 238). Walters (1995:793) describes *dasein* as the notion of human everyday(ness) existence. Thus Heidegger views a person as being in and out of the world, encountering and managing things.

3.7.1 Heidegger's philosophical assumptions

According to Heidegger's four philosophical assumptions about what it means to be a human being, people have a world; are self-interpreting; are in-the-world, and are in time.

- A person has a **world**, which, in a phenomenological sense, refers to meaningful relationship practices and language. A world that is given is a priori, thus a person is thrown into a particular cultural, historical, and familial world. Benner (1994:47) cites Hoy's (1986) statement that the world "sets up possibilities for who a person can become and who she/he cannot ... personal identity is not a matter of ownership". People are constructed by the world in which they live, then, and at the same time construct this world from their experience and background (Koch 1995:831). Heidegger's concept of being "thrown into" implies that the person is already situated as being in the world.
- A person is **self-interpreting**, self-defining, always in a cultural environment (Koch 1995:831). Understanding is being, so people's capacity to understand is rooted in their own definitions.
- **Being in-the-world** means people cannot exist apart from it; they are primarily in and of the world, rather than subjects in a world of objects (Reed 1994:337). In addition, the concept of a person's 'being-in-the-world' necessitates a view that the person and the world are *co-constituted*, in an indissoluble unity (Koch 1995:831). The world is "in" one's existence and existence is "in" the world "in the sense that the world is human and humans are worldly" (Dahlberg et al 2001:79). The term for this relationship is *dasein*. The notion of *dasein* contains three different elements that represent the past, present and future (Reed 1994:337).
- A person is **in time** (temporality). Being in time denotes a new way of perceiving time in terms of including the now, the no longer, and the not yet (Leonard 1994:49). Time was introduced as "the possible horizon for an understanding of being" (Cohen & Omery 1994:143).

Heidegger sees a person as being-in-the-world, embodied, in time and self-interpreting, encountering and managing things. A being for whom things have significance and values, “each one of us [is] what he pursues or cares for, and we understand ourselves and our existence by way of the activities we pursue, and things we take care of” (Benner 1994:49).

Nothing can be encountered independently of people’s background. Every encounter is an interpretation based on their background. Heidegger’s concepts of human being and temporality are linked closely with his concept of existence. The essence of human being lies in its existence, that is, in its possibilities to choose different ways of being (Cohen & Omery 1994:144). Heidegger believed there were many ways for the human being to be in-the-world, and distinguished between authentic and inauthentic ways to be. *Dasein* is always individualised into the life of the individual (Moran 2000:238).

That Heidegger views a person as being and in and out of the world has implications for nurse researchers. According to Heidegger, life is a text and the purpose of an inquiry is to understand that text. Research based on Heidegger’s tradition seeks to uncover what it means to be a person, and the researcher is an active part rather than a passive recipient in the interpretive process (Draucker 1999:361).

Furthermore, Heidegger’s view that a person is **embodied** also has implications for nurse researchers. The notion of embodiment is the view that the body is the way we can potentially experience our action in the world (Holloway & Wheeler 1996:119). The life-world is constituted by means of lived experiences in interaction with other people and things (Kvigne et al 2000:62). The notion of being-in-the world enables researchers to legitimately bring their experiences and understanding to the research (Walters 1995:795). For Heidegger, access to Being is to be achieved through an account of *dasein* in their “average everydayness” (Mackey 2005:182).

The Heideggerian definition of a person contradicts that of Cartesian dualism whereby a person is seen as subject and the world or environment as object; an uninvolved self passively contemplating the external world. Heidegger wanted to employ phenomenology as the proper mode of access to the phenomenon of concrete human life, as a way of thinking about human nature that remained faithful to the historical, lived practical nature of

human experience. Heidegger saw that people were caught up in living their lives, projecting themselves into possibilities (Moran 2000:228).

Heidegger's four philosophical concepts provide methodological insights into conducting phenomenological research, namely being-in-the-world, fore structures, time and space. Phenomenology for Heidegger leads to a new way of seeing rather than to a set of philosophical propositions. Heidegger radically reinterpreted phenomenology as hermeneutical or interpretive (Ray 1994:120).

3.7.2 Heideggerian interpretive research and hermeneutics

The word "hermeneutics" is derived from the Greek, *hermenia*. The Greek messenger, Hermes, was responsible for changing the unknowable to a form that humans could understand via language and writing (Wilson & Hutchinson 1991:265). The Greek root for hermeneutics suggests it is "bringing to understanding particulars where the process involves language" (Annells 1996:706).

The Heideggerian interpretive approach to inquiry provides interpretations of everyday human lived experiences in order to understand fully their richness and complexity (Baker, Norton, Young & Ward 1998:549). In Heidegger's philosophy, the essence of human understanding is hermeneutic; that is, people's own understanding of the everyday world is derived from their interpretation of it (Dahlberg et al 2001:78). All new things encountered in the life-world are related to people's earlier experiences. Heidegger's focus on fore structures of understanding raises grave questions about the validity of describing interpretation in terms of the subject-object relationship, also raising questions about the "so-called" objective interpretation or interpretation without presupposition (Dahlberg et al 2001:78).

Philosophical hermeneutics as a basis for interpretation is bound to hermeneutic phenomenology. Hermeneutic phenomenology is a combined method that describes the phenomenon as well as allows for interpretation, enabling the researcher to uncover the lived experience. It does not seek evidence first "as it is in itself" as foundational, but instead discloses the *horizon* by uncovering the presuppositions. Hermeneutic's goal is a

discovery of meaning that is not immediately manifest to people's intuiting, analysing, and describing (Cohen & Omery 1994:146). Interpreters have to go beyond what is given directly. Benner (1994:56) describes the goal of a hermeneutic or interpretive account as to "understand everyday skills, practices, and experience [and] to find commonalities in meaning, skills, practices and embodied experience; and to find exemplars or paradigm cases that embody the meaning of everyday practices". Heidegger emphasizes people's language, history and commitment to a culture that they inherited and intuitive sense called "embodied" knowledge (Wilson & Hutchinson 1991:265). The interpretations of everyday situations work to illuminate otherwise inconspicuous common experiences and shared meanings and practices that are embedded in social, historical, and cultural contexts (Baker, Norton, Young & Ward 1998:549). This tradition involves researchers in continuous dialogical engagement with the participants' narratives, "text analogues" (Baker et al 1998:549). The texts are analysed for recurring experiences, themes, and patterns during multiple stages of interpretation. This is achieved through reading a single text in depth, reading across all texts in a study, and continually reviewing pertinent nursing and philosophy literature. The literature brings or provides rich descriptions of the nature of shared practices (Baker et al 1998:550). Also, the researchers' engagement with literature calls for them to rethink and challenge the interpretations and extend understanding of the meanings created by the participants (Baker et al 1998:550).

According to Benner (1994:116), "the interpretive researcher engages in cycles of understanding, interpretation and critique". Geanellos (1998a:155) asserts that understanding and interpretation, and all that they involve, are the primary concerns of hermeneutics.

Annells (1996:707) states that philosophical hermeneutics as a basis for interpretive inquiry is methodologically bound to hermeneutic phenomenology. Hermeneutics is an ontological process; it is through the process of interpretation that the world shows itself, since "when we consider the ontology of the life-world, the invisible being-in-the-world structures become visible" (Dahlberg et al 2001:80). The steps for hermeneutic inquiry aim to identify and provide an understanding of the variety of constructions that exist about a phenomenon. Furthermore, the interpretation is open to re-interpretation and is dialectic in nature. The process of conducting research guided by Heidegger's phenomenology

requires the researcher to engage in both descriptive and interpretive activities. Research based on the Heideggerian tradition seeks to uncover what it means to be a person in the world, the world being understood as an integrated moment in the structure of existence (Dahlberg et al 2001: 79). The researcher is an active participant rather than a passive recipient in the interpretive process, and data generated by the participant is fused with the experience and placed in context (Draucker 1999:362; Koch 1996:176).

According to Dahlberg et al (2001:78), the introduction of fore structures and pre-understanding established hermeneutics upon phenomenological philosophy and in particular the notion of the life-world. Gadamer (1989) later converted hermeneutics to an existential philosophy (Dahlberg et al 2001:78).

3.8 GADAMER'S HERMENEUTIC PHENOMENOLOGY

Gadamer (1990) denounces the notion that the scientific method defines the exclusive avenue to truth (Ferguson 1996:836). For Gadamer, description pre-understanding is a necessary part of understanding. Unlike Husserl, who advocates a phenomenological reduction and bracketing as necessary for discovering truth, Gadamer believes people must be firmly situated in the world before understanding can take place. Gadamer embraces Heidegger's notion of hermeneutic circle, where people must "understand the whole in terms of the whole" (Ferguson 1996:836). Gadamer further articulated a hermeneutic in the context of both temporality and historicity of human existence. For Gadamer, because meaning is derived from the past as well as tied to the present situation and often enough to the future, interpretation must take into account the historical context, both past and present (Dalhberg et al 2001:83). By recognizing the role of historical influences or horizons of meaning of past traditions, human experience is understood in a new way (Ray 1994:121). Gadamer maintains that prejudices are the result of the history effect, and that prejudices nail people to the past as well as to the future, as understanding includes both memories and anticipation. Because of prejudices, people are inclined to anticipate the meaning of a thing or text long before they fully understand it (Dalhberg et al 2001:83).

Ricouer's (1981:101) definitions of phenomenology and hermeneutics support Husserlian, Heideggerian and Gadamerian views: "phenomenology remains the unsurpassable presupposition of hermeneutics. On the other hand phenomenology cannot constitute itself without a hermeneutical presupposition" (in Morse 1994:121).

3.9 MERLEAU PONTY'S EXISTENTIALIST PHILOSOPHY

Merleau Ponty's phenomenology is existentialist in the sense that it deals with the existence of people in a pre-given world. It is a philosophy that is not interested in the abstract, but in "historical persons" in as much as they engage with and live in the world (Sadala & Adorno 2002:286). Merleau Ponty (1945) proposed returning to the things in a search for the essences of objects, their qualities, but seeing these as part of the lived and experienced world, which is a world of things, that have not been reflected upon, and on which sciences are constructed (Sadala & Adorno 2002:286).

3.10 THE RESEARCHER'S ROLE IN INTERPRETIVE PHENOMENOLOGY: UNDERSTANDING THE LIVED EXPERIENCE

Deeper insights can be gained through interpretive phenomenology, and the process develops through three distinctive stages: fore-understanding/fore structures, interrogation, and reflection (Maggs-Rapport 2000:221).

3.10.1 Pre-understanding/fore structures

Researchers start with a phenomenon they wish to explore. Their initial understanding of the phenomenon need not be highly developed, but there must be some knowledge about the area (Maggs-Rapport 2000:221). Fore structures, also called pre-understanding or background, are what is understood or known in advance of interpretation (Plager 1994:71; Geanollis 1998b:155; Maggs-Rapport 2000:221). Fore structures mean context-dependent knowledge, opinions, and experiences that the researcher and participants bring to the research study (Mackey 2005:182). Husserl used the term "bracketing" to describe how people must take hold of the phenomenon and then place their knowledge about it outside of it. Geanollis (1998a:158) advocates that the way to allow a text to manifest itself is by

working out pre-understandings. Van Manen (1990:47) is of the opinion that if people simply try to forget or ignore what they already 'know' they may find that the presuppositions persistently creep back into their reflections. People should rather make explicit their understandings, beliefs, biases, assumptions, presuppositions, and theories.

According to Genealles (1998b:243), bringing pre-understandings to consciousness is an attempt to "maximise their facilitative aspect as it allows the interpreter to examine their origin, adequacy and legitimisation to: (i) the phenomenon under investigation; and (ii) textual interpretation". Thus interpretation overcomes the entrenchment of understanding or fails because of them.

3.10.2 Interrogation/Interpretation

Using an interpretative approach requires the researcher to accept and value the descriptions given by the participants as their reality, their understanding of the phenomenon (Koch 1999:24). Interpretive research requires more from the researcher than simply taking the role of recorder (Mackey 2005:182). Interpretation starts when the researcher engages with the phenomenon, as the researcher's prior awareness, attention is directed toward the phenomenon. Interpretation continues as the researcher listens to and reads the participants' descriptions of their experience and becomes immersed in this data (Mackey 2005:182). For Heidegger (1962:192), interpretation functions as "disclosure", it discloses what is "already there", and when things in the world have been understood through interpretation it can be said they have meaning. Heidegger's conception of interpretation is of a circular process whereby the fore structures are made explicit, and then considered in terms of the whole understanding of something.

Methodologically, this is seen in the concept of the hermeneutic circle (Leonard 1989:55). The hermeneutic circle refers to the flow of understanding that takes place through being-in-the-world (Mackey 2005:182). Yet, Mackey (2005:182) refers to Thompson (1990) who describes hermeneutic circle as a "process of moving dialectically between a background of shared meaning and a more finite, focused experience with it". The idea of a hermeneutic circle prescribes that, in interpretation of a text the meaning of the parts should be considered in relation to the meaning of the whole, which itself can only be

understood in respect of its constituent parts (Kelly 2002:406). According to Van Manen (1990:127-131), developing these circles of interpretation is the process of hermeneutical phenomenological writing, and through this circular process of writing and rewriting the researcher clarifies, promotes reflection, and allows for deeper meaning to be revealed. As a result, this process distances the researcher from the phenomenon, encouraging perspective, thus allowing focus on the phenomenon alone (Van Manen 1990:127-131).

The interpretive activity is not limited to a specific stage in the research process. Kelly (2002:406) emphasizes that interpretive accounts should never be completely denuded of the context, and details should never be presented without being positioned in relation to the overall structure of understanding. From listening and observation, Kelly continues, through thematising, coding and writing the final report, interpretation should keep one eye on the development of the whole and other parts which are integrated therein (Kelly 2002:406). Parse (1995:14) regards the process of interpretation as the gradual weaving of the findings into the theory to enhance understanding of lived experiences at the level of science.

3.10.3 Reflection

Reporting and interpreting the findings of qualitative research can be described as a hermeneutic project, a self-reflective personal journey and an empathic experience (Schultz 1994:414). Schultz (1994:414) refers to Benner and Wrubel's (1989) finding that uncovering meaning in data requires consideration of the context in which the phenomenon occurs. The reflexive elements in qualitative nursing research recognize the use of the researcher's own perceptions and knowledge. According to Bamberger and Schon (1991) (cited in Schultz 1994:416), personal experience recorded and reflected upon can also be an informant, in that this reflection could be a valuable source of understanding, and is both conscious and explicit when the researcher is "conversing with the materials". In order to grasp the essence, concrete experience is considered and then the researcher tries to imagine that experience from all aspects. To achieve this, phenomenologists engage in conversation with others, obtain descriptions from literature and poetry, watch movies and reflect on phenomenological literature (Morse & Field 1995:153).

Burns and Grove (1997:531) describe reflexivity as “critical thinking used to examine the dynamic interaction between self and the data during analysis. During this period the researcher explores personal feelings and experiences that may influence the study.” Geanolles (1998a:155) affirms that interpretation involves a background of presuppositions from which the interpreter can never be free.

3.10.4 The researcher’s pre-understanding in this study

Morse (1994:36) points out that in a phenomenological study, first reflecting on one’s own experiences attains having in-depth knowledge of a phenomenon, as these are often the first source of “data”. From encounters with people living with an SCI, the present researcher formulated her own preconceptions, which first influenced her choice of topic. These fore structures pointed to some assumptions she held regarding the nature of living with an SCI in rural areas. Valle and King (1978:55) offer guidelines on how phenomenologists interrogate their presuppositions about the phenomenon they intend studying. In 2004, the researcher wrote down the outcome of her self-interrogation prior to finally deciding on a research topic (see Appendix 7). At the time the researcher believed strongly that people living with an SCI were “at risk”, unidentified, underserved, and little understood. The belief has not changed although the findings refuted some of her assumptions. Ashworth (1997:221) states that research must start with certain presumptions, however ill informed; interpretation depends on the standpoint, and the meaning of something has to be in terms of the relevance thereof to the project. Ashworth (1997:222) quotes Gadamer (1989) who holds that “prejudice” is an essential feature of understanding as the interpreter cannot be “disembodied, dehistoricized and acultured”.

Thus, researchers using Heideggerian hermeneutics phenomenology need to address pre-understandings and how they influence the inquiry. Hermeneutically, access to truth is granted when interpreters fulfil specific obligations (Geanellos 1998a:155).

3.11 CONCLUSION

The focus in this chapter was to explicate the two distinct phenomenological methodologies, founded on the eidetic or descriptive, and hermeneutics or interpretive schools of thought. The differing philosophical approaches grew out of a particular view of what it means to be human and to be in the world and thus carry with them assumptions about the nature of being and the nature of the world in which people live. The two methodologies were discussed and compared. The objective was to grasp and describe the meaning of the experience (SCI) from the perspective of those who have had that experience.

Chapter 4 describes the research design adopted for the study.

Chapter 4

Research design and methods

4.1 INTRODUCTION

Chapter 3 dealt with the methodological framework and philosophical underpinnings of this study. In phenomenological research, methodology and methods are understood as different entities (Caelli 2001:275). Methodology refers to the philosophical framework that must be assimilated so that the researcher is clear about assumptions of the particular approach, whereas methods refer to the research technique and the procedures for carrying out the research (Van Manen 1990:28). Caelli (2001:275) emphasises that in qualitative research, the way of proceeding or method chosen must be defensible from the philosophical and epistemological positions that guide the study. According to Koch and Harrington (1998:866), the paradigm within which a given study is conducted, its philosophical underpinnings and assumptions, should be evident.

This chapter describes the study design, including the processes of data collection and analysis, and justifies its appropriateness for exploring living with an SCI as experienced in the context of a rural community. The eligibility criteria for participation in the study and the ethical considerations are discussed. The Heideggerian hermeneutic philosophy guided the study.

4.2 RESEARCH DESIGN

Durrheim (2002:29) defines a research design as “a strategic framework for action that serves as a bridge between research questions and the execution or implementation of the research”. Research designs are plans that guide “the arrangement of conditions for collection and analysis of data in a manner that aims to combine relevance to the research purpose” (Durrheim 2002:29). Polit, Beck and Hungler (2001:167) define the research design as “an overall plan for obtaining answers to the questions being studied, and handling difficulties encountered during the research”. Schwandt (2002:229) defines it as a “strategy of linking research questions, methods, and evidence”. A research design,

therefore, provides a plan that specifies how the research is going to be executed, in such a way that it answers the research question.

In developing a research design, Durrheim (2002:33) points out that researchers must make a series of decisions, on four dimensions: (1) the purpose of the research; (2) the theoretical paradigm informing the research; (3) the context or situation in which the study will be carried out; and (4) the research techniques employed to collect and analyse data. Finally, the aim of a research design is to plan and structure a given project in such a manner that the eventual validity of the research findings is maximised (Durrheim 2002:33).

In this study, the main focus was on the lived experiences of an SCI. This interview-based study was established on the principle that an understanding of being a person living with SCI could only begin to emerge by asking interviewees to reflect on their own experiences in an unstructured way, so as to allow them to set the priorities (Jowett 1995:40).

The challenge was to develop a research design that maximized the quality and usefulness of the data collected. The aim of the study was not to identify prevalence of a phenomenon, but to seek and explain participants' experiences and to develop a thorough understanding of being a person with an SCI. The researcher used a phenomenological qualitative design that is descriptive, interpretive and contextual. Qualitative research Jowett (1995:40) is of value because it is fully comprehensive and definitive, and it also provides a realistic account of the world as participants experience it. Madjar and Walton (2001:41) state that "qualitative research, with its focus on the processes and the context of human experience can be explored and understood in ways that allow research participants to provide their own meanings and explanations and to challenge the outsiders' views or theories".

4.2.1 Qualitative aspect

According to Babbie and Mouton (2001:270), the main features of qualitative research are that the research is conducted in the natural setting of social actors and the actor's perspective (the "insider" or "emic" view) is emphasized. The primary aim is in-depth ("thick") descriptions of understanding of actions and events so as to understand social action in terms of its specific context (idiographic motive) rather than attempting to

generalize to some theoretical population. The research process is often inductive, and the researcher is seen as the “main instrument” in the research process.

Thorne (1999:400) supports the nurse’s engagement in qualitative inquiry about the meaning domain of an illness experience. Some of the advantages are that nurses begin to appreciate that apparently illogical or irrational patient responses may instead be a product of clashes between patient values and professional socialization, and also recognise that certain events which may be considered relatively unimportant by professionals may actually instead represent catastrophic meaning for the patients involved.

4.2.2 Phenomenological aspect

The purpose of the study was to explicate and appreciate the nature of the experience. Phenomenology is partly about “what is being” or “how we know” (Farley 2003:160). With its focus on the subjects’ experience, phenomenology provides an approach for viewing people as having their own rationality for explaining their meanings and behaviours. The phenomenologist emphasizes that all human beings are engaged in the process of making sense of their life-world. According to Kvigne et al (2002:62), phenomenology was developed as a critique of and alternative to traditional objectivist ideology of modern science, in which scientific objectivity is conceptualised as depictions of material world existing independently of humans, or events, in the everyday world.

Phenomenology offers a descriptive, reflective interpretive and engaged method of inquiry (Van Manen 1990:176). Terre Blanche and Kelly (2002:126) state that the commitment to understanding human phenomena in context, as they are lived, using context-derived terms and categories is often referred to as the phenomenological perspective.

The decision to utilize a phenomenological approach was mainly guided by the nature of the research question and the capacity of the method to facilitate the inquiry. In addition, the researcher’s own philosophical beliefs as a person and researcher made the phenomenological approach appropriate.

Phenomenology was also chosen because of its underpinning assumption that the meaning of any phenomenon is described by the person who experienced it (Parahoo 1997:41). The belief that reality is not an empirically derived reductionist determination, but rather a subjective individually formulated and interpreted judgement, is inherent in this method (Parahoo 1997:43).

Emanating from this underpinning assumption, the following assumptions were deduced for the study:

- The inquirer and the inquired-into are merged into a single interactive entity, and findings that result from the inquiry are created by the interaction between the researcher and the researched (Lincoln 1992:380).
- Reality becomes accessible across the different perspectives.
- In-depth phenomenological interviews would elicit the required information.
- Lived experiences give meaning to each particular phenomenon, and are influenced by everything internal and external to the individual (Streubert & Carpenter 1999:44).
- Each person has his own unique story, but a combination of these interrelating experiences enhances understanding and convergence of these (Van der Walt 2004).

The key distinguishing characteristic of phenomenology is its overriding concern with the subjective dimension of personal experience (Purdy 1997:192). Furthermore, this approach is grounded in a particular ontology (theory of being), which claims that the social world is qualitatively different to the natural material. This ontology generates a specific epistemology, in which knowledge of the social world is seen to be the product of individual rather than of theory (Purdy 1997:192).

Babbie and Mouton (2001:28) contend that because people are continuously interpreting creating and giving meaning to, their interpretations of their world should be taken into account. Phenomenology offers the possibility of studying human experience in the context

of the life-world. This context includes the physical and social environment, but also people's history, their concerns, and aspirations (Madjar & Walton 1999:4).

Madjar and Walton explain why phenomenology holds an appeal for nurses that it is its attempt to overcome the traditional mind-body dualism through the ideas of bodily 'consciousness' or the 'lived body'. Phenomenology also fits well with person-centred, contextual approach that is of interest to nurses (Madjar & Walton 1999:4). The focus of this study was to understand the experience of being a person living with an SCI. The phenomenological method used in the study acknowledges that being is immersed in people's experiences of being-in-the-world (Ferguson 1996:836).

Annells (1996:708-709) points out that phenomenology is suitable for researching nursing questions about nursing phenomena because of the following positive features:

- a focus on the experiences of nurses and patients existing in a health attainment or maintenance environment
- a valuing of whole persons who create personal meanings
- a consideration of contextually meaningful experience
- the consideration of nurses and patients as 'entities, or beings of Being' (Taylor 1994)

In this study, then, the researcher used interpretive/hermeneutic phenomenology as the methodological approach. Interpretive phenomenology uncovers meanings embedded in the worlds of the participants (Maggs-Rapport 2001:379).

Specifically, the benefits of using a hermeneutic approach for nursing research include a fostering of the skill of listening to the speaker and to the context/meaning of the expressed language; lived experience being seen to precede understanding, and the deepening and broadening of understanding through fusion of horizons of past, present, and the future of persons in different situations with an emphasis on the universality of language as relevant among and across persons receiving and giving care (Rheeder 1985 in Annells 1996:709).

The subjectivity of interpretive research values investigators as persons who may interpret in their unique way, and yet integrity must be evidenced in the process to ensure that data is valid and grounded within data. The data generated by the participants is fused with the experience of the researcher and placed in context (Koch 1996:176). Koch (1996:178) emphasises that the participants' perspective, the researcher's presuppositions and how their viewpoints are merged should be described in enough detail that readers can audit the events and actions, and also that the disciplinary relevance is preserved. Hence it is important for researchers' preconceptions to be made explicit at the outset of the research study. This process reflects the belief that it is impossible to apprehend the meaning of a phenomenon *tabula rasa*, since the phenomenon studied, the rationale, research question are influenced by the researcher's beliefs (Parse 1995:22).

Mackey (2005:180) found that nurse researchers also draw on Gadamer's (1975) and van Manen's (1990) interpretive methods, which are derived from Heidegger's phenomenological philosophy. While Heidegger does not explicate a method for phenomenological research, he suggests that access to Being is to be achieved through an account of *Dasein* (being there) in their everydayness. By so doing, the essential structures of Being can be revealed (Mackey 2005:182).

Although the research design occurs at the beginning of a study, it involves all the steps of the subsequent project.

4.3 RESEARCH PROCESS

The research process is a process of scientific inquiry, a way of learning and knowing things about us (De Vos, Strydom, Fouche & Delpont 2002:77).

4.3.1 Methods

Methods refer to the research technique and the procedures for carrying out the research (Van Manen 1990:28). The aim of a research design is to plan and structure a given project in such a manner that the eventual validity of the research findings is maximised. Accordingly, the researcher planned and executed the study in order to obtain answers to

the question of the lived experiences of an SCI. The planning included access, population and sample, data gathering and analysis, including the observation of ethical principles throughout the project.

4.3.2 Gaining entry and access

Wilson (1989:422) refers to getting into the selected setting so that the researcher can observe and ask questions as “clearing the hurdle”. The researcher approached the authorities for permission to conduct the study, explaining the nature, purpose and significance of the study. The researcher also provided an abridged research proposal, including information to be given to participants in order to secure their consent and how ethical principles were to be observed.

Entrée is a continuous process of establishing and developing relationships not only with a chief host but also with a variety of on-site-persons (Wilson 1989:429). When visiting the rural areas the researcher had the company of a village health worker under the jurisdiction of the local health centre.

The researcher identified the “hurdles” to deal with before entering the site, and those who could facilitate finding prospective participants for the study. The gatekeepers identified were:

- The Provincial Department of Health: Research Coordinating Committee/Ethics Research Committee in the Eastern Cape.
- The medical superintendents of the hospitals, to locate discharged patients and to access records for medical information of those who would participate in the study.
- The community-based (clinic) nurses.

The identified gatekeepers were approached in writing and telephonically.

4.3.3 Population and sample

The population refers to the total subjects or aggregates that conform to a set of specifications. According to Polit and Hungler (1999:37), 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 living with an SCI, within the boundaries of the OR Tambo district municipality of the Eastern Cape. The target population is a subset of the population, namely all SCI persons in the area who met the inclusion criteria. The target population, once defined, becomes the population of interest from whom the data can be collected (Parahoo 1997:219). The choice of participants included inclusion and exclusion criteria. To be included, the participants had to meet the following criteria: had sustained a traumatic SCI; lived in the community following discharge from hospital; were 21 years of age and above at the time of the interview; used a wheelchair; resided within the OR Tambo district municipality; able to communicate in Xhosa or English, and were mentally sound. Those with a history of mental health problems, with known communication problems, and experiencing bereavement were excluded. Having identified the target population, the sample was selected.

4.3.4 Sampling technique

Sampling is a procedure to select a small portion of the target sample. A sample is a subset of the target population. The research question should guide the choice of sample and sampling (Parahoo 1997:240). In qualitative studies the researcher is interested in the range of their experiences in order to obtain as complete an understanding of the phenomenon as possible (Parahoo 1997:241). Phenomenology uses non-probability sampling procedures where participants are included because they have certain knowledge of the phenomena; therefore the term “purposive sampling” is used (Carpenter & Streubert 1995:22; Holloway & Wheeler 1996:76; Burns & Grove 1997:306). Coyne (1997:624) refers to Paton’s (1990:169) assertion that the “logic and power” of purposeful sampling lies in selecting information-rich cases for study in depth. Information-rich cases are those from which one can learn a great deal about issues of central importance to the purpose of the research. In keeping with the aim of illuminating the richness of individual

experience, the sample size is deliberately kept small (Holloway & Wheeler 1996:104). Purposive sampling of people living with an SCI would ensure that only those who met the criteria were included. In this study, the researcher used selective sampling, which refers to the calculated decision to sample a specific locale, and other set dimensions such as time, space and identity (Coyne 1997:624). This distinction is meant to distinguish the difference between selective and theoretical sampling where researchers cannot know in advance precisely what to sample for and where it will lead them (Coyne 1997:624).

Purposive sampling was chosen as this permitted only those who met the criteria to participate. The initial access to a network of potential participants was gained through a local health centre and a rehabilitation institution. The researcher contacted some participants through a village health worker, after obtaining a list of discharged SCI persons from a nearby spinal unit, and others through referral by other people living with SCI in the community, a process referred to as “snowball sampling” (De Vos et al 2002:208).

Locating participants proved to be time consuming and difficult, as some of the people sought were not at their homes, as they were readmitted and others had died from SCI-related complications. Readmission after initial discharge mirrors one’s inability to manage him/herself at home and this includes the family not being able to cope. De Vivo et al (1991:605) acknowledge that about a third of persons with SCI are readmitted during the first year post-discharge, and this however gradually declines over the years, such that by the twelfth post-injury year only 25% are readmitted. Oliver et al (1988:26) found that medical problems or complications, which necessitate readmission, may rise for those discharged to their homes, as was the case in this study.

4.3.4.1 Sample size

Researchers using phenomenological methods generally study small samples, and even two to five subjects can evoke data saturation, which is an acceptable indicator of an adequate sample size (Morgan 1994:795; Parse et al 1985). Sandelowski (1995:179) states that adequacy of sample size in qualitative research is relative. Six to eight data sources will often suffice for a homogenous sample (Kelly 2002:381). According to Sandelowski (1995), a sample of ten may be judged adequate for certain kinds of

homogeneous or critical case sampling, or too small to achieve maximum variation or to develop a theory. According to Kelly (2002:381), shorter interviews require a larger sample of ten to twenty, while about the same number are needed when looking for disconfirming evidence although there are no hard and fast rules, since there may be deadlines and budgetary constraints facing the researcher. The researcher chose a sample of ten (10) because the study aimed to discover meaning, rather than a measure of the distribution of attributes within a given population (Field & Morse 1985). Saturation was reached by the sixth interview when it became evident that no new information was forthcoming. The researcher nevertheless continued with all the interviews.

4.3.5 Data-collection method

The researcher was the primary data-collection instrument, which is a characteristic of a hermeneutic approach; also, the philosophical underpinnings of qualitative research paradigm obligate the researcher to accept the self as part of the research (Streubert & Carpenter (1995:5). Lincoln and Guba (1985:192-194) discuss the following characteristics unique to human beings to qualify them as human instruments, which are advantages:

- *Responsiveness.* The human being can sense and respond to all personal and environmental cues that may exist.
- *Adaptability.* The human being is capable of collecting information about multiple factors happening at the same time.
- *Holistic emphasis.* The human instrument is capable of grasping the phenomenon and its context, all in one piece.
- *Processual immediacy.* Only the human instrument has the ability to process data as soon as they become available.
- *Opportunities for clarification and summarisation.* Data can be summarised on the spot and clarification sought from the participants.
- *Opportunity to explore atypical or idiosyncratic responses.* Such responses can be explored to test their validity and to reach understanding.

Lincoln and Guba (1985:195) maintain that human beings have the ability to learn and profit from experience, and that with an experienced mentor, remarkable improvements in performance as human instruments can be achieved, but are also concerned about trustworthiness of the human instrument. Cormack (2000:53) refers to the “personal integrity” of the researcher, thereby emphasizing intellectual honesty and integrity. Parahoo (1997:62) 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. Cobb and Hagemaster (1987:140), however, state that much of data gathering depends upon skilful observation, listening, and communication abilities for which nursing perhaps more than any other discipline is prepared.

4.3.5.1 Choice of interview as method

In phenomenological research the interview is the primary data-collection method even though participants may exclude painful experiences.

Heideggerian phenomenology attempts to understand the semantic and textual meanings of everyday life and recognises that the ready-to-hand mode of engagement with the world is the starting point for hermeneutic inquiry (Walters 1995). The choice of interviewing as a method of information gathering is based on the premise that an interview provides insights about the present-at-hand mode of engagement with the world because it encourages the participants to adopt a detached and objective perspective (Walters 1995:797).

Walters (1995:791) stresses that phenomenology is not a homogeneous philosophical school that lends itself to the development of a nursing research method. Hermeneutic phenomenology is a combined method that describes the phenomenon while also allowing for interpretation, enabling the researcher to uncover the lived experiences from text (Nelson 1996:60). However, there is no “hermeneutic” interview, and moreover no a priori reason to prefer one interview approach (i.e., open-ended, semi-structured, or structured) to another (Allen 1995:179). The interview process must nevertheless be justified on the basis of the theory and questions being addressed. According to Terre Blanche and Kelly (2002:128), if researchers want people to talk about their feelings or experiences, they should plan for unstructured interviews. Kvigne et al (2002:65) add that an advantage of

using an interview is that it provides access to articulate and body language, both of which express meaning in an inter-subjective world. The body language may both reinforce and weaken what is said or even communicate a message at odds with what is expressed verbally. Hence the researcher preferred the phenomenological interview to ascertain the participants' own perspectives on the meaning of living with an SCI in a rural community. None of those approached declined, although two were excluded because their condition was congenital, therefore they had used walking aids all their lives. The researcher then planned for in-depth unstructured individual phenomenological interviews.

4.3.5.2 *Phenomenological interviews*

“There is uniqueness in being human ... simply asking research participants to describe the fullness of their experiences, and then rigorously analysing this data, is at the heart of phenomenological method of inquiry” (Valle & King 1998:X).

Hermeneutic phenomenology is concerned with interpreting concealed meanings of phenomena. The purpose of the phenomenological interview is not to explain, predict, or generate theory, but to understand shared meanings by drawing from the respondent a vivid picture of the lived experience, complete with the richness of detail and context that shape the experience (Sorrell & Redmond 1995:1120). Sorrell and Redmond (1995) emphasise that the interviewer attempts to gain insight into an “inside-out” experience of the respondent through an engaged, profound approach to listening, the narrative or story being an important source of data. Heidegger maintained that people dwell in the narrative as self-interpreting beings; living a life is listening to each other's stories (Sorrell & Redmond 1995:1120). Moreover, in a phenomenological interview, the interviewer shapes the interview but is also shaped by the process. Thus phenomenological interviews are not “conducted” but rather “participated in” by both interviewer and respondent.

From a phenomenological perspective, the interview is “a specific type of in-depth interviewing grounded in the theoretical tradition of phenomenology” and the acknowledgement of the relationship between the philosophical tradition and method distinguishes this interview from other forms (Wimpenny & Gass 2000:1485; Marshall & Rossman 1995:82). This distinction is clearly seen between the researcher and the

participant where this moves from observational in quantitative research to dialogical in qualitative research and then to reflective in phenomenological research (Munhall & Boyd 1993:12). Such reflexivity appears to acknowledge that the researcher is an important component in the research process. The interview is the main method of data collection in phenomenological research as it provides a situation where the participants' descriptions can be explored, illuminated and gently probed (Wimpenny & Gass 2000:1487).

Sorrell and Redmond (1995:1120) hold that unstructured conversations encourage participants to share their stories so as to uncover common meanings in their experiences. For both parties, the interview situation may be characterised by positive feelings, or be anxiety provoking and evoke defence mechanisms in them.

Clarke (1991:248) identifies the following factors that may affect the interview situation:

- the interviewer's values and biases may affect the truthfulness of the respondent's accounts
- the interviewer's personal characteristics, such as age, race, 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 this 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.

Interviews should be seen as a form of discourse, constructed jointly by the interviewers and respondents and with the meaning of questions and answers contextually grounded. Furthermore, in line with the philosophical assumptions underpinning this study, interviewing, as a data-collection method, provides insights about present-at-hand mode of engagement with the world, because it encourages the participants to adopt a detached and objective perspective (Walters 1995:797).

The study sought to understand the situated meanings of living with an SCI in the rural communities of the Eastern Cape Province. From the hermeneutic perspective, practical activity and its context are inseparable (Walters 1995:798). With this as a starting point the participants were invited to talk openly about their experiences with living with an SCI. In conducting the interviews with the participants, the researcher accepted what the key assumption of phenomenological interviewing that “no one story exists, but rather there are multiple stories that are shaped by the particular clearing created by the interview situation” (Benner 1994:111). This assumption acknowledges the uniqueness of individuals and their relation to the world and to others and highlights that the meaning of the experience can only be understood by reflecting on the context of the experience (Bergum 1991). In order to fully comprehend each story, the researcher must listen actively so as to be attuned to cues, nuances and particulars.

4.3.5.3 The interview process

In preparation for data collection, the researcher pre-tested the interview technique in order to practise using the tape recorder, and test the audibility of her voice in order to control the tone, by conducting a “mock” interview with a colleague.

4.3.5.4 Pilot study

The researcher conducted a pilot study with two individuals in order to assess the effectiveness of the interview situation. After establishing rapport, the researcher encouraged the participants to describe their unique experience of living with an SCI.

One of the participants briefly described his physical recovery in an institution and how he carried on with physiotherapy hoping to walk again. The researcher did not change the question, but accepted their reality, realizing that being a person living with an SCI starts at the time of injury. This was encountered in most of the interviews, because the participants were beings in time, and nothing can be encountered independently of people’s background (Leonard 1994:51). The life-world is constituted by means of bodily experiences in interaction with other people and things (Kvigne et al 2002:62). According to

Carpenter (1994:615), what is important is the experience, as it is presented, not what anyone thinks about it.

From the first interview the researcher learned that she was afraid of silence, so quickly asked a question. As the interviews progressed her nervousness that something might go wrong gradually subsided and she was more relaxed.

4.3.5.5 *The main study*

Individual interviews were arranged through the village health worker for those who were interviewed at home. The researcher visited the four participants who were in an institution, and arranged a convenient interview time with them together with the person in-charge of the unit. On the day of the interview, after obtaining informed consent from each participant (see appendices 4a, 4b), biographical data was sought which was entered by hand. The participants were reminded that the interviews would be recorded to assist with the analysis of data, and that they could withdraw from the process at any time. All the participants spoke a local language. The researcher conducted all the interviews. Prior to conducting each interview, I explained the nature and purpose of the study and questions were invited. Informed consent was given in writing or verbally and tape-recorded. The interviews were tape-recorded with the participants' consent, and lasted 20 to 45 minutes, in a secluded room at the rehabilitation centre or in the participants' homes.

The researcher asked an open-ended question, designed to encourage the participants to express the lived experiences in their own words: "What is it like to be a person living with a spinal cord injury? Could you please tell me about your experience." The goal of the interview was to obtain the participants' the meaning of the experiences. The probes used were determined by the course of the conversation.

The researcher established rapport with participants in an observer participant role, where the researcher's time is spent observing and interviewing and less in the participatory role (Burns & Grove 1997:530). Neuten and Rubinson (1996:153) state that one should be unobtrusive in behaviour and attire, play down one's expertise, and a reflexive listener. The researcher made no mention of her status in some tertiary institution, but was just a health

worker who was interested in them as human beings. The use of clan names (the researcher's and participants') bridged the social gap.

Most of the participants were most willing to tell their stories. The researcher was vigilant of the participants' emotional cues, and adopted silent probing, when necessary (Sorrell & Redmond 1995:1121). 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 2001:168).

Price (2002:275) points out that qualitative researchers face the problem of probing in an ethical manner. Consequently, the researcher frequently used the "Uh-huh probe" (Price 2002:276). Furthermore, in spite of the participants' willingness in the case of the tetraplegic respondents, the researcher had in some instances to sustain the interview, when they answered for a limited time.

The researcher kept a journal for each interview as a supplementary source of data and documented the setting, the questions and experiences. Morgan (1994:795) 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. Furthermore, Koch (1996:179) states that to enter into a hermeneutic circle, the researcher should maintain a reflexive journal. Ten interviews were conducted over a period of eight months. In phenomenological terms, it was not considered necessary to interview the participants again. The notion is that the "openness" remains irrespective of how many interviews take place because the emphasis is purely on experience (Wimpenny & Gass 2000:1487).

4.3.5.6 Field notes

In order to enrich the tape-recorded interviews, the researcher made use of field notes. According to Eisenhardt (2002:15), field notes are a running commentary to oneself, an important means of accomplishing an overlap of data analysis with data collection. Henning (2004:90) describes field notes as a chronological description of what happens, and should be a thick description, filled with discussion analysis and rich in explanation and

arguments. Field notes include observational, personal (contain the researcher's reactions, reflections, and experiences) and theoretical notes (derive meaning from the observational notes) (Mavundla 2000:1572).

- *Observational notes* are objective descriptions of events, behaviours and conversations that took place; including time and place, and also any external distractions that may have occurred. The researcher also noted the respondents' behaviour whilst being interviewed. This included body language and other non-verbal behaviours. Kvigne et al (2002:65) view observational notes as intuitive experiences of being with informants that give meaning because the researcher is part of the inter-subjective world, and may therefore understand possible meanings that body language expresses.
- *Personal notes* describe the researcher's reactions, reflections and experiences during the interview.
- *Theoretical notes* are interpretive attempts to attach meaning to observations.

The researcher integrated the field notes during analysis and discussions.

4.4 RESEARCHER'S EXPERIENCE OF FIELDWORK

The researcher encountered an unanticipated major delay in gaining access to the research site. Due to the resignation of key persons, it took ten months to be given ethical clearance by the Provincial Ethical Committee. After this hurdle was cleared, there were no more problems.

The researcher experienced no insider/outsider dilemma (Kauffman 1994:179). The researcher was received enthusiastically, because she came from the region and shared the same background as the participants, in terms of language and ethnicity. Furthermore, the researcher addressed the participants by their clan name, which in their culture is regarded as warmth and respect towards one another. That approach also bridged the

social class gap. Listening to their stories, the researcher experienced a range of emotions including sadness, anger, and feelings of helplessness.

From the interviews it was clear that they did not see themselves as subhuman. The feeling that they would rather be dead did not last long. They wanted to be given a chance. They have an “indomitable human spirit” (Oliver et al 1988:12). Although some lived in poorly constructed temporary structures, they hoped for better accommodation someday.

One tetraplegic participant, with no family, no compensation as he was injured in a road accident five years ago, profoundly affected 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 poverty was palpable. People in this area depend on subsistence farming, and with the prevailing drought, the only source of income for families is the government welfare services, namely old age pensions and disability grants. Koch (1996:178) maintains that credibility is enhanced when researchers describe and interpret their experience as researchers.

4.5 PARTICIPANTS' CHARACTERISTICS

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

- **Age**

The respondents' ages ranged from 25 to 63 and their age at injury from 20 to 43, with a median age of 27 years. Yarkony et al (1997:S48) found that SCI is a male-dominated injury, and most victims are single, older adolescents and young adults, with a median age of 26 years. Of the participants, 80% were injured at 30 years or less, at a time when, according to Schultz and Decker (1985:1164), these young people were about to embark upon the potentially most productive period of their lives. The injuries at the time of interviewing were from 2 to 33 years old.

- ***Causes***

Six (60%) of the injuries were related to road accidents (MVA), of whom one was a pedestrian, one was a driver, and the other four participants were passengers in the vehicles. The remaining participants (40%) sustained their injuries from a gunshot wound, stabbing, mining industry accident, and a fall from horseback.

- ***Marital status***

Of persons living with SCI who were interviewed six (60%) were single at the time of injury, and still so at time of interview, a fact that is not surprising given the young age at which the injuries occurred. Four persons (40%) were married at the time of injury, two of the marriages subsequently failed, although one managed to find a new companion, just two months before the interview. He was very grateful to have achieved this: "It is not easy when you are like this to find someone..."

- ***Educational level and employment***

Only one participant (10%) has a tertiary qualification, and one reached high school (10%) the rest (80%) ranged from three to nine years of schooling. This sample mirrors the low literacy level of this province. It is not surprising therefore that employment opportunities for the sample were in low paying jobs, and more physical (labourer), before the injury and chances for re-employment after the injury very slim. One is assists in the occupational section at a rehabilitation centre, otherwise the rest of the participants remained unemployed at the time of interviewing.

Table 4.1 Respondents' characteristics (N=10)

Code	Cause	Level of injury	Type and extent	Age at injury	Marital status	Education	Occupation At time of injury
A1	MVA	T-8	Paraplegia <i>incomplete</i>	23	Divorced/ remarried	8 years	Messenger
A2	Stab wound	T-10	Paraplegia <i>Complete</i>	23	Single	9 years	Taxi industry
A3	MVA	C 4-5	Tetraplegia <i>complete</i>	29	Single	15 years	Electrician
A4	MVA	C 4-5	Tetraplegia <i>complete</i>	43	Single	3 years	Labourer
A5	MVA	T-10	Paraplegia <i>complete</i>	30	Married	8 years	Driver
A6	Fall-horse Back	C4-5	Tetraplegia <i>incomplete</i>	29	Single	3 years	Labourer
A7	Gun shot	C-5-6	Tetraplegia <i>incomplete</i>	33	Married	8 years	Driver
A8	Mine accident	L-1	Paraplegia <i>Not determined</i>	20	Divorced	7 years	Mineworker
A9	Mine accident	T-1	Paraplegia <i>Not determined</i>	26	Married	5 years	Mineworker
A10	MVA	T-3	Paraplegia <i>complete</i>	20	Single	11 years	Learner

4.6 DATA MANAGEMENT

Soon after the interview each tape was marked with date, time and code for the participants. Each tape was transcribed verbatim soon after recording Interviews were in the participants' home language, same as the interviewer. The interviews in Xhosa were translated into English by the researcher, taking two to another bilingual translator for back translation from English to Xhosa to increase the equivalence of meaning (Porter & Villarruel 1993:60). The meaning was retained. Pauses were denoted on the transcript with dashes while a series of dots denotes gaps or long pauses. The researcher made notes on the interview style, content, changes in vocal tone, inflections, and emphasis which might indicate that the topic was highly important or emotionally charged (Hardiman 1993:1026). 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 (Mackey 2005:183).

4.7 DATA ANALYSIS

Polit and Beck (2004:570) regard qualitative data analysis as particularly challenging for the following reasons:

- There are no universal rules for analysing and presenting qualitative data. Because of this, qualitative researchers are expected to specify what Creswell (1994:144) refers to as ‘verification steps’, so that the validity of the findings is apparent.
- An enormous amount of work is required. The analyst must organize and make sense of pages and pages of narrative materials.
- Reducing data for reporting purposes.

Morse (1994:25) advances four cognitive processes integral to all qualitative research methods, namely comprehending, synthesizing, theorizing and recontextualizing. Morse also points out that the research method for a particular study provides the “lens” by dictating how the four processes are weighted, targeted, and sequenced. The method also restricts the intensity to which they are used and the level of abstraction attained and ultimately dictates how the findings are presented. The four cognitive processes occur more or less sequentially, because the researcher must reach a reasonable level of comprehension before being able to synthesize i.e making generalized statements about participants. Theorising is dependent on ability to synthesize, and recontextualising cannot occur until the concepts or models are fully developed (Morse 1994: 26).

Comprehension is reached when the researcher has enough data enough data to write a complete, detailed coherent and rich description. Synthesizing is the ability of the researcher to merge several stories or cases to describe the typical, patterns or behaviour or response of the group. Theorizing may be considered as the sorting phase of the analysis. A process of constructing alternatives explanations and holding these against the data until a best fit that explains the data better is obtained. Whilst, recontextualization is the development of the emerging theory. The established theory provides a mechanism with which to demonstrate the usefulness and implications of the findings (Morse 1994:26-34).

4.7.1 Application of the cognitive processes in phenomenological analysis

In phenomenology, comprehending (i.e., having in-depth knowledge of a phenomenon or setting) is attained by first reflecting on one’s own experiences; these experience are the

first source of “data” in a phenomenological study. Next researchers may dialogue on the topic with others to obtain experiential descriptions and may tape-record these dialogues (Morse 1994:36). The researcher then examines the transcript and inspects the dialogue, highlighting descriptive words and searching for idiomatic phrases to add to the understanding of the experience (Morse 1994:36) referring to van Manen (1990). Data from literature complement the participants’ experiences and provide the researcher with understanding, insight and comprehension of the meaning of the experience (Morse 1994:36).

The intuiting strategy was applied. Intuiting is defined as “a process of thinking through the data so that true comprehension or accurate interpretation of what is meant in a particular description is achieved”, or ‘the process of being totally absorbed with the phenomenon under investigation’ (Streubert & Carpenter 1995:316; Oiler 1982:179). Through this process the researcher began to understand what living with an SCI meant to the participants.

Synthesizing or merging data is the process of conducting thematic analyses. These analyses are conducted primarily by identifying common structures of the particular experience, and these provide the researcher with “our understanding of the world” (Van Manen 1990:79).

In phenomenology linkages from data to theoretical knowledge are achieved through reflection, by using phenomenological literature, through writing and rewriting, thus increasing the level of abstraction. Phenomenological reflection is the process that develops the experiential themes, moving the phenomenology away from a lived body, lived time, and lived space and recontextualizes the lived experience to one that people can identify (Morse 1994:36).

Hermeneutic phenomenology has both descriptive and interpretive elements (Whitehead 2002:409). Colaizzi (1978); Giorgi (1985); Van Kaan (1959) and Dieckelman, Allen and Tanner (1989) advocate a step-by-step set of procedures to aid in the interpretation of phenomenological data. However Van Manen (1990) maintains that interpretation occurs through the deliberate act of describing aspects of experience in textual form. He maintains

that making something of a text or a lived experience by interpreting its meaning is more accurately a process of insightful invention, and that discovery or grasping and formulating a thematic understanding is not a rule-bound process but a free act of “seeing” meaning (Van Manen 1990:79).

Baker, Norton, Young and Ward (1998:549) explain that the Heideggerian hermeneutic approach to inquiry provides interpretations of everyday human lived experiences in order to fully understand their complexity. They further state that, this tradition involves the researcher in continuous dialogical engagement with participants narratives (text). The text are analysed for recurring experiences, themes, and patterns during multiple stages of interpretation. Conducting multiple stages of interpretation helps the researcher to stay in the interpretation and includes reading a single text in depth, reading across all texts in a study, and continually reviewing pertinent nursing and philosophy literature (Baker et al 1998:549). Baker et al (1998:549) state that engaging with the literature continually calls the researcher to re-think and challenge the interpretation and to extend understanding of the meanings participants create.

According to Kelly (2002:406), the idea of a hermeneutic circle prescribes that, in the interpretation of a text, the meaning of the parts should be considered in relation to the meaning of the whole. Hermeneutic reflection is a dialectic that occurs between the various forms of data. It is a dynamic process that involves reflecting on particular aspects of the experience and then seeing it in relation to the whole experience (Van Manen 1990; Ray 1990).

To achieve a hermeneutic circle of understanding in this study, the hermeneutic process entailed reading the whole text (transcription) several times so as to ‘apprehend its essential features’, ‘dialoguing’ with the data in order to capture the fundamental meaning or the main significance of the text as a whole (Sandelowski 1995:375; Van Manen 1990:93). Each transcript was reflected upon and the notations taken at the time of the interview, as a whole as well as part of the person’s entire experience (Thibodeau & McRae 1997:69).

- *Thematic analysis*

“Thematic analysis involves the search for and identification of common threads that extend throughout an entire interview or set of interviews” (Morse & Field 1995:139). Thematic analysis in this study refers to the process of an insightful discovery of the underlying meanings of the experience. As the researcher transcribed each interview, she had the opportunity to listen and re-listen to each conversation enabling her to gain a better appreciation of the lived experience.

Transcripts were read several times and each reading yielding salient statements or phrases that were gradually labelled and coded into themes or categories. Whole case (individual interviews) were compared to other cases (other interviews), to identify themes that cut across other interviews. Recurring themes were identified, with supporting excerpts from each interview.

The researcher needed to identify the underlying ontological characteristics that embody being in the world as an SCI person in a rural community. The researcher used colour coding as same feelings were often expressed at different times during the interview, and across interviews. The needs and feelings were identified and also how they manage things themselves. Statements indicating a particular feeling were grouped and given a label. This information formed the foundation for the development of themes. The literature review supported the interpretation of the themes.

The shifting back and forth between cases help in revealing new themes, patterns and a global picture of what it means to live with a spinal cord injury in the rural communities. Themes describe an aspect of the structure of the lived experience that is common to all participants but not necessarily experienced by all in the same way or to the same extent. Themes are hermeneutic constructs rather than statements of content, and so the themes had to be worded in a way that allowed for the demonstration and exploration of varied experiences. A theme, according to DeSantis and Ugarriza (2000:362), can be seen as an expression of the latent content of a text, as themes are not the exact words, but exact meanings implied and inferred from the words, behaviours and events. In a phenomenological study, Kearney (2001:148) explains that, themes are experiential

components integrated into a narrative depiction of a multifaceted phenomenon. Choosing thematic formulations that both animated the phenomenology and gave it direction and structure was one of the most difficult aspects of the analysis. As the text was worked on, by moving from text to the data, reflecting and writing, re-writing and reflecting in a painstaking effort to try to understand and interpret the meanings of the experiences. In the process the contents of the chapter in which the findings are presented and discussed were reordered several times as links and relationships between themes were explored and different thematic description tried. The thesis, as a result combines the themes from the analysis together with the existential themes from the life-world.

4.7.2 Review and confirmation of analysis

Two unmarked interview transcripts were submitted to two qualitative nurse researchers, with the purpose and objectives of the study. Emerging themes were identified and these were compared with those the researcher had already identified. Consensus was reached regarding the overall experience of living with an SCI. This was early in data analysis, to give the researcher a sense of reassurance. In Heideggerian phenomenology, research relates to understanding human experience and the final interpretation is tentative rather than absolute or true.

4.8 VALIDITY AND RELIABILITY IN QUALITATIVE RESEARCH METHODS

Validity in research is concerned with the accuracy and truthfulness of scientific findings. There is a general contention among the investigators that the findings from qualitative research are not objective fact, but rather subjective interactive constructions which need no verification quantitatively (Bailey 1997:19). In addition, qualitative constructionist theory suggests that reality is not only subjective in nature but essentially the construction of participants as they react with the environment, and interpretation of this reality by qualitative researchers, yet another construction (Bailey 1997:19). Brink (1993:35) affirms that validity and reliability are key aspects of all research. Meticulous attention to these two can make a difference between good and poor research and help assure the findings are accepted as credible and trustworthy by fellow scientists.

Morse and Singleton (2001:844) state that external validity in qualitative studies is demonstrated by assessing “pragmatic fit”, when the results of one qualitative study are applied to another setting or context. Thus pragmatic fit is the basis for generalisation and utilisation of qualitative studies. Whittemore et al (2001:522) contend that validity standards in qualitative research are challenging because of the necessity to incorporate rigor and subjectivity, as well as creativity into the scientific process. In addition, different qualitative methods use different evaluation criteria. Another issue is the blurring of terminology, because qualitative researchers use the language of the qualitative paradigm inconsistently (Bailey 1997:19).

Ashworth (1999:221) argues that external validity is irrelevant, the researcher is “debarred” from querying the validity of the life world. The researcher must adopt no position on the correctness or falsity of the claims, which are implicitly made by the research participants, in the views and judgements pertaining to their life-worlds. The validation process can be done by the process of analysis open to scrutiny, and receive some form of consensual validation, by possibly involving participants after formulating the themes.

Qualitative researchers concede that the very nature of qualitative research methods does not lend to statistical or empirical calculations of validity. However, the qualitative researcher seeks basically the same ends through different methods, which are better suited to a human subject matter (Brink 1993:35). Whittemore et al (2001:523) in their discussion of the tension between qualitative and quantitative research, specifically validity, refer to Lincoln and Guba’s (1985) attempt to convince the scientific community of the merits of qualitative research.

According to Whittemore et al (2001:523), translated standards of validity are useful criteria for demonstrating rigor and legitimacy of qualitative research. In qualitative research language the term “validity” is avoided and “trustworthiness” used instead. Tobin and Begley (2004:392) cite Sparks (2001); Smith (1993); Gallagher (1995) and others who challenge the concept of trustworthiness and highlight the inconsistency of developing criteria that are parallel to positivist paradigm.

Furthermore, the concept of “checking” is antithetical to the epistemology of qualitative inquiry, and reveals philosophical inconsistencies (Tobin & Begley 2004:392). Guba and Lincoln (1994) (cited in Tobin & Begley 2004:392), introduced *authenticity* as a fifth criterion. Authenticity involves the portrayal of research that reflects the meanings and experiences that are lived and perceived by the participants (Whittemore et al 2001:530).

Rigour demonstrates integrity and competence. *Goodness* is one application of rigour (Smith 1993; Denzin & Lincoln 2000a; Armino & Hultgren 2002; Tobin & Begley 2004: 391). The concept of goodness is an integral and embedded component of the research process. Six elements demonstrate goodness in an interpretive study (Tobin & Begley 2004:391):

- Approach (methodology) – specific grounding of the study’s logic and criteria
- Collection of data (method) – explicitness about data collection and management.
- Representation of voice (researcher and participant as multicultural subjects) – researchers reflect on their relationship with participants and the phenomena under exploration.
- The art of meaning making (interpretation and presentation) – the process of presenting new insights through the data collected and chosen methodology.
- Implications for professional practice (recommendations).

4.9 MEASURES TO ENSURE TRUSTWORTHINESS IN THIS STUDY

While there is a lack of consensus regarding the idea of rigour, legitimacy of knowledge claims says (Koch 1996:178) are dependent upon demonstrating that the research study is trustworthy and believable. Koch (1996) further advises the researchers to engage in the literature and thus be able to select or develop the most appropriate criteria for their particular study, and it rests on the researcher’s shoulders to decide on the appropriateness of criteria (Koch 1996:178).

When applying rigour to their research studies qualitative researchers have traditionally used terms such as establishing ‘truth value’, ‘applicability’, ‘consistency’ and neutrality

(Appleton 1995:995; Guba and Lincoln 1985; Sandelowski 1986; Marshall & Rossman 1989). De Witt and Ploeg (2006:217) point out that the methodology and method of interpretive phenomenology “amplifies” the risk of inconsistencies with philosophies that inform other qualitative methodologies or the very criteria used to evaluate rigour.

Credibility refers to confidence in the truth of the data (Polit & Hungler 1999:427). For Lincoln and Guba (1985:298), credibility can be enhanced by prolonged engagement, persistent observation, triangulation, peer debriefing, negative case analysis, referential adequacy. Graneheim and Lundman (2004:109-110) describe credibility as an element dealing with the focus of the research, and referring to confidence in how well data and processes of analysis address the intended focus. Graneheim and Lundman (2004) state that the first question about credibility arises when making a decision about the focus of the study, selection of context, participants and approach to data gathering, and another critical issue is to select the most suitable meaning unit, and also how well categories and themes cover data.

De Witt and Ploeg (2006:222) caution that the generic qualitative criterion of credibility is inadequate as an expression of rigour for interpretive phenomenology as the underlying assumption of credibility is that the goal of research is truthfulness. In contrast, the goal of interpretive phenomenology is increased understanding of multiple understandings of the human experience since there is “no one true meaning” (Annells 1996; Draucker 1999).

Interpretive phenomenologists suggest that credibility of a study can be enhanced by firstly, carrying out the investigation in such a way that the believability of the investigation is enhanced, secondly, as the investigator describes his/her relationship with the informants through her interactions, impressions or behaviours (Yamashita 1993:1520). Credibility for Yamashita occurs when the reader immediately identifies with the experiences described by another person. Benner (1994:72) states that as part of the credibility of the project, the investigator lays out preconceptions, biases, past experiences and perhaps even hypotheses that make the project significant for the investigation, and how they may affect the interpretation. In this study, the researcher outlined her own preconceptions, biases and assumptions, and reasons for conducting the study (see appendix 5).

Transferability is dependent on the degree of similarity between two contexts (Koch 1994:977). Graneheim and Lundman (2004:109) hold that the culture, context, selection and characteristics of participants, data collection, and process of analysis must be described adequately so that judgement of transferability can be made. Graneheim and Lundman demand a rich and vigorous presentation of the findings with appropriate quotations. Polit and Hungler (1999:430-31) add that in addition to a thorough description of research setting and context, that of the transactions and processes observed during the inquiry is important.

In this study, the researcher described context of the study in chapter 1 (see section 1.2.8). Furthermore, the findings are presented with appropriate excerpts and examples of living with an SCI in a rural community. Regarding transferability, Tobin and Begley (2004:392) emphasise that there is no single correct or “true” interpretation in the naturalistic paradigm.

Dependability refers to the stability of data over time and over conditions (Polit & Hungler 1999 430). This is met when decisions taken about theoretical, methodological, and analytical choices are explicit so that another researcher can follow the decision trail (Koch 1994:977; Tobin & Begley 2004:392).

Throughout the study, the researcher justified her decisions by referring to the assumptions underlying the methodology, as assumptions in qualitative research take the place of conceptual frameworks in quantitative research. The researcher opened up the study to scrutiny by, among other things, revealing that she had decided to concentrate only on experiences after discharge from hospital (De Witt & Ploeg 2006:225). When the respondents related how they reacted to the injury, however, the researcher realized that being a person with an SCI starts at the time of injury.

Confirmability. Requires researcher to show how interpretations have been arrived at. thus the findings are grounded in the data (Koch 1994:978; Lincoln & Guba 1985:323). Confirmability is concerned with establishing that data and interpretations are not figments of the inquirer’s imagination, but clearly derived from the data (Tobin & Begley 2004:392).

However, findings of interpretive phenomenological studies are not neutral and value-free. Instead the researcher's preconceptions and biases and assumptions are clarified and become an integral part of the study findings. This is "a defining characteristic of interpretive phenomenology" (De Witt & Ploeg 2006:222). Confirmability is established when credibility, transferability and dependability have been achieved. An attempt was made to meet the conditions for credibility, transferability and dependability, thus confirmability has been established.

4.10 ETHICAL CONSIDERATIONS

Given the vulnerability of people living with an SCI, it was paramount to safeguard their interests at all times; that is, their situation should not be exploited.

4.10.1 Consent

Permission to conduct the study was first obtained from the Ethics Committees of two institutions, namely the University of South Africa and the Department of Health of the Province of the Eastern Cape (see appendices, 1a, 1b and 3), and the head of the institution where some participants were to be found (see appendices 2a and 2b)

The participants' consent was sought before the commencement of interviews, which, in most instances, was in the presence of one or two family members so that there was no undue pressure. For those who could not write, a family member signed, and for others consent was verbal and thus recorded (see appendices 4a and 4b)

Ethical considerations in research are mainly to protect the informants from harm.

4.10.2 Potential for harm

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 emphasized. The ethical obligation to care was at all times seen to override the need to gain information for the purpose of the study.

The researcher was alert to non-verbal cues, and there was no undue probing. Rather than causing harm, it was envisaged that being invited to tell their story 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”.

4.10.3 Maintaining anonymity and confidentiality

Anonymity assures that the information cannot be linked to participants. The researcher promised the participants that all information provided would be treated with the strictest confidentiality and would not reveal their identity. No names were used on the transcripts and the audiotapes erased on the completion of the study. Data collected in the form of field notes and interview scripts were kept locked. Only aggregate demographic information was reported to maintain anonymity (Morse & Field 1995:176).

4.11 CONCLUSION

This chapter described the research design, setting, participants, and the methodological processes used to collect and analyse data.

Each aspect of the research was informed by and consistent with hermeneutic phenomenological inquiry. The researcher provided an audit trail by outlining the procedures, processes and ethical issues considered. The philosophical tenets underpinning this study were accounted for throughout the research process.

Chapter 5 presents the findings. The two major themes deal with how the participants dealt with the situation, and explore the relationships with other people and the environment.

Chapter 5

Research findings

5.1 INTRODUCTION

In accordance with phenomenology, this chapter removes the phenomenon of living with an SCI from the private arena of the participants into the public domain (Madjar & Walton 1999:14). To that end, the researcher transformed the participants' language into a personal understanding of the experiences (Madjar & Walton 1999:14). Edited excerpts from the interviews support the interpretation and grounding the text in the data.

The participants were allowed to start anywhere in relating their experiences. Although they tended to start with the day the accident happened and seemed to relive the events of that fateful day, their stories were not linear. That day was seemingly perceived as the defining moment of what their life was going to be. That day was regarded as a symbolic bridge between the past, present and future. Interpretive phenomenology looks below the surface for hidden meanings. Two main themes emerged from the data, namely *reconceptualising being-in-the-world as a person with an SCI* and *experiencing being-in-the-world as a world with other*. Data analysis revealed six separate sub themes related to the two main themes.

For example, three sub themes: *a search for meaning in the experience; an attempt to regain mastery over the event and one's life*, and *an effort to enhance one's self-esteem*, were linked to the first theme and identified as meaning that each participant had to regard himself as a person with a physical disability/impaired mobility, *reconceptualising being-in-the-world as a person with an SCI* (corporeality). The second major theme, i.e. *experiencing being-in-the-world as a world with other*, was formulated from experiences relating to the environment, and to relationships with other people, notably families, health professionals and the community in general (relationality). Figure 5.1 presents themes that depict the personal and embodied experience of living with SCI as derived from data collection and analysis.

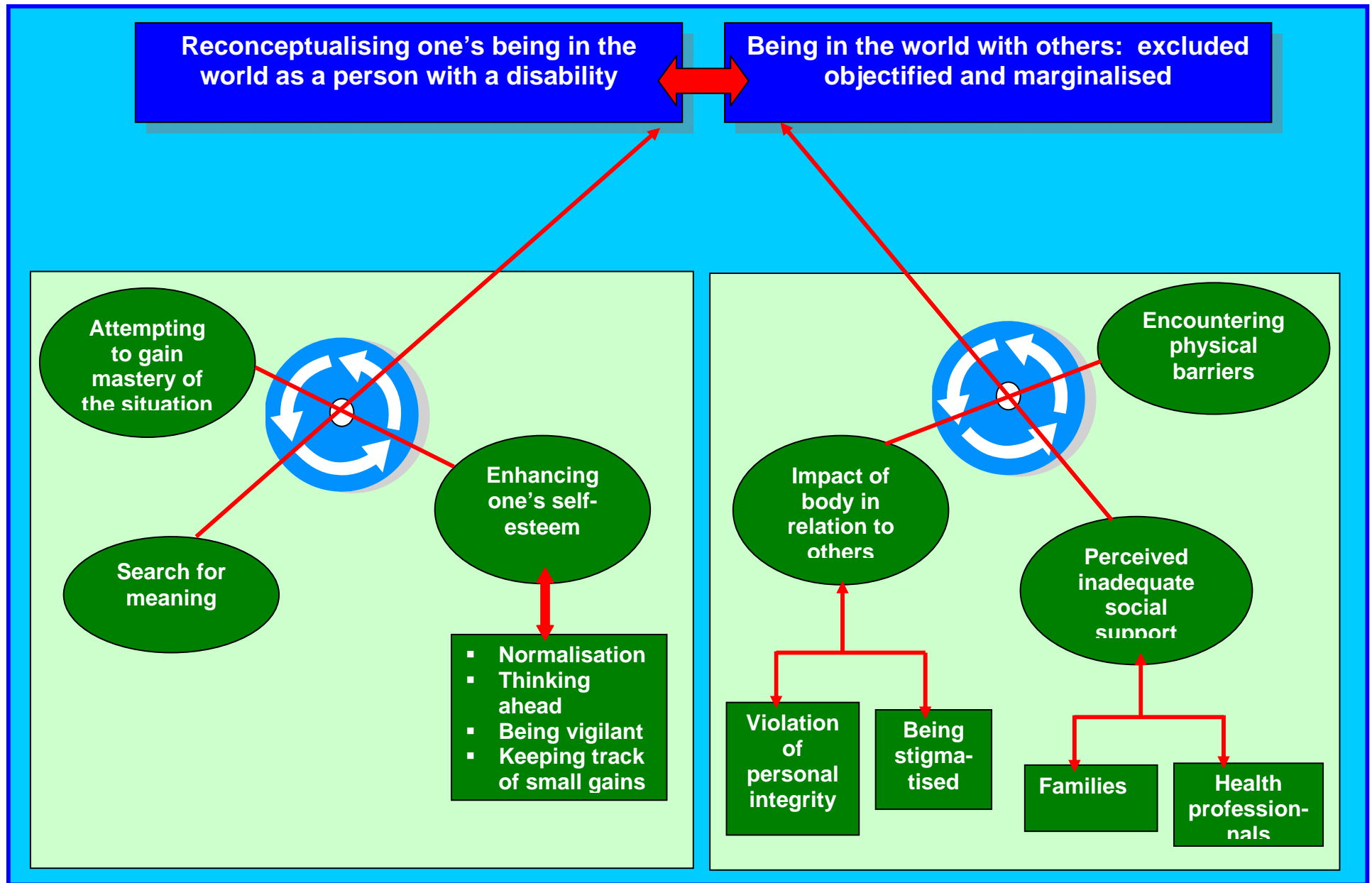


Figure 5.1
The personal and embodied experience of living with a SCI

5.2 RECONCEPTUALIZING ONE'S BEING-IN-THE-WORLD AS A PERSON WITH A DISABILITY

To reconceptualize one's being-in-the-world in this instance means incorporating into one's self-image being-in-the-world in a new way, as a person with impaired mobility. *Reconceptualizing* one's self is actually trying to establish new self-definitions or reintegration of self (Lucke 1999:251). People's sense of self is a springboard from which they relate to the world around them. That sense of self is a product of both their internal psychological and emotional make-up, and the external influences around them that colour their perceptions, the social and cultural values that define who they are (Fitzgerald 1997:407).

According to Sedler (1987:437), a person's reality is imbued with personal meanings and values, which are essential in determining how the self and the world are defined, identifying "who I am", "how the world works" and "is the world a good place to be"? A traumatic experience such as SCI leads to objectivisation and examination of assumptions about the world, that have previously been relied upon though unquestioned and unchallenged prior to the crisis situation (Janoff-Bulman 1989:116). The person's reality follows assumptions and expectations held by that person and his/her life is structured in such a way as to create meaning (Sedler 1987:437). The traumatic event may threaten the breakdown of the entire conceptual system. The individual must integrate the new information so as to make it 'fit' them to maintain old assumptions or revise them. Finding meaning is a process of changing life schemes so that feelings of order and purpose are restored (Lustig 2005:153).

Becker (1992) (cited in Cody 1999:121) describes the phenomenological position on meaning as the exchange between the person and the experience. For Heidegger, meaning lies in the individual's transaction with a situation such that the situation constitutes the individual and the individual constitutes the situation (Annells 1996:708). The loss of body function becomes a loss of sense of self, and a person's experience of an SCI begins with the exploration of the lost "integrity of the self with the body" (Hanna & Rogovsky 1991:58; Stiens et al 1997:s68). The self-image is altered after an SCI and this requires new positions, gestures and emotions. Madjar and Walton (1999:4) point out that

the body is a person's mode of being, while Leonard (1994:49) states that it is characteristic of *Dasein* that things show up as threatening or attractive or useful.

Being-in-the-world with an SCI means adjusting to the functional limitations associated with the condition, where adjustment is defined as emotional acceptance of the disability into one's self-concept. Adjustment is a continuous life transition rather than a time-limited process (Livneh & Antovak 1997:22).

The participants were, initially, not aware of the extent of their injuries. People are said to generally operate on the basis of an illusion of invulnerability (Janoff-Bulman 1989:116). As a way of preserving and enhancing the self, and restoring self-esteem, the participants engaged in what Taylor (1983:1161) calls "intrapsychic" efforts, or "cognitive strategies" used at recovery to find ways to feel good about oneself again (Janoff-Bulman 1989:116). For them to make sense of what had happened and to maintain some form of equilibrium, they made determined efforts to handle the situation by employing certain coping strategies.

5.2.1 Attempting to gain mastery of the situation: using cognitive coping strategies

Wineman, Durand and Steiner (1994:185) refer to Lazarus and Folkman's (1984) definition of coping strategies as those "constantly changing cognitive efforts used to manage specific external or internal demands that are appraised as taxing or exceeding the resources of the person".

According to Fife (1994:312), the most frequently used methods of coping focus on ways to define meaning so that individuals are able to regain a sense of control.

Seifferridge-Krenke (1995:44) refers to Lazarus and Folkman (1991) who point out that the coping process has three features: the individual's action, the specific context, and how an individual's actions change as the stressful encounter unfolds. The entire coping process may occur within a few minutes or hours or may continue for weeks or years. The reevaluation of a shifting person-environment relationship influences subsequent coping efforts. Coping efforts focus on ways to cognitively define meaning so that individuals can

ultimately be able to regain a sense of control. The illusion of control is the basis of hope and optimism and enables the person to ward off depression and despair (Fife 1994:312). The participants' initial reaction to the injury was to preserve the self and, as such, they engaged in denial and hope, denying its seriousness and hoping it would soon pass.

Janoff-Bulman (1989:123) defines *denial* as “a psychological process that facilitates the course of cognitive integration, particularly when the potential for total schema breakdown exists”. According to Power and Orto (2004:57), denial can serve as an adaptive process for it can allow the individual to maintain a sense of self-esteem, reduce stress and possibly generate encouragement and hope. Lustig (2005:153) 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.

Triechmann (1988:22) found that denial can play an important function in helping individuals to cope with a traumatic experience. Denial may include minimisation of any personal threat, loss of cognitive or physical abilities or the possibility that one will not completely recover. Thus, it reduces the threatening information to “tolerable doses” (Janoff-Bulman 1989:12). Safinasky (1980:22) cites Rosenbaum and Raz (1977) who assert that the greater people's sense of mastery, the longer the period of denial they require in order to regroup forces after a catastrophe.

Disability is a confusing experience, the subjective appraisal of what is happening and the implications of the events are likely to be distorted. The confusion that may follow a traumatic SCI is illustrated in the following incidence of denial: “It was very interesting that as soon as I had my accident, I knew I'd broken my neck. The second I hit my head on the seabed I knew ... when my mates came out to me and towed me back, I was moaning that I had broken my back and that I was going to be paralysed, yet within an hour my mind submerged all that, it was too painful to live with. For the next three months I buried it deep and then what had happened gradually started to seep through ...” (Mike Martin in Thomas 1994: 45).

In this study, all the participants were under the age of 35, when their injuries occurred. It was not unusual for them to express disbelief at the timing of the injury in relation to their age:

It can't happen to me, not at this time of my life!

Why me?

Denial and hope can be said to be two sides of the same coin, because as denial recedes, hope emerges.

Hope is a person's belief that in a situation that has more than one possible outcome, a positive outcome will result. It is derived from relationships with others, oneself and the world where a person believes that what is desirable is possible (Soeken & Carson 1987:609). The participants expressed hopes of returning to their earlier state of health and everyday life as it was before the injury. All the participants, except one, anticipated that their injury to the spinal cord would not be permanent. The one exception may have intuitively realized that the chances of recovery were small, because he remarked during the interview:

Ndaqonda nje, kwangoko ukuba kuphelile. (I knew immediately it was all over.)

Regarding hope, Farran, Herth and Popovich (1995:ix) state that "catastrophe evokes numbness; hope reconstitutes the will to struggle and survive". Farran et al (1995:5) describe hope as mysterious and elusive because it can be expressed as a way of feeling (affectively), as a way of thinking (cognitively), and as a way of behaving. As a way of feeling, it propels a person when the odds seem against them. As a way of behaving hope, expresses itself as an active process in which the individual seeks appropriate alternatives. Yet, as a way of thinking, hope is associated with a sense of fortitude, as dealing with facts beyond the visible and certainty or if dreaded possibility does occur, it functions as a creative process that seeks another way of dealing with these circumstances.

According to Bishop (1980:20), 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. The participants in the study were no different; even participants with high level injuries hoped for recovery:

Ndandicinga ukuba yinto nje. (I did not think it was serious.)

Ndandibona abanye bephuma behamba ... ndanethemba ke. (I thought I would be like those who eventually walked.)

Bendiba ndakuba sendihamba ngoku. (I thought I would be walking by now.)

They could not bring themselves to face the fact that from then on, they would never walk again; it was too devastating. Walking was a status symbol, like “walking tall”. In the beginning the participants’ emotions were unstable; denial, accompanied by the realization that this could be true and also hoping that perhaps the loss of function was only temporal, and suicidal thoughts crossed their minds. They expressed the following feelings:

At the time I thought it was the end of the world. I asked myself what is the point? If I could have laid my hands on some poison, I would have taken it. I kept praying to die.

Of what use am I now? I can’t do anything for myself, or my children.
Why did this happen to me?

People with a demanding condition or disability harbour such thoughts due to the loss of independence, loss of control over life and means of productivity. Olivier et al (1988:41) reported a spouse of an SCI person who observed:

There wasn’t a man there who did not wish he had died.

None of the participants in the present study still harboured such thoughts, but some SCI individuals do take their lives soon after discharge:

I decided I was not going to kill myself like others. I was at the hospital [long pause] the nurses told me when I visited, that so and so did that at home.

The participants demonstrated that they never gave up hope, but used it affectively or cognitively and in behaviour, when appropriate. Another attempt by the participants to restore a sense that their life was orderly and purposeful was the search for the meaning of the events.

5.2.2 Searching for meaning

Suffering triggers a search for meaning in which the individuals (victims) have a powerful need to make sense 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. Huberman and Miles (2001:261) state that a search for meaning is a search for coherence and purpose, and meaning is biographical, emotional and felt in the person's streams of experience. Following the traumatic event, the participants used cognitive strategies in order to master the situation. Bishop (1980:35) states that an acute catastrophe summons into action mechanisms that can best be described as a process of realization, of making events real inside the self, which have already occurred in reality.

Meaning in the fullest sense of the word has implications for the coping process (Thompson & Janigan 1988:262). An important aspect of the coping process is the struggle to maintain a sense of meaning that is not devastating to the self and which allows the individual to maintain a sense of wholeness and personal integrity (Fife 1995:1022). The search for meaning involves the need to understand why a crisis occurred and what it symbolizes in one's life, i.e, implicit meaning (Taylor 1983:1162;Thompson & Janigan 1988:260). Furthermore, Taylor (1983:1162) regards a search for meaning in the experience as an attempt to regain mastery over the event, and an effort to enhance one's self-esteem in order to feel good about oneself again, despite the personal setback. The attribution, control, social comparison and the just world theories have contributed to understanding how people adapt to traumatic events. The participants' attempts to make sense of the injury embraced some of these theories.

Some of the participants tried to explain the accident as having happened for a good cause to curb their waywardness and thus having come out better than what would have been. Because former friends did not make it, a lot of gratitude was shown. Life is to be

celebrated because meaning has been found. Past events and life styles were re-examined in order to find an explanation. The participants generally felt the accident was God's will and, in some instances, meant to correct their wayward ways. According to the participants,

Maybe I would be gone by now, like some of my friends. I mean, the way we were carrying on, we were partying that night and drank quite a lot. Even the attack, I do not recall how it happened ... I was tipsy, woke up in hospital.

God allowed this to happen for my sake. I see people dying, and here I am still, sitting in this thing (*mna ndisahleli ku lento*).

One of the participants could not understand why this had happened to him, as he was the breadwinner:

Uyazi, ezinye izinto zifane zenzeke nje ... nyhani. Ndinga ngosapho lwam. (You know, some things just happen ... really. I am thinking about my family.)

According to Janoff-Bulman (1989:123), victims often report benefits from their traumatic experience, a mechanism that helps them believe that the world is still a just place to be. Positive interpretations of the trauma serve to reduce the attacks on the person, and serve as a "vehicle for self-enhancement" (Taylor 1983:1161; Janoff-Bulman 1989:123). Furthermore, when positive meanings can be constructed, it produces significantly better psychological adjustment (Janoff-Bulman 1989:123).

- **Spirituality**

Spirituality played a big 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). The experience of disability shaped the development and expression of the participants' spirituality, and they generally perceived that their experience of disability resulted in a stronger sense of spirituality:

Ndakhula kwizinto zakwa Thixo ngenxa yalemeko. (I grew in God's word.)

Ndazixelela, yintando kamDali. (I just told myself, this is God's will.)

I had not accepted this ... sermons from the church ... I accepted being in a wheelchair.

Spirituality also served as a support during difficult times. One participant, who was distressed and depressed, described the difficulties of using a wheelchair as a means of mobility and stated that the only thing that kept him going was the belief that "it will not be like this in the next life".

Boswell, Knight and Hammer (2001:230) found that informants used spirituality as a "springboard" for meaning and acceptance of disability: "It is probably not a freak accident that I became a quadriplegic, there is some reason God intends to fulfil." Some expressed gains, "I am almost grateful that I had my accident...the change in me has been so positive" (Carpenter 1994:622). McCall et al (2000:561) found that SCI persons commonly believe there is a purpose in their lives "even if it was not yet apparent". By emphasizing benefits, individuals continue to believe that the world is a good place to be. Positive interpretations serve to reduce the trauma's attack on their assumptive worlds (Janoff-Bulman 1989:123).

Lustig (2005:147) refers to Davis, Nolen-Hoeseema and Larson (1998), who emphasise 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. It was evident from the interactions during data collection that the participants had not given up on life.

It should be noted that individual emotions to major losses in life, such as in disability, are not static, but developmental. The participants' stories indicated how they came to reconcile themselves with the situation in which they found themselves, and tried to embrace the impairment as part of their lives. Finding meaning is a process of changing

life's schemes so that feelings of order and purpose are restored (Richer & Ezer 2000:1108).

- **Coming to terms with the disability**

Coming to terms meant that individuals/persons had resigned themselves to the realities of what had happened and that nothing could be done to change the situation. Eventually, the person acknowledges a disrupted reality and acknowledges that the prior reality is permanently irreversibly altered. Acknowledging is admitting the truth about what happened and the prior reality must ultimately be relinquished (Seider 1987:440). Morse and O'Brien (1995:895) describe this stage as preserving self by "recognizing and confronting the ramifications of the injury, and then regrouping, choosing to move on, and learning to get back into the world". The participants found meaning by assenting to the condition, on the one hand, and reframing its meaning, on the other. As participants had felt that it has been a long time hoping for complete recovery to embrace the reality that they are more likely never to be able to walk again, despite rehabilitation interventions. The majority of the participants were remarkably philosophical in their acceptance of the permanent disability as a fact of life that could not be ignored. Being able to acknowledge irreversibility of a disrupted reality, according to Sadler (1991:449), is a major achievement, which supports engagement in life transitions.

I had attended physio --- trained, trained, and trained, but my legs remained stiff. I saw others leave in wheelchairs and told myself I would be like them. I mean, I was there [rehab unit] for more than a year.

This is my third year after the accident ... not much change.

I can't say I have accepted it. I was so devastated at first, but now, I know I am going to live with it.

Similar findings were found in a study by Bach and McDaniels (1993) on a group of persons who were living with a tetraplegic injury, who also made remarks such as "*we are*

in this situation, there isn't much we can do to change it, we just have to make the best of it' (McDaniels 1993:366). These sentiments were echoed in Manns and Chads (2001:801).

Acceptance seems to be a much longer process, and Gill (1999:1) thinks it is never achieved. Some suggest that coping with SCI was more of an adjustment to the disability as opposed to acceptance (Manns & Chad 2001:801). 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 got left" (Hanson & Ahlstrom 1999:259).

Having reconciled with their situation, that is, more or less accepted the loss intellectually, the participants devise other means of coping, normalisation, and enhancing one's self-esteem is one such strategy.

5.2.3 Enhancing self-esteem

"Our level of self-esteem affects virtually everything we think, say and do. It affects how we see the world and our place in it ..." (Sanford & Donovan 1984:3).

SCI persons have to "carve out" a new identity based on feelings of self-worth and of being valued (Dewis 1989:395). 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 human psychological well being (Hancock, Craig, Tennant & Chang 1993:455). Self-esteem is one of the dimensions of the self-concept, the later comprises attitudes about oneself, perceptions of personal abilities, body image and identity and a general sense of worth (Smelter & Barre 2000:56). People have self-concepts that might also fluctuate depending on what is happening to them, how they feel about these changes will have meaning to them in the context of their lives (Chen, Boore & Mullan 2004:257). 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 internal factors, as SCI may alter the ability to obtain external sources of self-esteem.

Work on coping with change in body image is particularly pertinent to individuals with SCI (Partridge 1994:14).

According to Lillesto (1997:289), being able to manage on our own is connected with independence and self-mastery, and contributes to the development of our identity and self-respect. 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.

- **Normalisation**

In the process of normalisation the 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. 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. They promoted their self-image by projecting self-worthiness as they contributed positively to society, including taking part in religious activities, feeling independent, helping other SCI's who were worse off, and most importantly believing that they were as efficient as anyone else. Gill (1999:5) emphasises that whatever form of involvement enhances a person's self-worth and self-esteem. Normalization helps them maintain an acceptable body image and feeling normal is vital to psychological health.

The participants minimised the limitations, if any, of SCI:

I mean, it's no big deal. I attend conventions ... and do other things, eh, yes, yes, for instance, standing over the grave and conducting a burial service.

It is just the body; mentally, I am okay. I was able to supervise people tubing a house at home sitting on this

I am just like you. I am gifted with my hands. I even repaired a wheelchair for one of us, that one is neglected by her family ... it is very sad.

The participants in the study appeared to have engaged in a cognitive effort referred to as “distancing” which means detaching oneself from the problem and minimising its significance (Hanson & Ahlstrom 1999:259).

Manns and Chad (2001:802) found that SCI people regard themselves as the same person as before the accident, “I am no different; just get around on wheels”. Lustig (2005:153) refers to Swann and Pelham’s (2002) finding that individuals with SCI may seek “self-verification, because verification bolsters perceptions that the world is coherent and predictable”.

With regard to the pressure felt by the disabled, Marks (2000:205) emphasises that people with disabilities internalise negative societal values about their disability, consequently achieving independence and normality “is a gold standard” for the disabled to obtain so as to overcome their devalued status as a disabled person, and achieve the rank of an overcomer.

Triechmann (1980:54) found that persons with spinal injuries have to “minimise the difficulties of living with a disability as a means of coping with the prejudice, and thoughtlessness of able-bodied persons, and the hard work of everyday survival”.

The participants in the present study did not see the injury as the end of the road, but were able to focus on positive things, and have plans for the future.

- **Thinking ahead: yearning for independence**

The participants were found to be positive, hopeful and future oriented. They appeared to be trying to hold on to what might have been had the injury not occurred. The participants yearned to maintain the right to choose their own life styles, run their own show within the scope of their limitations, which is “just using a wheelchair” according to them. Participants had aspirations to be independent, including owning property and being financially independent, enabling them to be like everyone else. In spite of their situation, they remained hopeful. Aspirations to own a home were expressed regardless of the level of injury and functional ability. A few lived in their own homes; some lived with their parents in

the same house, or in shacks of corrugated iron and wood in the backyard at home, or rented temporal structures set up in other people's backyards.

The participants felt strongly about their independence. For example, one of the participants was not looking forward to moving into a "quad house":

I am still hoping to get money from the accident fund ... build a house and find someone to live with ... that is all I wish for. (*Ndibe nendawo yam, qha.*)

One of the participants regarded the pending transfer (to a "quad house") as an opportunity to meet the "old hands" for guidance, as they had experience. He nevertheless had no intention of remaining there "for ever", as one day he would "build a house for his children". They could not imagine themselves spending their lives in enforced isolation and idleness, with their social contacts reduced to interacting with other disabled people only. They were still proud of who they were, and the independence yearned for extended to the financial sphere, wishing to be able to support themselves:

I want to do something, anything ... I am still hoping to go back to work.

Being able to do something that felt meaningful was important to the participants, who did not want to be a burden. The participants were unhappy that they were unable to work and left with no option other than to depend on the social grant. Through the accident, they had lost their social status because of unemployment. One of the participants, living in a rented shack, also expressed a wish for the government to provide a place, like a warehouse, to enable him to be productive and self-supporting:

I am prepared to get my friends who are sitting at home with nothing to do, then we can make a lot of things and make money. You can see for yourself, the condition of this place.

Besides the wishes expressed, there were also realities that they had to contend with as persons living with an SCI, hence the process of reconceptualising being-in-the-world.

Living with an SCI involves dealing with the possibility of the occurrence of complications. The person living with an SCI has no option but to be vigilant, in order to maintain some control over the consequences of living with a SCI.

- **Being vigilant**

Spinal cord injury as it is lived is experienced bodily. Living with an SCI is characterized by the presence of or being at risk of medical complications. Alterations to embodiment are experienced when one has to deal with potential and actual complications. The participants had to cope with ongoing physical symptoms, such as spasms and pain and the major threat of pressure sores and contractures. Consequently they have to be vigilant and engage in activities to maintain health and well-being. The participants had developed ingenious ways of dealing with the physical symptoms:

I know how to deal with spasms ... just hold my leg and straighten it gently.

Exercises are ignored at one's own peril, as the potential for loss of function and contractures is always present. They took this responsibility seriously, and were prepared to exert some control and not allow the "body's unreliability" to dominate their lives (Madjar & Walton 1999:52):

Ndandixelelwa e sibhedlela ukuba zakushwabana izandla xa ndingazisebenzisi ... nangoku ziva ngam. (I was warned at the hospital to use my hands lest contractures develop ... now they [hands] are under my control.)

Maintaining a healthy skin is very challenging to people living with SCI, and pressure sores account for many re-admissions, especially for high-level injuries. Many develop septicaemia and some even succumb to it. Pain is a debilitating symptom for persons living with SCI. It is a constant background discomfort, a permanent fact of paralysed life, which they have to live with:

Se ndide ndayi qhela. (I have almost gotten used to it.)

It is always there, yes ... yes.

In her poem about pain, Emily Dickinson (1994:8) conveys the completeness of the control that pain exerts over people's lives:

Pain has an element of blank
It cannot recollect
When it began - or if there were
A time when it was not ...

The hope of achieving complete recovery becomes less and less realistic. Nevertheless, the participants held on to the possibility of getting better. The hope to recover made them keep track of small gains. Vigilance extended to noting any sign of improvement, no matter how insignificant it seemed.

- **Keeping track of small gains**

The slightest sign of improvement encouraged the participants to work harder. They perceived each increment of progress as worthwhile, even though it fell short of their original hopes, and remained optimistic. Farran et al (1995:120) define optimism as a "disposition that expects the best possible or emphasizes a positive orientation toward future improvements, and is associated with health and well-being as a way of feeling".

One of the participants appeared to be making sufficient progress to become less dependent and resume some of his former activities. He was very proud of this achievement, as he had not been able to use his hands for this kind of activity for several years:

I keep on exercising. When I left the hospital I could not do anything, but now I can use my hands. Just yesterday I did some washing, a few items, then tomorrow I can do the rest.

Another participant said,

The neck moves slightly now, and the wrists. But, the hands are still stiff. Maybe as time goes on ..., I mean, I was told by the doctor that I would never be able to do anything.

Morse and Penrod (1999:145) refer to hoping for minute gains by SCI persons as a pattern of “incremental hope”. The implication therefore for the health professionals is that information about a disability must not destroy the patients’ hope that they might get better. Dewis (1989:393) found that a quadriplegic stated that being able to shave and brush his teeth made him feel “great” and have a “purpose”.

Yoshida (1994:96) refers to Ruth (1963), who observed that persons suffering from tuberculosis developed “time tables” in terms of time and physical functioning, and Davis (1963) found that patients recovering from polio, and families used “benchmarks” of muscle function.

Whilst the participants in the study were working towards reconceptualising the self and maintained a positive self-concept, the environment was perceived as not being supportive. This perception has negative implications for maintaining a positive self-concept, as people confirm their self-concept through current social interactions (Zhan & Shen 1994:511).

5.3 EXPERIENCING BEING-IN-THE-WORLD AS A WORLD WITH OTHER: BEING EXCLUDED, OBJECTIFIED AND MARGINALISED

“One cannot lose sight of the fact that a human being, physically limited or normal, is a social or gregarious creature; he operates and functions in a social milieu” (Coulter & Wolamin 1974:30).

Human beings cannot exist except in the framework of an encompassing world, although that world does not entirely constitute or determine the human being (Mackey 2005:181). Heidegger (1962:26) considered being-in-the world to be a priori, implying that as humans people are already in a world context, a world of tradition, a world of history, as well as a

world of other human beings. The process of reconceptualising self was shaped largely by the presence and actions of others. Being-in-the-world means being-with-others, a situation the participants sometimes found difficult because of the way others treated them.

Northway (1997:738) 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”. 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. Issues raised included devaluation of the disabled person by society, stress on family relationships, and environmental barriers. The participants experienced being seen and treated as objects. The meanings participants attached to their experiences were explored through the themes of *impact of the body in relation to others, perceiving inadequate social support and lived spatiality*.

5.3.1 Impact of the body in relation to others

Having an SCI means being trapped in a body that is imperfect, which has a negative impact on relations with others. This imperfection is a source of social unacceptance, disrespect and most times it results in unequal balance of power.

The lived body imbued with personality and biography is overlooked. The participants found that others react more quickly to the obvious characteristics imposed by the disability, than to the more intimate basic qualities of the person. This is experienced as violation of personal integrity.

- **Experiencing violation of personal integrity**

Lillesto (1997:284) regards the concept of violation as ambiguous, complex and multifaceted. Violation may include infringement, humiliation, negligence, carelessness and harassment. Lillesto adds that violation can cover the experience of unpleasant feelings as well as physical and psychological pain. The whole person is affected by these feelings. When a person feels violated, they do so, no matter what the performer of the act

says (Lillesto 1997:287). Violation, then, includes thoughtless and inconsiderate remarks, actions, verbal harassment, and lack of common sense and good manners towards people living with an SCI. They feel they have been exposed to humiliating and embarrassing situations and infringement of body barriers. They are treated with disrespect and subjected to excluding attitudes of able-bodied persons. Venturing outside the home, for the participants meant risking potential humiliation, whether in a meeting or simply trying to use public transport. The participants were not taken as productive members and part of society.

The participants experienced being teased needlessly, poked fun at, and exposed to public contempt. They felt that they were being treated as “others” by the general public, during their interactions in different settings. The members of the public had negative attitudes, which were either patronizing or hostile. Hostility was experienced when the violation was intentional, such as having to put up with hurtful remarks like “*aba bantu bayasidina*” (“these people are a nuisance”). The sidewalks (pavements) are narrow and the wheelchairs were seen as blocking the way. Perhaps the most difficult to understand and come to terms with is how badly they were treated at meetings. Nobody paid any attention to their point of view.

South Africa is in its second decade of democracy, and everybody wants to feel liberated by making a contribution to matters that affect one’s life. SCI persons are not allowed to enjoy that basic right. They are snubbed. This is oppression. The participants had come to realize that a person with a mobility disability was not only physically challenged, but also had to overcome social attitudes in order to participate fully in the community:

Masibayeke aba kuske kuhanjwe nabahambayo ... kuba thina asikwazi kuxhuma-xhuma. (Let’s ignore them ... [and that is] because we are not able jump up and down and dance when making a point.)

People look down on a disabled person like you are not normal upstairs.

To the participants, non-disabled members of society seemed to think they were better or cleverer because they were not in wheelchairs, so by definition those using wheelchairs for mobility were assumed to have their minds paralysed, too. In the UK, Thomas and Mullan

(1994:24) refer to a person living with an SCI who remarked that “people seem not to recognize the fact that the only difference is that people with SCI may not be able to run around, but that is as far as it goes”.

In marginalization, power from the centre forces majority concepts to be expressed in the majority voices, and marginalized persons are thus silenced (Hall et al 1994:32). People living with an SCI suffer discrimination in all spheres. Even planning a journey is accompanied by anxiety over when and how they will arrive at their destination. They have to plan ahead, cannot be spontaneous and do things on the spur of the moment. Most taxi operators will not stop for an SCI person at the side of the road in the rain, because:

Le nto yakho iyasilibazisa, bandishiya ndimile. (They said, “this thing of yours [wheelchair] is wasting our time”, so they left me there.)

The participants also found it demeaning and patronising when people stand around and remonstrate that they should not be straining themselves by pushing the wheelchair without aid:

I don't like it when they talk like that ... and them standing around me, I find it annoying, because if I wait for someone, my life will be like on hold. I am independent, and don't want to be waited on.

The participants suffered various forms of humiliation and invasion of privacy. Their lives became a public affair:

People talk about your condition publicly, even when doing their washing in the river.

Barton (1993:236) maintains that the absence of disabled people's voices and concerns is not because they have nothing to say, but rather that they are not given an opportunity [by able bodied persons]. According to Chun (1997) (quoted in Kim & Kang 2003:146), people with disabilities are regarded as inferior to normal people in their social position because of society's admiration of normal function and appearance. Non-disabled persons still hold socio-historical perceptions about disabled people.

- **Experiencing being stigmatised**

Within stigma is the idea of “otherness”, a distancing of the stigmatised person from oneself (Bunting 1996:65). A person with a stigma is reduced in others’ minds from a whole and usual person to a tainted, discounted one (Bunting 1996:65). Stigma is “that special insidious kind of social categorization carrying with it devalued status” (Hanna & Rogovsky 1991:54). Christopherson, Coulter and Wolamin (1974:9) point out that the disabled serve as a reference for gauging the dimensions of normality and in this way assist “normals” in maintaining their sense of identity and personal integrity.

Hanna and Rogovsky (1991) add that stigma shapes the behaviour of non-stigmatised and stigmatised people, giving each a reason to avoid each other. Stigma is an aspect of marginalization, marking of “outsiders” (Hall et al 1994:30). In this study, the stigma represented the perception that the participants had of others’ attitudes toward them as people with an SCI. The participants’ responses revealed that they experienced distress due to the stigma linked to the use of a wheelchair. Feelings of indignation, anger and despair were evoked by other peoples’ reaction towards the participants. They were treated with disrespect and their contributions to society undervalued. The act of stigmatisation by others put limits on the life of the participants.

The participants experienced stigmatisation in areas of relationships. All reported some disruption in relationships with friends and family, especially with their peers. The participants experienced rejection by those around them. One participant reported how he would notice people talking by means of gestures when they approached him, or at times changed direction. To him, this denoted that people experienced him as an embarrassment, therefore avoided speaking to him, “I mean these were my former schoolmates”.

For the participant, it meant he was denied the opportunity of experiencing peer relationships and a sense of belonging where he could share and discuss the “deepest secrets, joys, sadness, problems and feelings” associated with his stage of development – adolescence (Azmitia 2002:175).

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

My wife left after the accident.

When you are like this, you can't guarantee a relationship.

What kind of person could possibly find someone like me attractive?

It is not easy if you are in a wheelchair ... my wife left me.

Bates et al (1993) explored the experience of a patient's adaptation to a wheelchair during inpatient rehabilitation. The findings showed that patients struggled with personal prejudice as the wheelchair was seen as a symbol of finality.

Chan (2000:272) found that people living with SCI related how their friends would find excuses not to have them around, 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 2000:4).

Cogswell (1968:12) found that all paraplegics face problems from the stigma of the disability. When they returned to their homes, the definitions of their disabilities as a social stigma reach the height of "salience" (Cogswell 1968:12). The participants felt that the general public did not regard them as people who were entitled to live and fully participate in social events. They are isolated from the real world and forced into the disabled population (Chan 2000:272). Stiens et al (1997:S67) contend that successful social interaction within the environment requires an unbiased appraisal of a person's capabilities in spite of mobility limitations.

A stigmatised individual is one who is disqualified from full social acceptance, as a result of being different from others. Goffman (1963:3) defines stigma as an "attribute that is deeply discrediting" and results in a spoiled identity. According to Goffman, possession of a deviant attribute results in global devaluation of the individual. This devaluation marginalizes the individual, causing loss of respect and creating an assumption that the individual is not fully human and is unable to fulfil the requirements of social interaction.

Goffman (1963:15-16) emphasizes people's need to draw distinction between individuals who are stigmatised and themselves. People do this to protect themselves from the thought that they could be similarly afflicted.

Three types of stigma are identified, namely physical deformity; character blemishes, and tribal stigma because of race or religion. Joachim and Acorn (2000:244) refer to Jones et al's (1984) six dimensions of stigma, and state further that the dimensions affect the interpersonal roles of those stigmatised. The six dimensions are:

- *Concealability*: The degree to which the condition is hidden or visible. Visibility plays an important role in producing social reactions.
- *Course*: The extent to which the condition changes over time.
- *Strain*: That the stigma places on interpersonal relationships.
- *Aesthetic qualities*: The extent to which the condition affects the appearance of a person.
- *Cause*: Is the condition congenital or acquired
- *Peril*: The dangers associated with the stigmatised person; for example, crime or mentally ill.

No one can conceal a broken back and paralysed limb. The person stands as a discredited person in an unaccepting world, an aspect of life that many non-disabled persons do not deal with on a day-to-day basis (Manns & Chad: 2001:807). Triechman (1980:91) states that it appears that "we learn to perceive differences among people and to value those who are most physically attractive, we tend to avoid those who markedly deviate from our expected standards of appearance, thus we do not learn how to behave in their presence". Along with the negativity experienced from the general public, the participants were not always happy with their social network.

5.3.2 Perceiving inadequate social support

Wineman et al (1990:295) define social support as "the degree to which individuals' needs for socialisation, 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 belongs to a network of communication and mutual obligation".

According to Gill (1999:5), 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 (1997:1270) contends that a person with a physical impairment due to cerebral palsy or 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 network available to them, and how it was experienced.

- **Being with health professionals**

Professionals are key determinants in successful rehabilitation and convey their expectations and values to their disabled clients by their manner of interactions (Florian & Kehat 1987:57). The participants in this study experienced their encounters with health professionals as positive as well as negative.

The participants came from different rehabilitation units and in the period spent there they found the health professionals generally supportive. Since it was necessary for them to receive care from the nursing personnel, they were forced to adapt in some manner.

One way of mastering the "invasion" of the body by health care professionals is to "hire" it out (Lillesto 1997:290). The body is public property while the nurses are there; the clients have to let the nurses take over in order to get the help they need. The participants expressed a loss of a sense of control and concurrent loss of power at times like these:

I would allow the nurses to care for me, knowing that I depended on them. They also said to me, "Don't worry, even when we do these things to you, you remain being yourself."

What can you say, when you find yourself unable to do anything for yourself?

These statements convey the meaning that ownership of their own being had been lost, that they had become the property of caregivers.

Experiences post discharge were disappointing, humiliating and demeaning at the worst resulting in anger and resentment from the participants. Some health professionals were described as insensitive, overbearing and patronizing.

- **Health professionals experienced as dominating**

Any advice that conveys a negative attribution to the recipients of care has a negative effect on self-esteem and well-being. Health professionals are used to authority and giving commands, often ignoring the fact that people living with an SCI are not mentally retarded, they know what suits or does not suit them. Insensitive remarks were received from certain health professionals, for instance a social worker refused to listen to a request to consider a wheelchair replacement. The participants' rights to choose and personal autonomy were eroded because of competing power relationships between the professional and the disabled person, which produced mixed feelings:

They seem not to understand that I use this wheelchair every day on gravel roads. Our roads are not tarred, and I use it every day. I was told at the hospital to keep on exercising. You are not told when to have your chair changed.

If this wheelchair is not replaced, I will have no choice, but to stay in bed. I will be bed-bound. She told me this wheelchair is mine forever. When these wheels get finished, I will stay in bed ... stay in bed. Yes ... never be able to get out ...

From the above, health professionals seemed to be sending a double message: take care of your body and we will make decisions for you.

Disabled persons often see encounters with health professionals as demeaning and oppressive, because their voice is not listened to, and their opinions are undervalued (Goodall 1992:25).

There were times when the health professionals fell short of expectations, and their competencies were given a low score, producing feelings of vulnerability.

- **Nursing personnel experienced as incompetent**

One of the participants expressed disappointment over how he suffered at the hands of incompetent nurses who were incapable of taking care of him and, as a consequence, developed complications. They did not seem to be tuned in to the needs for turning and the extra problems of a paralysed SCI person. The participant had been discharged from the rehabilitation unit to await transfer to a “home for people like us”:

Babe ngena buchule boku ndikhathalela. (They lacked expertise in caring for me.)

This is consistent with Biley’s (1996) finding that nurses acknowledged that training and education on caring for patients with physical disability was minimal or non-existent, and that only a few had previous clinical experience in this highly specialized area.

Health professionals were also perceived as *not providing adequate follow-up care*, leaving the participants to battle alone, together with ill-prepared family members regarding care of an SCI person.

Some of the participants expressed the need for a follow-up from the health professionals, and were appreciative of this study, as it could mean a new beginning. There was no structured follow up for them after coming home. The rate of re-admission indicated that no adequate support was given to the families and no supervision of the individual’s progress:

Siya li thanda elikhono nilenzayo, noko sisi qalo esihle masilandelelwe kubonwe indlela esiyiyo, abanye bethu baya a- buzwa ngabantu babo. (We appreciate this effort, it is like a new beginning. There is a need to keep in touch with us and

see for yourself our circumstances and how some of us are being abused by our own people.)

Ndiyavuya uzile, kudala be buza ukuba kuziwa nini aphe khaya, nibone ukuba kunjani apha ngaphandle, baya buza nalaphe khaya, ngakumbi umakhulu endihlala naye aphe mini. (My people keep on asking when are we getting a visit from them (professionals) to see how things are out here. My grandmother will be happy now; we both stay here during the day together.)

One participant raised the matter of counselling services during the in-patient period. He felt that, had those services been available during the first admission, he could have coped better with his circumstances, as he was receiving the services now during the second admission. He felt neglected. Rehabilitation counsellors counsel clients to help them realistically assess problems and accept the limitations resulting from their injuries. Furthermore counselling helps in the reduction of negative emotional states (Stewart 1996:40). According to the participant:

Waye ngekho kuqala {who?} u-social worker, usanda kufika nangoku uqale ngo March or April this year. Kuqala sasancedwa ngama-nurse. (There was no social worker during my first admission. She has just started March or April this year; nurses used to help us.)

The interview with this participant took place in June 2005. He had been re-admitted in November 2003 for management of pressure sores, after spending about ten months at home, and was now awaiting transfer to a “quad house”, as “all that we experience out there [home] is hardship, yes, extreme hardship, nobody to turn to”.

This indicated that people living with SCI in that community yearned for some form of support, even if only to talk about their lives. One of the participants thanked the researcher for the opportunity “to talk about this matter” (*Khe ndithethe nga le nto*).

Madjar and Walton (1999:51) emphasise that when nurses truly listen, they create a supportive space within which patients can start to make sense of their world, and this is an important way that nurses (can) make a difference.

Northway (1997:739) refers to Lonsdale (1990) who stresses that the very qualities which can help disabled people to cope with their situation, namely being assertive and a desire for self-determination, can lead them to be viewed as “problem” clients by service providers.

- **Being with families**

When the participants first came home from hospital, or the rehabilitation unit, their families received them cautiously, because no one knew what it would be like, or how they should relate to their relative who had changed. Most of them were treated in far away places, where relatives could not visit. According to one participant:

When you get home there is the family who do not know how to handle the situation, and you have to put them at ease, and you, too, are finding everything strange. You cannot get into your house without help. In hospital everything is accessible, doors are wide and everything is at the right level.

Some families were supportive but others were experienced as lacking understanding and sensitivity. There was a stark contrast between palpable family support and feeling utterly alone among the participants. One of the participants was content and happy with the attention he received at home:

Ndandisazi uba bazondi-nesa aphe khaya. (I knew that I was going to be looked after here at home.)

This participant was the only one whose home was within 30 kilometres from a specialized spinal unit, and as a result his close relatives came to visit and were shown how to give physical care. He had not been readmitted since being discharged.

- **Participants needs not prioritised**

Family members had their own priorities, regardless of the needs of the disabled member. For example, two participants mentioned the problem of inaccessibility at home:

If there is no one to help me, as you can see, the entrance to my shack is steep I can sleep outside even if it is raining. Yet my family says I must not rush them, to build a place that I can move in and out without assistance. Yes, such things are a problem.

You just stand there wet in front of your house, hoping that a neighbour will see you.

Some of the participants referred to the struggle between appearing resilient and concealing their desperation. Sometimes the overwhelming and oppressive nature of their circumstances made them wish they had died. Some of the participants experienced so much hardship at home that they realised that things had changed forever:

Uqonde ukuba kwaku ngenje kuqala. (It was not like this before the accident.)

Sometimes you ask yourself what is the use of surviving the accident.

Their days often seemed wasted and empty and appeared to lead to nowhere:

There is not always somebody to get you. People have their business. For instance, my brother plays soccer, and my next-door neighbour will put me next to the bed and rush out. I think he is uncomfortable with helping with me. So I will spend hours in a wheelchair until my brother comes ... What happens in the morning is that my younger brother washes me, helps dress me and with my breakfast, and they wheel me outside.

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

I would go round and round the house the whole day with nothing to do and no one to talk to. They would give me breakfast, and go wherever. The next meal would be about 3 or 4 in the afternoon. This is not good for us quads. You can't even get fruit as it must be shared with the children first. We were able to buy

fruit enough for ourselves in hospital. In fact, families are not equipped to look after us quads. It is better for paras, they have got hands ... even meals are not regular.

Krause (1998:901) holds that active engagement in life enhances adjustment or subjective well being, while others refer to the problem of unstructured free time following SCI. Yerxa and Locker (1990:320) found that adults with SCI spend three times more of their day watching television than those without disabilities. Loy, Dattilo and Kleiber (2003:232) refer to Coyle's (1990) finding that time not spent in active engagement often led to depression.

Madjar and Walton (1999:7) point out that illness narratives are frequently stories of confusion, futility, helplessness and lack of coherence.

Many 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.

- **Experiencing being abandoned by family**

Some had been left to fend for themselves because their family members had either abandoned them or their whereabouts were unknown. They faced a future on their own in a wheelchair:

I have no family. My parents died, I have no home ... My brother went to the mines and never came back after the accident . I don't know what happened to him.

My aunt who brought me up ... because my mother is no more, she abandoned me at three months. My father won't have anything to do with me ... I think my aunt too ... You won't believe there was a time I went to look for other relatives. I was given a shack to live alone. My life became worse (*kwakukubi*). It's not easy to access medical care ... no one to accompany me. In that time pressure sores had formed.

These people are missing the most important forms of social support – family and finances. They are really thrown into the deep end, yet they can't swim, figuratively and literally.

I realized the seriousness of family involvement or lack of it in the care of their family members who were paralysed and have lost control over bladder and bowel movements, when I went to two of the would participants, only to learn that they had passed on. They had developed deep wounds, so I was told and were always wet. For those who were back in the rehabilitation unit during data collection, one was awaiting skin graft to aid healing of the pressure sores that were quite deep. Only one participant had not been readmitted after he had spent 'over a year' for his first admission, and the family members had been involved in physical care during the hospitalisation period.

Finance is another source of stress affecting all the people living with an SCI in this community.

- **Experiencing financial hardship**

Bearing in mind that the Eastern Cape is one of the poorest provinces, the source of employment for the majority of the people is mainly in the mining industry, in other parts of South Africa. Thus, being disabled, with a low education level, and living in a remote rural area compound the issue. People living with an SCI in this region are extremely under-privileged.

Many aspirations of the participants are likely to be frustrated by a lack of resources. Access to resources and material goods is through adequate finances. For the participants, the disability means perpetual poverty. They have no choice, having lost their former jobs, which were more physical, their chances of being re employed are null. The disability grant is less than one thousand Rands, and hardly enough to meet their needs. The chances of the participants improving their living conditions are remote. Hence their request that the government provide a building where the paraplegics could come together,

to make objects that they can sell to supplement the grant and try to make ends meet. Moreover, they would appreciate it if special houses were built for them:

But not a village for the disabled, eh, we are not like lepers. I want to be with the able-bodied so that I can shout, "Hey! young man, come here and help me.

The quadriplegic participants were concerned over the fact that they were not able to contribute in any way to the upbringing of their children, financially or otherwise. They would be moving to a "quad house", and so would their social grant, as soon as arrangements had been completed. They would not be able to fulfil their parental role or help provide for their children. Their families would be deprived of the feeling of safety and security provided by a father. In one case there was also a possibility of losing the children to strangers, despite the availability of a reliable family member to care for them:

I have approached the officials to arrange foster care for my two children because my mother is going on pension ... so her income is going to be reduced, and she still has to pay for my sister's education. The officers there said I must hand over my children. It is not for me to choose where they go ... just like that. My disability is going to pay for my boarding at the quad house.

I am in a difficult position. If I go back home, as you know I had to come back because of problems ... mhmh ... like there is no nurse there [at home] but now if I go to the quad home so will be my disability grant. Who is going to feed my family? I have four children, my wife is not employed ... she has to look after the children. I just don't know what to do.

For some quadriplegics and others, disability grants proved a source of suffering because unemployed relatives exploited them.

Bach and McDaniel (1993:366) found that people living with SCI had financial problems because the cost of living was very high; they need adequate finance to have accessible housing, meet family needs, purchase supplies, and pay for attendants and health care.

Finances affect the quality of life (Manns & Chad 2001:807). The participants in this study, and their families will remain trapped in poverty, and that thus affect their quality of life negatively, as they cannot access or afford the basic needs.

Oliver et al (1988:11) emphasise that people's material circumstances are crucial to how their disability will be experienced. Triechmann (1992:59) found that the fight for financial survival adds to the stress of the physical and emotional penalty of SCI. Furthermore, evidence from long-term survivors indicates that this stress may take its toll in terms of earlier onset of physical decline associated with aging than in non disabled population.

5.3.3 Lived spatiality: encountering physical barriers

One of the most fundamental aspects of the life-world is its spatiality, that things are close or remote. Fjelland and Gjengedal (1994:19) state that when people want to measure remoteness they measure it according to what is required to overcome the remoteness; in other words, the distance in the life-world is an obstacle to be overcome. The participants constantly had to deal with physical barriers.

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 (1968:12) points out 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. According to one of the participants,

When you come home it is awful and desperate ... it is a hell of a shock.

For the participants, getting into or out of their dwellings and even moving around the homestead was extremely difficult. Their safety is not guaranteed. The path leading to the doorway is either steep as in shacks and huts or there are steps around the house, making it virtually impossible for them to enter or get out on their own. They are not able to escape from danger, whether hail, storm or fire. Doors are narrow. Uneven terrain between the huts makes wheeling difficult.

The life of a person with an SCI takes dependency to embarrassing if not dangerous levels. According to Tim Marshall, an SCI person, “Toilet – that is the most critical thing. If you have got a loo you can get to, then the rest more or less follows” (Thomas & Mulherm 1994:68). In this study, the toilets (latrines) are situated at the bottom of the garden. Besides the problem of the condition of the path leading to the amenity, the participants also faced other obstacles:

Who is going to open the gate to the garden in the first place? As if the trouble getting there was not enough, you find the door to the toilet small and the wheelchair cannot turn around.

The participants reported the following constant frustrations and obstacles in their homes:

You can't even get a cup of water, because the water tank is not accessible.

If nobody comes, I can spend the night outside, raining or not.

Izindlu, asikwazi kungena kuzo ngenxa yezi wheelchair, siya bethakala zezinto, ade aqonde uba hey! akwaba uTixo waye se wandithatha, ndingabikho elizweni.
(We are unable to get in because of the wheelchairs. These things are inconveniencing us, to the extent that at times we do wish God had taken us.)

Inadequate water and food intake are serious risk factors for the development of pressure sores (Mudzi 2001:9). Besides inaccessibility, for shack dwellers, the dwellings do not protect them against the elements; instead, they are exposed to the adverse effects of the weather and the seasons. For them, then, the expression “in the safety of your own home” does not apply in their circumstances. They are constantly exposed to health-threatening environments.

With regard to infrastructure, the roads are virtually non-existent or in such poor condition that the participants cannot be spontaneous and do things on the spur of the moment. They have to think twice before taking a trip in the villages, even with assistance, because there are virtually no roads. The existent bumpy strips and rough terrain hurt when one is driven over them.

There is no way you can just get up and go ... the footpaths in the rural areas make wheeling a difficult task ... and it hurts. You even regret having subjected yourself to the suffering.

The participants were virtually imprisoned in their own homes and isolated in their remote villages. Although SCI persons can apply to the social welfare department, for an extra R150,00 a month, as an incentive for an assistant, it is not easy to access because they are expected to go to the offices themselves. Transport is the main problem. Of the ten participants, for example, only two were able to access this amount. A respondent in Manns and Chad's (2001:800) study on quadriplegic and paraplegic SCI's stated, "I have to live in the city. I can't go wheeling down a gravel road, it's just impractical."

Transport is another restricting factor in their lives. The participants found getting to town an ordeal, because the wheelchairs are cumbersome, and the taxi operators were impatient and unsympathetic:

They [taxi operators] say we are wasting their time because have to fold the thing and push us in.

There is no form of adapted public transport yet to accommodate wheelchair users. No legislation to make provision for them to travel in comfort.

Barton (1993:236) found a general absence of disabled people in public places. Goodall (1992:27), a disabled nurse, points out that "only repeated encounters with flights of steps, narrow doorways, rough pavements and ignorant or intolerance of the public, provide some measure of understanding about the indignity of disability".

Stiens et al (1997:S67) state that the physical and social environment constantly challenges persons using mobility devices. They go on to say that to afford full participation in society, the physical environment must accommodate wheelchair users with compatible ramps, grades and surfaces.

Barton (1993:236) refers to Morris (1991:26-27), who emphasises that disabled people resent their needs not being considered in the planning of public buildings:

We receive so many messages from the non-disabled world that we are not wanted, that we are considered less than human. For those with restricted mobility or sensory disabilities, the very physical environment tells us we don't belong. It tells us that we are not wanted in the places that non-disabled people spend their lives in – their homes, their schools and colleges, and their workshops, and their leisure venues.

5.4 MATTERS NOT RAISED BY THE PARTICIPANTS

The researcher noted that none of the participants referred to the impact that lack of bladder and bowel control had on their lives. This could be attributed to gender and cultural taboos. The same could hold true for sexually related issues. No mention was made of sex or sexuality in the interviews. Thomas and Mulhern (1994:33) report that “the beautiful thing about a neck break as opposed to a back injury is that you normally retain the ability to get a reflex erection, whereas with a back break you go permanently flaccid”.

5.5 CONCLUSION

This chapter focused on how the participants experienced their own being-in-the-world. Two main themes emerged: having to reconceptualize one's being-in-the-world as a person with a disability, and experiencing being excluded objectified and marginalized. The participants engaged in a process of reconstructing the self, and experienced difficulties in coping with health and disability problems, family interactions and relationships, and non-accessibility of amenities, including their dwellings. It was noted further that being a person living with a spinal cord injury in the rural communities of the OR Tambo district municipality carries a high physical and social risk due to poverty and a lack of resources. For disabled people, external influences play a disproportionately large role in shaping self-perception, because society has constructed disability within a very mechanistic utilitarian framework, that has allowed society to heap abuse and denial on people with disability (Fitzgerald 1997:407).

Chapter 6 presents guidelines to support SCI victims in the rural communities of OR Tambo district municipality.

Chapter 6

Framework and guidelines

6.1 INTRODUCTION

Chapter 5 examined what it means to live with an SCI in a rural community in the OR Tambo district in the Eastern Cape. From the discussion it became evident that being-in-the-world as a person with an SCI means redefining one's self as a person with a physical disability. The participants' energies were therefore directed at attempts to manage the situation so as not to lose their sense of self.

The challenges facing people living with SCI are due to gaps in the rehabilitation programme, which, according to Kendall et al (2003:50) should include alterations to physical function, body image, and self-esteem, as well as social and familial roles and community access, integration and participation.

6.2 CONCEPTUAL FRAMEWORK

In order to support people living with SCI, the researcher puts forward the following conceptual framework, based on Dickoff, James and Wiedenbach's (1968:420-423) survey list's six aspects of activities. According to the survey list, there are six questions about the activity. The activity engaged in here is to support people living with SCI in the context of area community to be fully integrated. The six questions cover the following aspects:

- **Purpose or terminus:** What is the *goal* of this activity?
 - (1) To enable SCI persons to transcend their disability and take control of their lives.
 - (2) To be successfully reintegrated into the community.

- **Agent:** Who *practises* this activity?

Health care providers, who include the rehabilitation team, and the individual's social network.

- **Recipient:** Who *receives* this activity? The SCI person and the family.
- **Framework (context):** In what *context* does this activity take place?

The external environment (social, economic, political, legal, and institutional) in which the activity takes place, and the internal environment (interaction between health practitioners and the SCI person).

- **Dynamics:** What is the *energy source* for the activity?

The energy source or motivating factor is to enable the SCI person to achieve independence and a feeling of worthiness.

- **Procedure:** What is the *guiding procedure*, technique, or protocol for the activity?

A holistic model of rehabilitation that encompasses

- alterations to physical function, namely loss of motor and sensory function, and medical complications
- body image, self-esteem
- social and familial roles
- community access, integration and participation
- support systems

Figure 6.1 depicts the framework to support people living with SCI in rural communities of OR Tambo district municipality.

Figure 6.1
Framework to support people living with SCI in rural communities of OR Tambo
District Municipality

Adapted from: Dickoff et al 1968: 420-423.

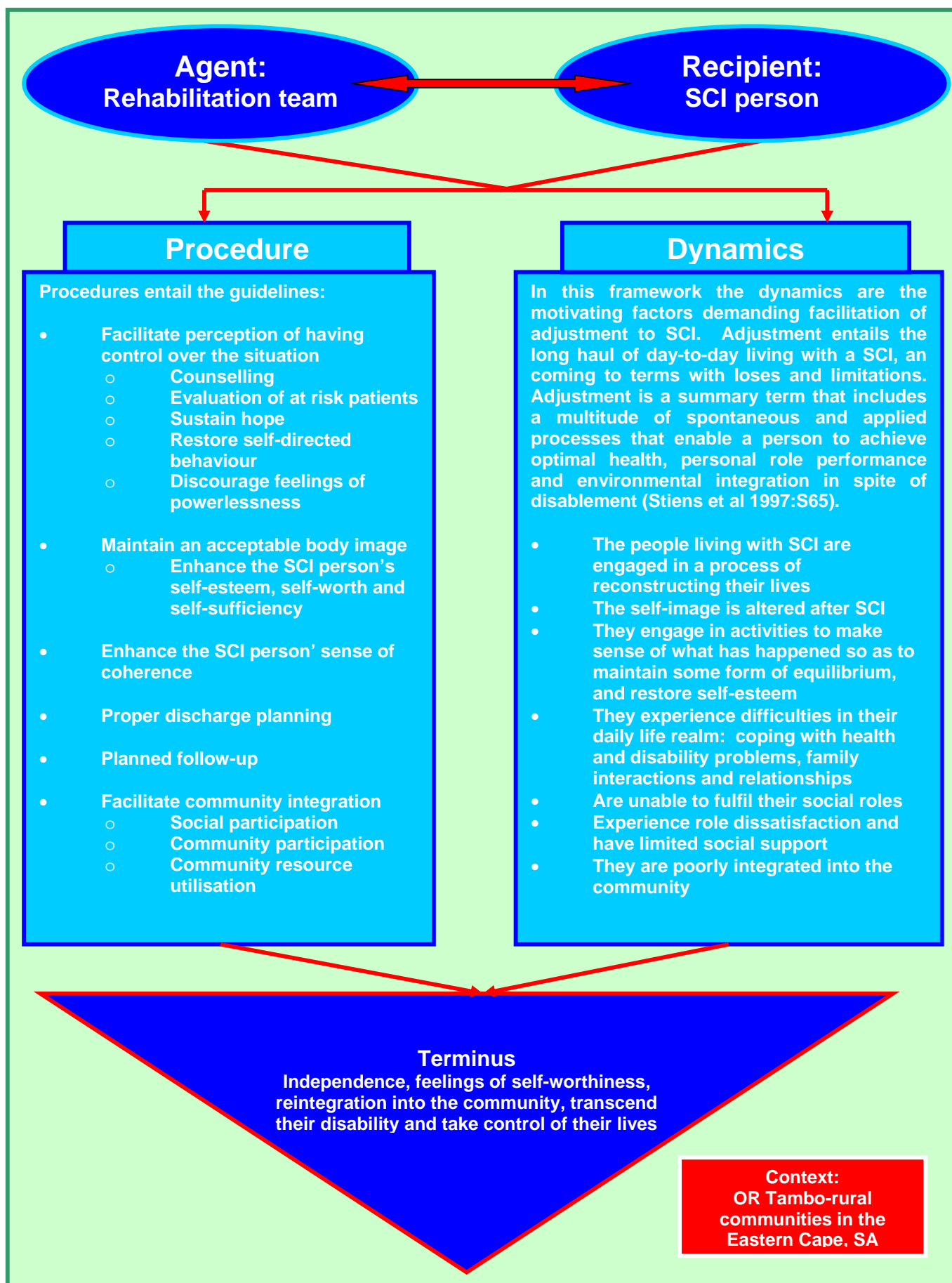


Figure 6.1
The framework to support people living with SCI in rural communities of OR Tambo District Municipality
 (Adapted from: Dickoff et al 1968: 420-423)

6.3 GUIDELINES FOR SUPPORT OF SCI PEOPLE

The rationale for the study was to use the findings to build a base upon which clinical wisdom could be constructed. The main objective of the guidelines is to assist the participants to reconceptualize their new identity, as persons living with an SCI. This can be achieved by (1) facilitating the perception that the SCI persons have control over the situation, (2) maintain an acceptable body image, (3) effective medical management after discharge, (4) planned follow-up care, (5) promoting a sense of coherence and (6) facilitating community integration.

6.3.1 Facilitate the perception of having control over the situation

The study found that the participants were not prepared for the consequences of their injury and used strategies to gain some mastery over the event. In order to reduce the impact of the injury, most of them used denial/hope and spirituality to fight off the threat posed by the injury. Denial in a recurrent model of adjustment is seen as an attempt to retain the meaning, control and identity associated with pre-disability schemas (Kendall & Buys 1998:18). The participants also engaged in positive refocusing to minimize the significance of the condition. To be able to move on and thus acknowledge their situation, they sought to find the meaning of the event. Rehabilitation practitioners should assist SCI people to live happy and productive lives by enhancing their beliefs about their abilities to cope with life's challenges. This enhancement can be achieved through building successful coping experiences for the client, providing positive reinforcement, providing role models and appropriate counselling (Hampton & Marshall 2000:27).

During the in-patient period, therefore, and continuing post discharge, there is a need for psychological counselling and support. Therapy should be available to patients to assist in coping with the multiple losses experienced to facilitate the normal adaptation process. Therapy utilizes the principles of grief work and supportive psychotherapy and aims to promote patients' best psychological and social functioning by restoring and reinforcing their abilities to manage life (Judd & Brown 1988:422).

Therapy (counselling) may include:

- Support in the expression of affects aroused by the injury, such as anger, sadness, and guilt, and feelings associated with the change of life style, which must now change.
- Explanation, focused on day-to-day practical questions.
- Reassurance, particularly the removal of doubts and misconceptions, and emphasis on individuals' assets.
- Making clearer the nature of the problems the patient faces, offering direct advice.
- Encouragement and bolstering of self-esteem.
- Gentle encouragement to recall the accident, if appropriate, and to begin to discuss hopes and fears for the future.
- Resource counselling, i.e. emotional, legal, finance and support organization.

Evaluation of patients 'at risk' of committing suicide

- Thoughts of suicide had crossed the minds of some of the participants during the early days of injury; they just lacked the means.
- Particular care must be taken to identify those patients at risk of developing depression, or other manifestations of failure to adapt to their injury.
- Assess the patient's behaviour for signs of suicidal ideas owing to feelings of doom, failure, and poor self-concept.
- A patient's past or family history of depression.
- Previous personal difficulty in coping with loss.
- Difficulty with interpersonal relationships.
- Lack of family support.
- The patient's family should also be evaluated, particularly for the needs of all family members.
- Family or marital therapy may prove valuable where pathological family interactional patterns are identified, and the children show difficulty in coping (Judd & Brown 1988:422).

- The nurse therefore needs to be aware of signs of the patient becoming increasingly isolated and discuss with the patient's family.
- The nurse can help the patient and family mutually devise a plan in which the patient's needs for companionship, diversions and support are recognized and met.
- The nurse also can explore ways that the patient can be assertive and reach out to others to get the support needed. This approach also enhances the patient's belief of being in control of personal destiny and not the whims of others (Soeken & Carson 1987:608).
- Enhancement of patients' feelings of control will help them perceive their ability to cope with other demands more positively (Chen, Boore & Mullan 2004:256).
- Further assessment of community and home environment for suitability for sending patient home, and estimating the adaptations necessary (Partridge 1994:14).

Sustain hope:

The findings indicated that the participants held on to their hopes – hoping for improvement of their lot, from improvement of the physical and living conditions to life in general. Hope has several components: future orientation, the setting of goals, the taking of action to meet those goals and the importance of interpersonal relationships (Soeken & Carson 1987:609). Health professionals often have a pessimistic view about their patients' mood and recovery. The fact that such individuals have a positive outlook has received little attention (Nolan & Nolan 1998:98). Fostering hope and inspiring realistic hope is important, for without hope, there is despair. Therefore the implications for practice are:

- In dealing with SCI persons, nurses should be aware that they have hopes for future-oriented goals, even if it means changing aspirations to be consistent with limitations imposed by the disability.
- They are hoping for support, love and constancy provided by the important relationships in life, in order to fulfil their dreams.
- The individuals need clear and accurate information in a consistent way with as much reinforcement as necessary, and a trusting relationship with the nurse.

- Information regarding the severity of the injury, treatment planned and hopes for recovery.
- Equally important is the feeling that progress is being made; the nurse can encourage self-care activities (Partridge 1994:14).

Discourage feelings of powerlessness owing to loss of control over oneself

- By providing sufficient information about the spinal cord injury.
- Teach them problem-solving skills and provide support for self-care efforts.
- Encourage verbalization of feelings such as frustration, anger, hostility and fear.

Rehabilitation interventions to promote adaptation should restore self-directed behaviour.

- Triechman (1980:55) emphasises that for SCI persons to take control of their own lives, the environment should facilitate, support and guide such efforts. Bandura (1993:117-148) states that environments that construe ability as an acquirable skill, de-emphasise competitive social comparison and highlight self-comparison of progress and personal accomplishments are all suited for building a sense of self-efficacy. From this perspective, rehabilitation practitioners should create an environment that emphasizes the acquirable nature of coping skills and encourages clients' self-comparison of rehabilitation progress. Facilitating the feeling of and possibility for control and self-direction is one of the biggest challenges for rehabilitation. Therefore, to promote adaptation and restore self-directed behaviour, one should:
 - Establish and maintain caring relationships. The individual care plan should incorporate not only the goals of the health care team, but also those of the SCI person, by learning what the injury means to the individual.
 - Know how this traumatic event fits in with his or her life plan, so that the plan of care addresses the whole person.
 - Engage patients in independent thought and problem solving to restore power. The team enhances this process of learning by acting as patient and family consultants.

- Specific education to patient and family serves as support to challenges of adjustment (Lucke 1999:259).
- Particularly important is the development of assertiveness in order to become skilled in directing others to attend to personal needs in an appropriate way.

6.3.2 Maintain an acceptable body image

It was deduced that maintaining an acceptable body image and feeling normal were of prime importance to individuals with SCI, most of their energies were directed on coping with the change in body image. Work on coping with changes in body image is particularly pertinent to SCI individuals, hence Partridge (1994:12) warns us that changes in body image with SCI should not be underestimated and helping the individual come to terms with may significantly reduce psychological trauma. Chen, Boore, and Mullen (2004:256) propose that self-concept is composed of self-image and self-esteem, and that, if patients have a negative self-concept they will never return to their previous life style and personal relationships will deteriorate. Normalization is crucial for maintaining self-esteem and facilitating adaptation. The implications thus are ongoing interventions including enhancing a person's self-esteem, self worth, and self sufficiency, which empowers him or her to make decisions and to regain control of life.

Build self-esteem

For people with SCI, in the immediate period in hospitalisation after the accident, it may be difficult for the patient to feel good about himself/herself. Health professionals play a key role in the enhancement of a spinal cord injured person's self esteem. Emphasis on independence in individuals with SCIs instils self-sufficiency, which precipitates self worth and self esteem (Gill 1999:6). Health care professionals, families, and friends of individuals with SCIs need to empower the person with an SCI in issues of decision making, and problem solving to foster independence. The self-esteem can be enhanced through the following suggestions:

Facilitate the feelings of feeling good about ones self

- Convey to the patient that you care about him or her.
- Treat them as normal socially and physically using touch, could improve acceptance of their body image (Partridge 1994:12).
- Encourage verbalization of feelings about self.
- Provide feedback by focusing on positive aspects, i.e. evaluating function rather than dysfunction, and concentrating on the patient's ability.
- when giving information to the patient in the presence of the family do not talk to the family about the person, but to the person in the presence of the family, nor should we refer to the patients as 'para or quad in bed 3'. These ways of talking to and about a person send a message that he or she is less worthy of respect since the injury (Trieckman 1980:210). Feeling different from and inferior to others can lead to a desire to retreat from all interactions and from all social activities.
- A person's spirit is uplifted when feeling good about one self. It is also helpful for the nurse to share beliefs about God's love and concern about each one of us.
- Develop mutual trust and caring relationships by providing time to listen, giving non-verbal reassurance through posture, expression, and touch.
- Encourage visitors to help prevent boredom and maintain the patient's social skills and friendships (Partridge 1994:15).

Encourage individual to be self-sufficient

- Promote independence by encouraging them to participate in self-care as much as possible, the increase in self-care when appropriate helps to preserve self-esteem and provides a sense of control over a situation that may seem overwhelming (Womble 2004: 112).
- Self-care skills are learnt and practised in a safe environment before discharge.
- Select realistic goals and involve patients in their rehabilitation process, information about the prognosis of functional outcome (Schooner et al (2000:185).
- Encourage participation and autonomy in decision making in matters relating to treatment care.

- Bring in role models - recovered people living with SCI. It has been suggested that should take place during the first week of admission, and on-going peer counseling and group work “the group work modality provides group members an opportunity to develop and experience a mutual-aid system in which they share common concerns and ideas for handling them” (Hlongwana 2002:291).

Encourage productivity on the part of the individual

- The person should be encouraged to discuss feelings about the role as an individual, spouse, parent, and patient.
- Explore ways to be productive while hospitalized: reading, drawing, paintings and involved in what is happening out at home by taking part in family decisions.

Further, Chen et al (2005:259) has designed a framework based on how the nursing process can be applied in promoting positive self-concept in spinal cord injured persons. The six steps of the nursing process are applied as follows:

- The first step is the assessment of behaviour concerned with patients’ self-concept alteration following SCI including pre-accident self, post-accident hospitalized self, rehabilitation phase self and long-term self.
- The second step is the assessment of stimuli factors consisting of age, life experience, level of injury, perception of injury, emotional responses, coping strategies and self-blame.
- The third step is nursing diagnoses which will be identified, with each specified according to the individuals’ status as self-care deficit, affective states, body image disturbance, sexual dysfunction, and hopelessness.
- The fourth step is goal setting. This includes promoting self-care, enhancing self-esteem developing social role performance and increasing employability.
- The fifth is nursing interventions. These aim to promote independence within activities of daily living, develop effective coping strategies for loss and threats to self, encourage a positive body image, promote a positive understanding of his/her own sexuality and cultivate a positive and realistic outlook on life.

- The last step is evaluation of the nursing intervention (Chen et al 2005:259).

6.3.3 Guideline: Planned follow-up care

It became evident during data collection that there were no planned visits after discharge, if the SCI person does not show up, that will be it.

- Home visits. It is necessary to maintain frequent contact with them so that events during the last contact could be reviewed and assessed, and events for the coming period could be planned and encountered. Also getting an opportunity to reaffirm symbolic meanings of social encounters (Cogswell 1968:13).
- The rehabilitation team should provide SCI expertise to community health care providers.
- Coordination of care with community nursing services.
- Rehabilitation counselors must make provision for long-term follow-up services that can function in a “revolving door” manner, liaising with community-based services (Kendall & Buys 1998:18).
- Further, it is suggested by Cottone, in Kendall and Buys (1998) that rehabilitation counselors should adopt a systemic ecological model in their work, which would focus counselors towards the identification of environmental as well as coping resources which are crucial to adjustment, rather than employing a psychomedical paradigm ‘which has been pervasive in the history of rehabilitation’ (Kendall & Buys 1998:18).

6.3.4 Guideline: Effective medical management after discharge from SCI rehabilitation

Data collected revealed that medical complications plagued the participants after discharge and were the cause of subsequent readmissions and deaths for others. It was also noted that there was no planned follow-up. Health care professionals can be instrumental in changing the health care system to be more realistic and responsive to individuals with disability who return to the community, thereby reducing complications and readmission (Lucke 1999:259).

The initial goal of rehabilitation after SCI is to educate the patient about his/her body. The educational efforts are later to be extended to issues of community reintegration and personal adaptation (Bergman et al 1997:S-55). Education efforts must extend into the home care phase, involving the person with SCI, the family, caregivers, and the wider community. Lifetime follow-ups can help to maintain gains. Before the patient leaves the rehabilitation setting, follow-up medical care should be arranged.

Issues to be addressed during follow up include neurologic status, skin integrity, bladder and bowel functioning, spasticity, sexuality and vocational and avocational pursuits, fitness activity is also encouraged (Bergman et al 1997:S-56).

In addition information on what to do if autonomic dysreflexia occurs can be summarized on a wallet card, and patients warned about potentially dangerous fractures and burns. The risk of burns is increased because of sensory loss (Bergman et al 1997:S-56).

6.3.5 Guideline: Facilitate community integration

Eventual reintegration into society is a task that is frequently delayed by numerous complications; these include medical, social, psychological and or physical problems. These issues came up strongly in the findings of this study. Spinal cord injured persons have a diffuse image of a final goal – reintegration into the community as persons of independence and worth. There is, however, no awareness of the intermediate steps necessary to attain this goal (Cogswell 1980:12).

During hospitalization SCI persons may develop a self-image of independence and personal worth as it is easier to establish and maintain this image in the sheltered environment of the hospital than in the outside world. In hospital SCI individuals have been told or knew how their physical recovery was going to be assessed, e.g sitting, balance, wheel chair maneuvering, transfer, standing balance, were symbolized by staff as indicators of progress, and could assess own progress. Days had meaning and were filled with purposive activity. But when they are sent to their homes and communities the definition of their disability as a social stigma is enforced.

It was noted in the findings that persons living with SCI in the community spent their time idling, no sport no meaningful tasks that occupied their time, and were confronted with environmental barriers including finances, negative attitudes and physical barriers. Thus, they were poorly integrated into their community.

Community integration for individuals with a SCI is an important long-range goal of rehabilitation. The importance derives from the fact that, in general, integration into the community can be beneficial in many ways - living longer, having a better quality of life and being less depressed (Rintala, Hart, Priebe & Ballinger 1998:2). Rintala et al (1998), further explain that community integration is a composite construct comprising of three distinct concepts, namely: *social integration*, that is the extent and diversity of interaction with other people; *community participation*, being the extent of participation in religious, social, recreational, vocational, political, and other organizational community groups and activities and, *community resource utilization*, referring to accessing of goods and services in the community (Rintala et al 1998:2).

The more a person can become again an active member in the community, the better he or she will adapt to the SCI. Whatever the involvement, it enhances a person's feeling of self worth and self esteem and helps him or her to realize she can still be a valuable member of society. This integration is a process. Gill (1999:5) contends that the first step is to feel comfortable when interacting with family and friends. It becomes critically important for family and friends to be encouraged to visit the injured person during hospitalization. Feelings of embarrassment and humiliation may need to be addressed. An opportunity many of the participants did not get due to, mainly, distances where their relatives live. Reintegration involves education and counseling, the later concerned with identifying feelings of concerns, perceptions, and fears related to socialization. People who cannot bring themselves to feel comfortable around family and friends will be terror stricken when interacting with the general public (Gill 1999:5).

In order to facilitate community reintegration of the SCI person will require certain resources to be available. Hammel (1992) proposes that for a person with SCI to achieve a meaningful life the following community skills are needed: creative recreation, financial planning, negotiating community barriers (architectural and interpersonal), social skills

training (putting able-bodied people at ease), managing an attendant, creative problem solving, accessing community resources, assertiveness, sexual expression, vocational planning/training, and use of community transportation. There should be, therefore, a focus on outpatient services which may assist the person in finding solutions to problems once these have been identified. Inpatient rehabilitation is an environment ideally suited in learning self-care skills, what works best was accomplished in an environment that reinforced safe, creative problem solving in preparation for discharge, yet the implications of living in the community with a spinal cord injury can scarcely be anticipated by the newly injured individual, as the participants alluded to the fact that it was a great shock for them when coming home for the first time, and had to deal with families who were at a loss as to how to react to them. The families and friends had not had the opportunity of being educated and counselled so that they can offer support to the person with a disability. The physical barriers, more importantly the inaccessibility of their homes are due to poor discharge planning.

6.3.6 Enhance a sense of coherence

Participants engaged in cognitive activities in search for meaning of the event. A search for meaning is a search for coherence and purpose. Research provides some support for sense of coherence as a construct that affects an individual's adjustment to traumatic loss. The belief about the world as coherent is the global orientation, that the world is comprehensible, manageable and meaningful, and those with a strong sense coherence are able to manage the tension associated with stressors more successfully (Lustig 2005:147). It should be noted that a sense of coherence is not meant to be a specific coping style, rather a person with a strong sense of coherence who believes that he/she understands a problem and sees it as a challenge, is most likely to select the most appropriate coping behaviour for a specific problem (Lustig 2005:146).

The rehabilitation team should therefore bring about conditions to enhance the following:

- *A sense of comprehensibility*, which refers to the degree to which an individual perceives the world to be predictable. When comprehensibility becomes internalised, it turns into an order-seeking attitude and ability to find structure in

events. In order to build a sense of comprehensibility, one must have experiences of the environment that are structured to make it possible to anticipate events (Kalimo & Vuori 1990:77). Lustig (2005:154) contends that it could be enhanced through education about SCI.

- *A sense of manageability*, which is the degree to which individuals believe that they have the personal and social resources to handle a demand. Manageability is based on experiences of exercising control over the environment, which implies trusting that the challenges of living can be handled to a reasonable extent (Kalimo & Vuori 1990:77). This could be enhanced through development of self-management skills (Lustig 2005:154).
- *A sense of meaningfulness*, which is the belief that demands are challenges worthy of investment and commitment, or that it is worthwhile to engage in life's challenges. It provides an individual with motivation to search for order in the world and to seek out new resources for managing a demand. Experiences involving participation in shaping outcomes form the basis for meaningfulness (Kalimo & Vuori 1990:77). This could be enhanced through counselling and empowerment (Lustig 2005:154). A sense of empowerment is returned to clients when they are included in planning to meet care needs and have the opportunity to make choices about those needs (Womble 2004:109).

The individual experience of empowerment is expected to include a combination of self-acceptance, self-confidence and competence, self-determination and self-reliance, including intrinsic motivation, high self-esteem, positive self-concept, independent thoughts, decision making and belief in oneself, with an inner feeling of being in control of one's life, feeling of hope and a sense of connectedness and social justice (Nystrom & Segesten 1994:127).

The researcher is of the opinion that if all the guidelines are met, the sense of coherence of the individuals living with SCI can be enhanced to the extent that they will be able to live, more or less, satisfying lives. Furthermore, the implications of resources, such as money, religious faith, family, and social support that provide individuals with consistent life

experiences, and participation in determining outcomes, should be taken into consideration (Antonovsky 1987; Lustig 2005:147). The core of sense of coherence is based on early development because it is part of the man-environment system, but can be modified during life (Kalimo & Vuori 1990:77).

The *context* made this study unique because the participants had not had life experiences characterized by consistency, and participated in determining outcomes, given their socio-political background.

The guidelines set out in this study are in line with the recommendations of the International Year of the Physically Disabled (IYPD), 1981 (Brown 1992:77-82):

- The disabled desire to become active members of their communities.
- The emphasis should shift from “rehabilitation in hospital” to “rehabilitation in the home, community and at work”.
- The goals of rehabilitation should change from “discharge from hospital” to the development of a satisfying and productive life style after discharge.
- The message of rehabilitation must be that patients are healthy but disabled.
- The rehabilitative facility should not mirror the acute setting, with its emphasis on privacy and dignity.
- Psychosocial rehabilitation should emphasise helping the patient and family to cope with the disaster of SCI and support them in their search for a new, meaningful life.
- Professional roles in rehabilitation should include reconstitution of the psychological and emotional component of the family group.
- Psychosocial component and better community follow-up should be implemented.
- The psychosocial disciplines (psychiatry, clinical psychology, social work and chaplaincy) should be involved.
- Attendant care should be encouraged so that the severely disabled can stay out of institutional care, not be a burden on their family, and do what they want, when they want.

6.4 CONCLUSION

This chapter discussed the guidelines for the support of SCI people and their families. The guidelines are based on the findings of the study, the literature reviewed and the 1981 Year of the Physically Disabled recommendations.

Chapter 7 discusses the conclusions and limitations of the study and makes recommendations for practice and further research.

Chapter 7

Conclusions, limitations and recommendations

7.1 INTRODUCTION

This chapter concludes the study and discusses its conclusions and limitations, and makes recommendations for practice and further research.

7.2 CONCLUSIONS

The study set out to investigate the meaning of being in the world as people living with SCI in the rural communities of the OR Tambo District Municipality, in the Eastern Cape. The hermeneutic approach was chosen specifically for its positive features, namely valuing of whole persons who create meanings; consideration of contextually meaningful experience and seeking to understand the daily living and practical concerns (Annells 1996:709). The researcher chose a Heideggerian (1962) existential phenomenological approach. Merleau Ponty claimed that the body is fundamental for the constitution of the life-world as it is the basis for all experience, and thus, the life-world is constituted by means of bodily experience in interaction and communication with other people and things (Kvigne et al 2002:62).

It is a key assumption in phenomenology that understanding human beings and their actions is best achieved through examination of human experiences. Experience, including experience with living with SCI, offers itself as a record of human encounters; the interface between persons and their world.

Experiences and the people that embody them are constituted by past experiences, present situations and future aspirations and potentialities (Benner & Wrubel 1989). Thus experience is not just something that happens to a person, it is something the person lives, and therefore embodies in his or her life. Experiencing refers to the subjective involvement of persons with their world. People experience their world through perception. Perception

is an embodied phenomenon comprising corporeal, spatial, temporal, and relational characteristics.

In this study, the experience of living with SCI was sought through examination of the participants' perception of that experience. The overall goal was to increase awareness of their experiences of living with SCI, and to encourage incorporation of knowledge gained into nursing practice. The central question in the study was "What is it like to live with an SCI in a rural community"?

In daily life, human beings comfortably exist and are at home with the world in a bodily non-reflective way as *Dasein*, (a notion of human everyday(ness) existence (Annels 1996:709). in their average understanding of everydayness, people do not consider themselves different from the others, information is passed along, no dwelling in the significance of events. But with the sudden loss of movement due to paralysis the nature of the lived body has changed. The person must now think about the limbs reflectively (Doolittle 1994:219). One is forced to live authentically. Heidegger explicates the concept of authenticity in terms of "ownness" and ownership that *Dasein* has the structure of "mineness" something that is revealed in a first person way (Moran 2002:239). A spinal cord injury is a personal event. For the participants their experience was of being thrust suddenly into self-conscious living, forever confronted by physiological, social and environmental challenges. The SCI body could no longer be relied upon – the person cannot flee from danger; cannot always go where they wish to go – and, further, also determines how others react to them. Living authentically is being aware of, and wondering about one's own being. Being authentic is a kind of potential-to-be-whole, because humans have the urge to get their lives together in wholeness. The participants showed the urge to want to gather their lives when they made efforts to get their lives under control and reconceptualize their being-in-the-world as persons with a disability, and the resolution to continue with life within the limitations imposed by the disability. Being-in-the-world includes to be-with-others. According to Moran (2002:242), "the world of *Dasein* is a with-world". The experiences of the participants showed that the members of society were not comfortable in the company of the SCI persons, not eager to have them in their vehicles, or to listen to their contributions during deliberations in public meetings, thus their social identities were devalued. Some experienced being abandoned, or left alone for long periods, meaning that

the “a priori” existential category of being-in-the-world with others is lacking. They were lonely.

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 out and brought inside the house; put to bed; compensation for their injuries; lost relatives to return; financial independence; a decent place to live in, and most of all to be treated with respect and dignity, and able to access amenities with ease.

The participants were willing to talk openly about their experiences and their predicament. The willingness was accompanied by mixed emotions, such as a sense of hope, hopelessness, courage and discouragement. a sense of wanting to overcome obstacles prevailed, ‘if only’ they could get help in the form of social support. Most of what they raised pointed towards inadequate preparation for the outside world. In most instances, however, in-patient rehabilitation concentrates on physical recovery, with little or no attention to the whole person. The gap between discharge from hospital and re-entering the community was not bridged. They were sent home to fend for themselves. Of all who sustained their injuries in automobiles (n=6), who were entitled to receive compensation to live on, only one had received his, and as a result managed to make home adaptations.

The sudden and immediate nature of disruption was reflected in the way the participants engaged in denial of the reality or permanence of paralysis, namely inability to walk again. Several theories describe denial as a mechanism to ease or control uncomfortable or overwhelming thoughts (Wheeler & Lord 1991:311).

A further essential feature of living with SCI was the participants’ holding on to and never giving up on hope. The good thing about hope was its ability to empower the participants to wish for and imagine things in a way acceptable to them. The way in which participants came to terms with their situation highlighted the role of spirituality in a person’s life. A further significance was the need for social support and the effect of the negative societal attitudes experienced. The study revealed that being a person living with SCI is

characterized by relationships with others; such relationships are constituted by tension between perceptions of absence and presence. The presence and actions of others impacted on their perceptions of reality, safety and security.

The study findings reinforced other findings pertaining to living with an SCI, namely that being disabled entails social and economic hardships as well as assaults upon self-identity and emotional well being. Few disabled are economically well off, and this creates a culture of dependency in which their low status and vulnerability are reproduced (Barton 1993:239). The participants are located at the bottom of the income ladder, out of work and dependent on social welfare for survival. In addition, the participants were Black, semiliterate and unemployed. Class and race influence difficulties and responses to being disabled. They compound the experience of discrimination and oppression (Rintala, Hart, Priebe & Ballinger 1998:16).

SCI persons experience marginalization and discrimination at levels of social participation, social attitudes, independent family life, housing and transport. The participants had to contend with inaccessibility to amenities, including their own dwellings (Cock 1988). Society holds negative attitudes towards disabled persons, regarding them as less than “human”. Disability is much more than a question of health, it is not simply about constraints that arise from the physical condition, the body, and the organic disability. There is another dimension to disability and that is the disability that arises from society’s response to the physical condition, to the impairment (Goodall 1992). According to Fitzgerald (1997:408), disability is about the doors that society closes on a person with a disability – the denial of physical, mental, emotional and spiritual access to our social world. 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 (Marks 2000:206). Negative social attitudes that exist in almost every community toward people with disabilities remain a major obstacle to the social integration and rehabilitation of those who are disabled (Fitzgerald 1998:411).

The participants were concerned about being a burden to their families, and about medical complications following SCI, which are a constant threat in their lives. SCI due to trauma is an uncommon condition that has a significant impact on the injured person’s functional,

medical, psychological as well as economic well-being. Assistance from family, friends, various health care professionals and the community is vital in the adaptation process, which in this study was perceived as inadequate.

7.2.1 Rural setting: uniqueness of the investigation

The main differences with other studies are environmental variables, which include income, transportation, architectural and geographic barriers, i.e., the extent to which they were experienced were peculiar to this geographic area. The characteristics of the participants were semiliterate, unemployed Black males living in an impoverished rural community, participants one would hardly describe them as 'back on track'.

With regard to their social and economic context, the life experiences of the participants were influenced by socio-political, economic and historical factors, namely geographic location, poor infrastructure, poverty, low educational status, and unemployment of the participants and the community at large. The inadequate familial support and lack of resources were felt intensely. Families in this area have their energies consumed with eking out a meagre living and are trapped in a life of poverty and hopelessness. A perception of inadequate social support causes individuals to appraise situations as more stressful (Chan et al 2000; Elliot et al 1992).

Home visits by health professionals were not done to assess for required home modifications, such as ramps to the front door, widening of doors, toilet and bathroom, and also to encourage families to be involved in determining solutions, nor were there any follow-ups after discharge from rehabilitation units or hospital. The findings indicated that the in-patient rehabilitation did not prepare them for the outside world. Transportation issues facing the SCI persons are not addressed in the form of modified public transport. Pressure sores are still a common cause of hospitalisation.

These discrepancies led to poor reintegration into the community of the SCI persons residing in the rural communities of the OR Tambo district municipality in the Eastern Cape. Rintala et al (1998:16) maintain that if people of all racial and ethnic backgrounds have the necessary knowledge, appropriate assistance in equipment, sufficient financial

resources, and needed educational skills, and if physical and social environments are accessible, then individuals with SCI are more likely to be fully integrated. The findings of this study support Rintala et al (1998). The participants' unmet needs were suitable accommodation, care, social and financial support, accessible transport, recreation and leisure, and employment for them to enjoy a good quality of life.

The gaps in rehabilitation were identified, mainly the medical model approach with its emphasis on physical recovery, not paying much attention to the psychosocial functioning, preparation for discharge so that the persons can navigate the environment and interact successfully with society. The guidelines thus formulated were based on the holistic approach in the delivery of care to persons with SCI, which should begin with rehabilitation targeting psychosocial functioning and extends into a community support program that maintains rehabilitation.

The study found that people living with SCI were at risk, underserved and not well understood. For them, being a person living with SCI meant waiting and hoping to be given a chance to talk and be listened to, for financial independence, someone to wheel them into the house, for a glass of water, proper accommodation, acceptance and respect by the community, their needs to be considered, fair treatment and companionship. Yet, to assist people with SCI live a happy productive life, rehabilitative practice should help them enhance their beliefs about their abilities to cope with life's demands. Barnitt and Pomeroy (1995:89) regard the ultimate aim of rehabilitation as to secure "social well being or life satisfaction for an individual".

According to Brisenden (1986:177-178),

We desire a place in society, participating as equal members with something to say and a life to lead; we are demanding the right to take the same risks and seek the same rewards. Society disables us by taking away our right to take decisions on our own behalf; and therefore the equality we are demanding is rooted in the concept of control; it stems from our desire to be individuals who can choose for themselves ... we are victims of a vicious circle, for the control is denied the disabled

individual by the medical profession, social services, relatives, etc., conditions that [cause] individuals to accept a dependent status in which their life takes place by proxy.

This study portrayed the “voices” of the participants in their daily struggles. They struggle to integrate the new disabled self, and to be reintegrated to the community.

The United Nations Declaration on the Basic Human Rights of the Handicapped (Abang 1988: 75) stipulates:

- (1) Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizen of the same age, which implies first and foremost the right to enjoy a decent life' as full as possible.
- (2) Disabled persons are entitled to the measures designed to enable them to become as self-reliant as possible.
- (3) Disabled persons have the right to medical, psychological and functional treatment, including prosthetic, and orthetic appliances, to medical and social rehabilitation, aid, counseling, placement services and other services which will enable the to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration.
- (4) Disabled persons are entitled to have their special needs taken into consideration at all stages of economic and social planning
- (5) Disabled persons have the right to live with their families or with foster parents and to participate in all social, creative or recreational activities. No disabled person shall be subjected, as far as his or her residence is concerned to different treatment other than that required by his or her condition or by the improvement which he or she may derive therefrom.

7.3 LIMITATIONS OF THE STUDY

The nature of qualitative research relies on the researcher's judgement of data collection and analysis. The researcher was the main data-collection instrument. Although the admission criteria for the study had intended to include clients living with SCI in the community and thus interview them in their home environments, it was not always possible as some participants were found back at hospital having been readmitted for management of complications, so the interview setting was not the same for all participants. The fact that the participants were all males was not intended. Another limitation could have been that the researcher's gender prohibited discussing matters considered taboo. The findings are derived from a purposive convenience sampling process; therefore, the generalizability of the findings is limited. Despite these limitations, the researcher is of the opinion that the study offers enough insight into what it means to live with an SCI in a rural community.

7.4 RECOMMENDATIONS

Based on the findings of this study, the researcher makes the following recommendations for delivery of health care (practice), policy-makers, education, and further research.

7.4.1 Health care delivery system (practice)

According to Thorne (1999:401), the meaning of chronic illness is powerfully shaped and influenced by the social and political contexts in which it is enacted. The meaning dimensions of illness experience therefore include the health care system and society at large as relevant contextual environments. The study found a lack of psychological intervention during the in-patient rehabilitation for some of the participants; poor discharge planning in terms of involving the families and home adaptations, and development of social skills to be able to handle the attitudes of family and community members, which are based on fear and ignorance. Community support was lacking and their lives were compromised by poor infrastructure and lack of transportation.

In order to deal with the challenges facing the people living with an SCI, the rehabilitation programme should include alterations to physical function, body image, and self-esteem,

social and familial roles and community access, integration and participation (Kendall et al 2003:50).

Accordingly, the researcher recommends the following:

- SCI should be treated in **specialised units**, in order to develop sufficient expertise in all aspects of rehabilitation, and provide a diverse community of persons with SCI or peers, allowing the newly injured and their families to share their experience in a supportive environment, that is conducive to learning and adjustment (Bergman et al 1997:s56). In order to achieve the best functional outcomes, early transfer to a specialist centre is essential to manage their full psychological, physical and rehabilitation needs and educate them to maintain maximal independent function when they are discharged back into the community.
- **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. Holism considers the whole person, addressing the physical, social, emotional and cognitive needs. This implies that the therapeutic regimen has to involve some type of complete package relating to an individual in social context or the whole society (Barritt & Pomeroy 1995:88). The approach is centred on the experience of illness for the individual, considering all elements of illness, what is happening to the parts of the body (pathology and impairment) and also what processes are happening at the level of the person's experience (impairment and disability) and what is happening in their wider social context (handicap) (Barritt & Pomeroy 1995:91). A team approach to SCI treatment and rehabilitation is critical (Burton 2001; Carpenter 1994; Stiens et al 1997). In the holistic approach, a team delivers rehabilitative needs, with each member given equal value. The members of the rehabilitation team are the patient, doctors, SCI and rehabilitation specialists, nurses, occupational therapists, physiotherapists, social workers, counsellors (psychologist), and speech therapist, dietician and support staff.

- **A transitional rehabilitative phase**, designed to provide end-stage primary rehabilitation services, be introduced either in the client's own home or in a home-like setting away from the hospital environment (Kendall 1997:1011). The aim is to address the needs of clients in real-life situations. This home environment allows people to re-establish family relationships that have been disrupted by lengthy hospital stays, develop personal control and direction in their daily lives, hone newly acquired physical skills in a "real world" context and develop problem-solving strategies to overcome access and integration issues associated with returning home. The transitional programme should include learning to circumvent socialization barriers, hence the quality of interpersonal relationships should be addressed, income, essential public services, self-esteem, and life role for the person living with SCI (Clayton, Robert & Chubon 1994:636). The persistence of these problems emphasizes the need for long-term follow-up services.

7.4.2 Legislation and policy makers

The aim of rehabilitation is to teach patients with SCI how to achieve an optimal independent and satisfying life style in their community. Discharging patients to their own homes rather than to an institution is a measure of the effectiveness of a rehabilitation programme (Imman 1999:26).

A relevant factor in this regard is how much of the effort of the hospital team is rendered ineffective by poor provision in the community. The ways in which health care is distributed and the kinds of services deemed necessary are not always left solely to the discretion of health care personnel, but are determined within the social context. There are several restraining factors on the delivery of health care over which practitioners have no control. People living with SCI may be handicapped by social, environmental and vocational factors, which may be beyond the control of health care providers. For example, different government departments are responsible for certain aspects affecting the lives of SCI persons: the Department of Social Welfare for paying out disability grants; the Public Works Department for home adaptations and road maintenance; transport falls under the Department of Transport, and the Road Accident Fund pays out compensation for injuries

sustained involving motor vehicles. Yet, there is no legislation enforcing public transport to accommodate the disabled community.

It is therefore recommended that existing legislation on the accessibility of public buildings be rigorously enforced and legislation for public transport to be accessible to all citizens, including the disabled, be promulgated. A liaison officer should be appointed to act on behalf of SCI persons to enable them to access resources, such as home adaptations, and compensation from the Road Accident Fund.

Furthermore, the staff shortages experienced in the health services is beyond the health professionals' area of responsibility and seriously impacts on the quality of care. It is therefore recommended that the relevant policy makers and authorities improve the conditions of service in order to attract various specialists in areas of rehabilitation.

7.4.3 Education

Education as a tool to change behaviour is necessary to deal with the lack of knowledge about disabled people, particularly that they are not subhuman, and should be supported in their endeavours to lead normal lives.

- **Changing attitudes: dealing with stigma**

Overcoming stigma requires activism. Social consciousness increases as more people become aware of humanism behind the condition. Stigma can be countered by using culturally valued means in order to enable people to live culturally valued lives, and this is seen as normalization (Dewis 1989:395). In the context of this study, the participants engaged themselves in culturally accepted activities, in the form of religious activities, and helping other SCI persons whom they considered more disadvantaged. However, they were nevertheless denied other social activities.

Specially designed educational programmes are needed, particularly among younger persons. Various methods improve people's attitudes towards those who have a disability, for example, information and persuasion tend to influence the cognitive component of

attitudes; informal contact with exposure to disabled persons primarily influences behaviour; and disability simulation and role playing mainly influence the emotional aspect of attitudes. A combination of films, discussions, interviews, and role simulations was found to have a positive attitude change in high school students (Florian & Kehat 1987:57-58).

For the disabled, however, discrimination needs to be tackled rather than trying to make people aware of “what it is like to be disabled” (French 1992:264). What is needed is training in how discrimination can be prevented or dismantled by employers, organisations, and unions and how disabled people are affected by discriminatory practices. It is therefore recommended that recognised disabled trainers be approached for disability awareness training. According to French (1992:265), professionals should “listen to the voice of organizations of the disabled people and the example of awareness/equal opportunities training courses run by disabled trainers who never trivialise disability by providing so-called simulation exercises”.

Simulations become hilarious affairs to challenge and protest against discrimination (French 1992:259). During hospitalisation, visitors should be informed of the remaining capacities, as well as challenges and not barriers, and that SCI persons need help from their peers, especially young people, as traumatic SCI usually affects younger members of the community. Moreover, if the rehabilitation has been successful, people living with SCI should have enough self-confidence and adequate social skills to handle situations in the community by putting able-bodied persons at ease in their presence.

Regarding negative attitudes, several theories attempt to explain the source of negative attitudes towards deviant circumstances or conditions like physical disability. The *genetic or neurophysiological theory* suggests that the negative attitudes stem from an innate, instinctive fear of mutilated or paralysed bodies (Florian & Kehat 1987:57). According to the *psychodynamic theory*, negative attitudes towards the physical disabled arise from a perceived conscious and unconscious threat to body integrity and the self-image (Florian & Kehat 1987:57). The *sociocultural theory* states that acquired societal norms, beliefs, and values lead to an enforced social distance and a tendency to segregation between non-disabled and disabled persons. This segregation perpetuates negative attitudes towards the disabled (Florian & Kehat (1987: 57). Triechman (1980:89) points out that the

tendency to categorise people and develop expectations regarding them develops at an early age, and becomes a central feature of all interpersonal relationships. This is entrenched by children's stories, advertisements and commercials seen to reinforce the rejection, by suggesting that people who are beautiful are the most successful. To be handicapped, then, is perceived as having an undesirable difference from other people. In general, it is likely that these elements combine to produce negative attitudes toward disabled people, and attempts at modifying attitudes may need to take this into account.

- **Nursing education**

Implications for nursing education are to prepare the nurse for her role as a caregiver. Nolan and Nolan (1998:101) see the nurse's contribution to physical aspects, emotional, psychological and patient education and family. Nurses have a responsibility to coordinate and integrate multiple perspectives in developing and executing individualized patient and family centred care. Because nurses actively participate in the social and health care worlds of their clients, they can play an important role in shaping the illness experience (Thorne 1999:402).

The nurse's role should be an inspiring one, providing a sense of identity, worth, hope, and purpose in existence. The nurse's role should be that of enhancing the patient's own ability to cope. Enhancement of patients' feelings of control will help them to perceive their ability to cope. The most effective tool at the nurse's disposal is the use of self, which can be a means of healing, support, and affirmation to another (Soeken & Carson 1987:606). The offer of self serves as a conduit whereby the inner strength and hope of the nurse can flow to the patient. During rehabilitation in hospital the role of the nurse moves from an emphasis on care to a position in which she assists patients to motivate themselves to regain a measure of independent living and the ability to reintegrate themselves (Wirtz et al 1996). In so doing, they can learn to live with dignity (Chen et al 2005:257).

Nurses are required to blend quality care with the ability to help individuals to adjust emotionally and psychologically in order that they can rebuild their lives (Johnson 1995; Lucke 1999; Pellatt 2003). However, there is a lack of clarity on the role of the nurse in SCI rehabilitation, among patients and health professionals including the nurses themselves

(Pellat 2003). The rehabilitation of SCI persons takes place in several environments: intensive care units, rehabilitation units, and the community. Some SCI persons end up in surgical wards where the nursing staff were ill-equipped to provide care for such patients. The role of the nurse in rehabilitation should be emphasized. Physical aspects, emotional, psychological and patient education, including family, are important. Therefore the nursing curriculum is expected to prepare the nurses adequately for these roles. Nurses have a pivotal role to play in the psychological care of SCI individuals in rehabilitation (Nolan & Nolan 1998:102). Rehabilitation patients have within their life space – their family, friends, resources, their own perceptions of modified roles and circumstances and other various social and cultural components which have gone into fashioning their phenotype and constitutional space. It is therefore important for the nurse to have a broad base knowledge concerning these matters (Christopherson et al 1974:8). The lived experience of disability (SCI) offers important implications for clinical practice and education regarding SCI management. As practising nurses, it is important to uncover in nursing and care the meanings individuals hold relative to their lives.

7.4.4 Further research

Given the scope and limitations of this study, the researcher recommends that further research be undertaken on

- The needs and concerns of formal (nurses) and informal (family) carers of SCI persons
- Independence in bladder and bowel care, as many patients with SCI do not become continent.
- A comparison of the impact of gender and culture on life satisfaction among people with SCIs from different cultures/backgrounds in South Africa.
- A quantitative study to measure the coping styles of people living with SCI in the rural areas of South Africa.

7.5 CONCLUSION

This chapter concluded the study and discussed its conclusions and limitations, and made recommendations for practice and further research. The phenomenological approach was adopted in order to question assumptions about SCI's and investigate the participants' responses to their circumstances and care. The researcher's primary concern was to prompt health professionals to be thoughtfully aware of their responsibility in understanding and shaping the experiences of SCI persons. In this way phenomenology can achieve change, not only in perspective, but also in behaviour.

Phenomenological research originates in practice and, through careful descriptive and interpretive scholarship, enlightens practice (van der Zalm & Bergum 2000:217). Because of its focus on the detailed description of an individual's experience in the world, phenomenology is a type of inquiry that can meet the needs of nurse researchers who wish to focus their research on aesthetics, on personal ways of knowing, on questions of being, and on multiple realities (van der Zalm & Bergum 2000:217).

The phenomenological perspective enables researchers to discern relationships between human suffering and the structural contexts in which individual experience is embedded (Anderton, Elfert & Lai 1989:260). The phenomenological approach was therefore seen as appropriate to gain an understanding of living with a disability (SCI) in the context of everyday life in a rural community.

The findings of this study should benefit legislators, policy-makers, nurse educators and SCI persons and assist in building up South African society.

BIBLIOGRAPHY

- Abang, TB. 1988. Disablement, disability and the Nigerian society. *Disability, Handicap & Society*, 3(1):71-77.
- Abberly, P. 1995. Disabling ideology in health and welfare. *Disability and Society*, 10(2):221-232.
- Allen, DG. 1995. Hermeneutics: philosophical traditions and nursing practice research. *Nursing Science Quarterly*, 8(4):174-181.
- Alty, A & Rodham, K. 1998. Pearls, pith, and provocation: the ouch! factor: problems in conducting sensitive research. *Qualitative Health Research*, 8(2):275-282.
- Anderson, LA. 1985. A model of estrangement, including a theoretical understanding of loneliness. *Psychological Report*, 58:683-695.
- Anderton, JM, Elfert, H & Lai, M. 1989. Ideology in the clinical context: chronic illness, ethnicity, and the discourse on normalization. *Sociology of Health and Illness*, 11(3):253-78.
- Anells, M. 1996. Hermeneutic phenomenology: philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing*, 23:705-713.
- Anson, CA, Stanwick, DJ & Krause, JS. 1993. Social support and health status in spinal cord injury. *Paraplegia*, 31:632-638.
- Antonovsky, A. 1993. The structure and properties of the sense of coherence scale. *Social Science and Medicine*, 36:725-733.
- Ashworth, PD. 1997a. The variety of qualitative research. Part 1: Introduction to the problem. *Nurse Education Today*, 17:215-218.
- Ashworth, PD. 1997b. The variety of qualitative research. Part 2: Non-positivist approaches. *Nurse Education Today*, 17:219-224.
- Appleton, JV. 1995. Analysing qualitative data: addressing issues of validity and reliability. *Journal of Advanced Nursing*, 22:993-997.
- Appleton, JV & King, L. 1997. Constructivism: a naturalistic methodology for nursing inquiry. *Advanced Nursing Science*, 20(2):13-22.
- Atkinson, P. 1995. Pearls, pith, and provocation: some perils of parigigms. *Qualitative Health Research*, 5(1):117-124.
- Arpanantinkul, M. 2004. Midlife experiences of Thai women. *Journal of Advanced Nursing*, 47(1):49-56.

- Artinian, BM. 1998. Grounded theory research: its value for nursing. *Nursing Science Quarterly*, 11 (1):5-6.
- Azmitia, M. 2002. Self, self-esteem, conflicts and best friendships in early adolescence, in *Understanding early adolescent self and identity: applications and interventions*, edited by TM Brinthampt and RP Lipka. Albany: State University of New York Press: 166-187.
- Babbie, E. 2001. *The practice of social research*. 9th edition. Melbourne: Wadsworth.
- Babbie, E & Mouton, J. 2001. *The practice of social research*. South African edition. Cape Town: Oxford University Press. .
- Bach, CA & McDaniel, RW. 1993. Quality of life in quadriplegic adults: a focus group. *Rehabilitation Nursing*, 18 (6):364-374.
- Bailey, PH. 1997. Finding your way around qualitative methods in nursing research. *Journal of Advanced Nursing*, 25:18-22.
- Baker, C & Stern, PN. (1994) Finding meaning in chronic illness as the key to self-care. *Canadian Journal of Nursing Research*, 25 (2):23-36.
- Baker, C, Norton, S, Young, P & Ward, S. 1998. An exploration of methodological pluralism in nursing. *Research in Nursing and Health*, 21:545-555.
- Bandura, A. 1993. Perceived self-efficacy in cognitive development and functioning. *Educational Psychologist*, 28:117-148.
- Barnitt, R & Pomeroy, V. 1995. A holistic approach to rehabilitation. *British Journal of Therapy and Rehabilitation*, 2(2):87-92.
- Barton, L. 1993. The struggle of citizenship: the case of disabled people. *Disability, Handicap & Society*, 8(3):235-248.
- Barriball, JK & White, A. 1994. Collecting data using a semi-structured interview: a discussion paper. *Journal of Advanced Nursing*, 19:328-335.
- Bates, PS, Spencer, JC, Young, ME & Rintala, DH. 1993. Assistive technology and the newly disabled adult: adaptation to wheelchair use. *American Journal of Occupational Therapy*, 47:1014-1021.
- Beck,CT. 1994. Phenomenology: its use in nursing research. *International Journal of Nursing Studies*, 3(6):499-510.
- Benner, P. (ed.). 1994. *Interpretive phenomenology: embodiment, caring, and ethics in health and illness*. Thousand Oakes: Sage.
- Benner, P & Wrubel, J. 1989. The primacy of caring: stress and coping in illness and health. Belmont, CA: Addison Wesley.

- Best, JW & Kahn, JV. 1993. *Research in education*. 7th edition. Boston: Allyn and Bacon.
- Berg, A., Hallberg, IR & Norberg, A. 1998. Nurses' reflections on dementia care, the patients, the care and themselves in their daily care giving. *International Journal of Nursing Studies*, 35:271-282.
- Bergman, SB, Yarkony, GM & Stiens, SA. 1997. Spinal cord injury rehabilitation. 2. Medical complications. *Archives of Physical Medicine and Rehabilitation*, 78:S53-S58.
- Bergum, V. 1991. Becoming a phenomenological researcher, in *Qualitative nursing research: a contemporary dialogue* edited by J Morse. Newbury Park: Sage:55-71.
- Biley, AM. 1994. A handicap of negative attitudes and lack of choice: caring for inpatients with disabilities. *Professional Nurse*, 9(12):786-788.
- Bilton, T. 1986. *Introductory sociology*. London: McMillan.
- Bishop, DS (ed). 1980. *Behavioural problems and the disabled: assessment and management*. London: Williams and Wilkins.
- Boswell, BB, Knight, S, Hamer, M & McChesney, J. 2001. Disability and spirituality: a reciprocal relationship with implications for the rehabilitation process. *Journal of Rehabilitation*, 67(4):20-25.
- Botes, A 2002. Concept analysis: some limitations and possible solutions. *Curationis*, 25(3):23-27.
- Botes, A.1995. The operationalisation of a research model in qualitative methodology. *RAUCUR* 1(1):4-9.
- Boyatzis, R. 1998. *Transforming qualitative research information: thematic analysis and code development*. Thousand Oakes: Sage.
- Boyd, CO. 1993. Towards a nursing practice research method. *Advances in Nursing Sciences*, 16(2):9-25.
- Bozzaco, V. 1993. Long-term psychosocial effects of spinal cord injury. *Rehabilitation Nursing*, 18:82-87.
- Buckelew, SP, Baumstark, KE, Frank, RG & Hewett, JE. 1990. Adjustment following spinal cord injury. *Rehabilitation Psychology*, 35(2):101-109.
- Brink, H. 2001. *Fundamentals of research methodology for health professionals*. Cape Town: Juta.
- Brinsenden, S. 1986. Independent living and the medical model of disability. *Disability, Handicap & Society*, 1(2):173-179.

- Brown, DJ. 1992. Spinal cord injuries: the last decade and next. *Paraplegia*, 30:77-82.
- Bulman, RJ & Wortman, CB. 1977. Attribution of blame and coping in the "real world": severe accident victims react to their lot. *Journal of Personality and Social Psychology*, 35:351-63
- Bunting, SM. 1996. Sources of stigma associated with women with HIV. *Advances in Nursing Sciences*, 19 (2):64-73.
- Burnett, DM, Cifu, D, Kolakowsky-Hayner & Kreutzer, JS. 2001. Predicting 'charge outliers' after spinal cord injury: a multi center analysis of demographics, injury characteristics, outcomes, and rehabilitation charges. *Archives of Physical Medicine and Rehabilitation*, 82(1):114-119.
- Burns, N & Grove, S. 1997. *The practice of nursing*. 3rd edition. Philadelphia: Saunders.
- Burns, N & Grove, S. 2001. *The practice of nursing*. 4th edition. Philadelphia: Saunders.
- Burns, SA & Ditumo, JF. 2001. Establishing prognosis and maximizing functional outcomes after spinal cord injury: a review of current and future directions in rehabilitation management. *Spine*, 26(24S):S137-S145.
- Burton, C. 2000. A description of the nursing role in stroke rehabilitation. *Journal of Advanced Nursing*, 32(1):174-181.
- Burton, R. 2000. Living with stroke: a phenomenological study. *Journal of Advanced Nursing*, 32(2):301-309.
- Bracken, MB & Shepard, MJ. 1980. Coping and adaptation following acquired spinal cord injury. *Paraplegia*, 18:74-85.
- Brink, PJ & Woods, MJ. 1998. *Advanced design in nursing research*. 2nd edition. London: Sage.
- Brown, DJ. 1992. Spinal cord injuries: the last decade and the next. *Paraplegia*, 30:77-82.
- Caelli, K. 2000. The changing face of phenomenological research: traditional and American phenomenology in nursing. *Qualitative Health Research*, 10(3):366-377.
- Caelli, K. 2001. Engaging with phenomenology: is it more of a challenge than it needs be? *Qualitative Health Research*, 11(2):273-281.
- Cahill, HA. 1996. A qualitative analysis of student nurses' experiences of mentorship. *Journal of Advanced Nursing*, 24(4):791-799.
- Cahill, J. 1996. Patient participation: a concept analysis. *Journal of Advanced Nursing*, 24:561-571.

Carpenter, C. 1994. The experiences of spinal cord injury: the individuals' perspectives - implications for rehabilitation practice. *Physical Therapy*, 74(7):614-628.

Catz, A, Greenberg, E, Iztovich, M, Bluvstein, V, Ronen, J & Gelernter, I. 2004. A new instrument for outcome assessment in rehabilitation medicine: spinal cord injury ability realization measurement index. *Archives of Physical Medicine and Rehabilitation*, 85(3):399-404.

Cawley, MF, Yarkony, GR & Bergman, SB. 1997. Spinal cord injury rehabilitation. 5. Through the lifespan. *Archives of Physical Medicine and Rehabilitation*, 78 :S73-S78.

Chan, CK. 2000. How does spinal cord injury affect marital relationship? A story from both sides of the couple. *Disability and Rehabilitation*, 22(17):764-775.

Chan, CK, Lee, PW & Lieh-Mak, F. 2000a. The pattern of coping in persons with spinal cord injuries. *Disability and Rehabilitation*, 22(11):501-507.

Chan, CK, Lee, PW & Lieh-Mak, F. 2000b. Coping with spinal cord injury: personal and marital adjustment in the Hong Kong Chinese setting. *Spinal Cord*, 38:687-696.

Charmaz, K. 1990. 'Discovering' chronic illness: using grounded theory. *Social Science Medicine*, 30(11):1161-1172.

Charmaz, K. 1983. Loss of self: a fundamental form of suffering in the chronically ill. *Sociology of Health and Illness*, 5:168-195.

Charlifue, SW & Gerhart, KA. 1991. Behavioral and demographic predictors of suicide after traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation*, 72:488-92.

Clayton, KS & Chubon, RA. 1994. Factors associated with the quality of life of long-term spinal cord injured persons. *Archives of Physical and Medicine Rehabilitation*, 75:633-638.

Chen, H-Y, Boore, JRP & Mullan, FD. 2005 Nursing models and self-concept in patients with spinal cord injury: a comparison between the UK and Taiwan. *International Journal of Nursing Studies*, 42:205-272.

Chinn, PL & Kramer, MK. 1999. *Theory and nursing*. 5th edition. St Louis: Harcourt.

Christopherson, A, Coulter, PD & Wolamin, MO. 1974. *Rehabilitation in nursing: perspectives and applications*. New York: McGraw-Hill.

Christopher Reeve Paralysis: *Living with spinal cord injury*. Available on line at <http://www.christopherreeve.org/issueslist.cfm.?c=15>, p 1-5, [Accessed on 08-08-2003]

Christopher Reeves Foundation. 2004.

Chun, L, Pan, A & Wang, Y. 2003. A causal model of rehabilitation resource use for subjects with spinal cord injuries in Taiwan. *Journal of Rehabilitation Medicine*, 35:208-212.

- Clarke, A. 1998. The benefits of using qualitative research. *Professional Nurse*, 13(12):845-847.
- Clarke, A. 1999. Data collection: the research interview. *Professional Nurse*, 14(4):246-248.
- Clarke, A. 1999. Qualitative research: data analysis techniques. *Professional Nurse*, 14(8):531-533.
- Clayton, KS, Robert, A & Chubon, RA. 1994. Factors associated with quality of life of long-term spinal cord injured persons. *Archives of Physical Medicine and Rehabilitation*, 76:633-638.
- Clore, G & Jeffrey, KM. 1972. Emotional role playing, attitude change, and attraction toward a disabled person. *Journal of Personality and Social Psychology*, 23(1):105-111.
- Cobb, S. 1976. Social support as moderator of life stress. *Psychosomatic Medicine*, 38:300-314.
- Cock, J. 1988. Voices from the margin: environmental constraints experienced by spinal cord injured persons in Soweto. *The SA Journal of Occupational Therapy*, 7-15. November.
- Cock, J. 1989. Life 'Inside a shell'; a needs analysis of spinal cord-injured wheelchair users in a black South African township, Disability, Handicap.
- Cody, A. 1999. Health visiting as therapy: a phenomenological perspective. *Journal of Advanced Nursing*, 29(1):119-127.
- Cogswell, BE. 1968. Self-socialization: readjustment of paraplegics in the community. *Journal of Rehabilitation*, 11-13, 35. May-June.
- Cohen, MZ. 1987. A historical overview of the phenomenological movement. *IMAGE: Journal of Nursing Scholarship*, 19(1):31-34.
- Cohen, MZ & Omery, A. 1994. Schools of phenomenology: implications for research. In *Critical issues in qualitative research methods*, edited by JM Morse. Thousand Oaks, CA: Sage:136-153.
- Colaizzi, P. 1978. Psychological research as a phenomenologist views it. In *Existential phenomenological alternatives for psychology*, edited by R Valle & M King. New York: Oxford University Press.
- Colley, JM & Faul, AC. 1997. The psychosocial impact of pain on spinal cord injured patients. *The Social Work Practitioner-Researcher*, p100-119.
- Colyer, H. 1996. Women's experience of living with cancer, *Journal of Advanced Nursing*, 23(3):496-501.
- Concise Oxford Dictionary*. 2003. 2nd edition. Oxford: Clarendon Press.

- Coyne, IM. 1997. Sampling in qualitative research. Purposeful and theoretical sampling: merging or clear boundaries. *Journal of Advanced Nursing*, 26:623-630.
- Cormack, DFS. 2000. *The research process in nursing*. 4th edition. Malden, MA: Blackwell Scientific.
- Craig, A, Hancock, K & Dickson, H. 1999. Improving the long-term adjustment of spinal cord injured persons. *Spinal Cord*, 37(5):345-350.
- Crewe, NM & Krause, JS 1992. Marital status and adjustment to spinal cord injury. *Journal of American Paraplegia Society*, 15:14-18.
- Cusick, CP, Brooks, M & Whiteneck, GG. 2001. The use of proxies in community integration. *Archives of Physical Medicine and Rehabilitation*, 82:1018-1024.
- Cutcliffe, JR. 1999. Qualified nurses' lived experience of violence perpetrated by individuals suffering from enduring mental health problems: a hermeneutic study. *International Journal of Nursing Studies*, 36:105-116.
- Dahlberg, K, Drew, N & Nystrom, T. 2001. *Reflective lifeworld research*. Lund: Student literature.
- Davis, CG & Nolen-Hoeksema, S. 1998. Making sense and benefiting from the experience: two construals of meaning. *Journal of Personality and Social Psychology*, 75(2):561-574.
- Darbyshire, P, Diekelmann, J & Diekelman, N. 1999. Reading Heidegger and interpretive phenomenology: a response to the work of Michael Crotty. *Nursing Inquiry*, 6(1):17-25.
- Dempsey, A & Dempsey, AD. 1996. *Nursing research text and workbook*. 4th edition. Boston: Little Brown.
- Denzin, NK & Lincoln, YS. 1994. Introduction: entering the field of qualitative research, in *Handbook of qualitative research*, edited by NK Denzin and YS Lincoln. Thousand Oaks: Sage:1-17.
- Department of Health. 2003. *Spinal injury rehabilitation*. Available on-line at <http://www.doh.za/mts/reports/spinal.html>. P 1-5 [accessed on 20 November 2003]
- DeSantis, L & Ugarriza, DN. 2000. The concept of theme as used in qualitative nursing research. *Western Journal of Nursing Research*, 22(3):351-372.
- De Vivo, MJ, Kartus, PL, Stover, SL & Fine, PR. 1990. Benefits of early admission to an organized spinal cord injury care system. *Paraplegia*, 28:545-555.
- De Vivo, MJ, Richards, JS, Stover, SL & Go, BK. 1991. Spinal cord injury: rehabilitation adds life to years. *Western Journal of Medicine*, 154:606.
- De Vivo, MJ, Black, KJ, Richards, JS & Stover, SL. 1991. Suicide following spinal cord injury. *Paraplegia*, 29:620-627.

De Vivo, MJ & Richards, JS. 1992. Community integration and quality of life following spinal cord injuries. *Paraplegia*, 30:108-112.

De Vos, AS, Strydom, H, Fouche, CB & Delpont, CSL. 2002. *Research at grass roots*. Pretoria: Van Schaik.

De Witt, L & Ploeg, J. 2006. Critical appraisal of rigour in interpretive phenomenological nursing research. London: Blackwell.

Dewis, ME. 1989. Spinal cord injured adolescents and young adults: the meaning of body changes. *Journal of Advanced Nursing*, 14(5):389-396.

Diekelman, N. 2001. Narrative pedagogy: Heideggerian hermeneutic analysis of lived experiences of students, teachers and clinicians. *Advances in Nursing Science*, 23(30):53-71.

Dickinson, E. 1994. *The works of Emily Dickinson*. Ware, Hertfordshire: Wordsworth.

Dirksen, SR. 1995. Search for meaning in long-term cancer survivors. *Journal of Advanced Nursing*, 21:628-633.

Draucker, CB. 1999. The critique of Heideggerian hermeneutical nursing research. *Journal of Advanced Nursing*, 30(2):360-373.

Dunn, PA. 1990. The impact of the housing environment upon the ability of disabled people to live independently. *Disability, Handicap & Society*, 5 (1):37-52.

Durrheim, K. 2002. Research design, in *Research in practice*, edited by M Terre Blanche, and K Durrheim. Cape Town: UCT PRESS:29-53.

Eifred, S. 2003. Bearing witness to suffering: the lived experience of nursing students. *Journal of Nursing Education*, 42(2):59-67.

Eisenhardt, KM. 2002. Building theories from case study research, in *The qualitative researcher's companion* edited by M Huberman and M Miles. Thousand Oaks, CA: Sage:5-33.

Elliot, TR, Herrick, S, Witty, T, Godshall, F & Spruel, M. 1992. Social support and depression following spinal cord injury. *Rehabilitation Psychology*, 37:37-48.

Elliot, TR, Witty, TE, Herrick, S & Hoffman, JT. 1991. Negotiating reality following physical loss: Hope, depression, and disability. *Journal of Personality and Social Psychology*, 61:608-613.

Engebretson, J & Littleton, L. 2001. Cultural negotiation: a constructivist – based model for nursing practice. *Nursing Outlook*, 49(5):223-230.

Erickson, RP. 1980. Autonomic reflexia: pathology and medical management. *Archives of Physical Medicine and Rehabilitation*, 61:431-440.

- Eubanks, SP. 1990. Chronic care: a future delivery model. *Hospitals*, 90(1):42-46.
- Facts and Figures at a glance. 2001. Spinal cord injury information network.
- Farley, A. 2003. An introduction to qualitative research concepts for nurses. *Professional Nurse*, 19(3):159-163.
- Farran, CJ, Herth, KL & Popovich, JM. 1995. *Hope and hopelessness: critical clinical construct*. Thousand Oaks, CA: Sage.
- Felton, DJ & Revenson, TA. 1984. Coping with chronic illness: A study of illness controllability and the influence of coping strategies on psychological adjustment. *Journal of Consulting and Clinical Psychology*, 52:343-353.
- Ferrans, CE & Powers, MJ. 1992. Psychometric assessment of the quality of life index. *Research in Nursing and Health*, 15:29-38.
- Field, PA & Morse, JM. 1996. *Nursing research: the application of qualitative approaches*. London: Chapman & Hall.
- Fife, B. 1995. The measurement of meaning in illness. *Social Science Medicine*, 40(8):1021-1028.
- Fitzgerald, J. 1997. Reclaiming the whole: self, spirit, and society. *Disability and Rehabilitation*, 19(10):407-413.
- Fjelland, R & Gjengedal E. 1994 A theoretical foundation for nursing science, in *Interpretive phenomenology*, edited by P Benner. Thousand Oakes: Sage:3-25.
- Flannery, RB, Perry, C, Penk, WE & Flannery, GJ. 1994. Validating Antonovsky's sense of coherence scale. *Journal of Clinical Psychology*, 50(4):575-77.
- Flick, U. 2002. *An introduction to qualitative research*. 2nd edition. London: Sage.
- Florian, V & Kehat, D. 1987. Changing high school students' attitudes towards disabled people. *Health and Social Work*, 12(1):57-63.
- Formal, CS, Cawley, MF & Stiens, SA. 1997. Spinal cord injury rehabilitation. 3. Functional outcomes. *Archives of Physical Medicine and Rehabilitation*, 78:S59-S64.
- Forsberg, A, Backman, L & Moller, A. 2000. Experiencing liver transplantation: a phenomenological approach. *Journal of Advanced Nursing*, 32(2):327-334.
- Fox, S & Lantz, C.1998. The brain tumour experience and quality of life: a qualitative study. *Journal of Neuroscience Nursing*, 30 (4):245-253.

- Frank, RG, Umlauf, RL, Wonderlich, SA, Ashkanazi, GS, Buckelew, SP & Elliot, TR. 1987b. Differences in coping styles among persons with spinal cord injury: a cluster-analytic approach. *Journal of Consulting and Clinical Psychology*, 55(5):727-731.
- French, S. 1992. Simulation exercises in disability awareness training: a critique. *Disability, Handicap & Society*, 7(3):257-266.
- Frydenberg, E. 1997. *Adolescent coping: theoretical and research perspectives*. New York: Routledge.
- Fuhrer, MJ, Rintala, DH, Hart, KA, Clearman, R & Young, ME. 1993. Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injuries living in the community. *Archives of Physical Medicine and Rehabilitation*, 73:552-557.
- Garrick, J. 1999. Doubting the philosophical assumptions of interpretive research. *International Journal of Qualitative Studies in Education*, 12920:147-156.
- Gaynor, S. The long haul: the effects of home care on care givers. *Journal of Nursing Studies*, 4:208-212.
- Geanellos, R. 1998. Hermeneutic philosophy. Part 1. Implications of its use as a methodology in interpretive nursing research. *Nursing Inquiry*, 5:154-163.
- Geanellos, R. 1998. Hermeneutic philosophy. Part II. A nursing research example of the hermeneutic imperative to address forestructures/preunderstandings. *Nursing Inquiry*, 5:238-247.
- George, M. 1992. As others see us. *Nursing Standards*, 7(10):20-21.
- Gibbins, J & Thomson, AM. 2001. Women's expectations and experiences of childbirth. *Midwifery*, 17:302- 313.
- Giddens, A (ed). 1992. *Introductory sociology*. 2nd edition. London: Macmillan.
- Gift, AG. 1997. *Clarifying concepts in nursing research*. New York: Springer Publishing Company.
- Gill, M. 1999. Psychosocial implications of spinal injury. *Critical Care Quarterly*, 22(2):1-7.
- Glass, CA. 1992. Applying functional analysis to psychological rehabilitation following spinal cord injury. *Journal of the American Paraplegia Society*, 15:187-193.
- Glass, CA, Jackson, HW, Dutton, J, Charlifue, S & Orritt, C. 1997. Estimating social adjustment following spinal trauma: who is more realistic – patient or spouse? A statistical justification. *Spinal Cord*, 35:320-325.
- Glass, CA, Krishman, KR & Bingley, JD. 1991. Spinal injury rehabilitation: do staff and patients agree on what they are talking about? *Paraplegia*, 29:343-349.

Glass, CA. 1994. Psychological intervention in physical disability with special reference to spinal injury. *Journal of Mental Health*, 3:467-476.

Glass, GL, Kendall, M, Amsters, DI & Perhouse, KJ. 2004. Perceived causes of change of function and quality of life for people with long duration spinal cord injury. *Clinical Rehabilitation*, 18:164-171.

Glesne, C & Peshkin, A. 1992. *Becoming qualitative researchers: an introduction*. London: Longman.

Goodall, CJ. 1992. Preserving the dignity of disabled people. *Nursing Standard*, 7:25-28.

Goodall, J. 1988. Living options for physically disabled adults: a review. *Disability, Handicap & Society*, 3(2):173-192.

Goodall, CJ. 1995. Is disability any business of nurse education? *Nurse Education Today*, 15:323-327.

Goffman, E. 1963. *Stigma: notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.

Gouket, C, Bell, L, Tribble, D, Paul, D & Lang, J. 1998. A concept analysis of parent-infant attachment. *Journal of Advanced Nursing*, 28(5):1071-1081.

Graneheim, UH & Lundman, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nursing Education Today*, 24:105-112.

Gregg, MF & Magilvy, JK. 2001. Professional identity of Japanese nurses: bonding into nursing. *Nursing and Health Sciences*, 3:47-55.

Gullickson, C. 1993. My death nearing its future: a Heideggerian hermeneutical analysis of the lived experiences of persons with chronic illness. *Journal of Advanced Nursing*, 18:1386-1392.

Hallett, C. 1995. Understanding the phenomenological approach to research. *Nurse Researcher*, 5(2):55-65.

Hammell, KR. 1992. Psychological and sociological theories concerning adjustment to traumatic spinal cord injury: implications for rehabilitation. *Paraplegia*, 30:317-326.

Hampton, NZ & Marshall, A. 2000. Culture, gender, self-efficacy and life satisfaction: a comparison between Americans and Chinese people with spinal cord injuries. *Journal of Rehabilitation*, 66(3): 21-28.

Hancock, K, Craig, A., Tennant, C & Chang, E. 1993. The influence of spinal cord injury on coping styles and self-perceptions: a controlled study. *Australian and New Zealand Journal of Psychiatry*, 27:450-456.

- Haith-Cooper, M. 2003. An exploration of tutors' experiences of facilitating problem-based learning. Part 1- an educational research methodology combining innovation and philosophical tradition. *Nurse Education Today*, 23:58-64.
- Hanna, WJ & Rogovsky, B. 1991. Women with disabilities: two handicap plus. *Disability, Handicap & Society*, 6(1):49-63.
- Hanson, EJ. 1994. An exploration of the taken- for -granted world of the cancer nurse in relation to stress and the person with cancer. *Journal of Advanced Nursing*, 19:12-20.
- Hanson, B & Ahlstrom, G. 1999. Coping with chronic illness: a qualitative study of coping with postpolio syndrome. *International Journal of Nursing Studies*, 36:255-262.
- Hanson, S, Buckelew, SP, Hewett, J & O'Neal, G. 1993. The relationship between coping and adjustment after spinal cord injury: a 5-year -follow up. *Rehabilitation Psychology*, 38(1):41-52.
- Hardiman, RB. 1993. Teachers' experiences of their role following the implication of project 2000: a qualitative approach. *Journal of Advanced Nursing*, 18:1023-1032.
- Heidegger, M. 1962. *Being and time*. Translated by J Macquarrie and E Robison. New York: Harper Row.
- Heidt, PR. Openness: A qualitative analysis of nurses' and patients' experiences of therapeutic touch. *Image: Journal of Nursing Scholarship*, 22 (3):180-186.
- Heinemann, AW, Bulka, & Smetak, S. 1988. Attributions and disability acceptance following traumatic injury: a replication and extension. *Rehabilitation Psychology*, 33(4):195-206.
- Henning, E, van Rensburg, W & Smit, B. 2004. *Finding your way in qualitative research*. Pretoria: Van Schaik.
- Hewitt-Taylor, J. 2001. Use of constant comparative analysis in qualitative research. *Nursing Standard*, 15(42):39-41.
- Hlongwane, NM. 2002. The importance of peer counselling in helping to change attitudes of persons with disability. *Social Work*, 38(3):289-295.
- Holloway, I & Wheeler, S. 1996. *Qualitative research for nurses*. Cambridge: Blackwell.
- Holicky, R & Charlifue, S. 1999. Ageing with spinal cord injury: the impact of spousal support. *Disability and Rehabilitation*, 21 (5/6):250-257.
- Holmes, CA. 1996. The politics of phenomenological concepts in nursing. *Journal of Advanced Nursing*, 24:579-587.
- Holt, J. 2000. Exploration of hope in the Dominican Republic. *Journal of Advanced Nursing*, 32(5):1116-1125.

- Huberman, M & Miles, M. 2002. *The qualitative researcher's companion*. Thousand Oaks, CA: Sage.
- Hughes, R. 2003. The management of patients with spinal cord injury. *Nursing Times*, 99(50):38-41.
- Hughes, JA. 1990. *The philosophy of social sciences*. 2nd edition. London: Longman.
- Hughes, JT. 1988. The Edwin Smith surgical papyrus. *Paraplegia*, 26:78.
- Inman, C. 1999. Effectiveness of spinal cord injury rehabilitation. *Clinical Rehabilitation*, 13(1):25-31.
- Jakobsson, L, Hallberg, IR & Loven, L. 2000. Experiences of micturition problems, indwelling catheter treatment and sexual life consequences in men with prostate cancer. *Journal of Advanced Nursing*, 31 (1): 59-67.
- Jamerson, J, Scheimebuner, C, Bott, N, Chris, H & Hinton, K. 1999. *Heart and Lung*, 28(1):46:48.
- Janoff-Bulman, R. 1989. Assumptive worlds and the stress of traumatic events: applications of the scheme construct. *Social Cognition*, 7(2):113-116.
- Janssen, P & Friedman, B. 1995. Interaction with medical professionals following brain and spinal cord injury: relatives' reports. *South African Family Practice*, 16:514-524.
- Janssen, TWJ, van Oers, CAJM, Van der Woude, LHV & Hollander, AP. 1993. Physical strain in daily life of wheelchair users with spinal cord injuries. *Medicine and Science in Sport and Exercise*, 661-670
- Jasper, MA. 1994. Issues in phenomenology for researchers in nursing. *Journal of Advanced Nursing*, 19:309-314.
- Jasper, M. 1996. The first year as a staff nurse: the experiences of a first cohort of project 2000 nurses in a demonstration district. *Journal of Advanced Nursing*, 24:779-790.
- Joachim, G & Acorn, S. 2003. Life with a rare disease: the scleroderma. *Journal of Advanced Nursing*, 42(6):598-606.
- Johnson, BM & Webber, PB. 2001. *An introduction to theory and reasoning in nursing*. Philadelphia: Lippincott.
- Johnson, J. 1995. Achieving effective rehabilitation outcome: does the nurse have a role? *British Journal of Therapy and Rehabilitation*, 2(3):113-118.
- Johnson, B & Plant, H. 1996. Collecting data from people with cancer and their families: what are the implications? In *Nursing research an ethical and legal appraisal*, edited by L De Rauve. London: Balliere Tindall:86.

Kalimo, R & Vuori, J. 1990. Work and sense of coherence: resource for competence and life satisfaction. *Behavioural Medicine*, 16:76-89.

Kearney, MH. 2001. Levels and applications of qualitative research evidence. *Research in Nursing and Health*, 24:145-153.

Kelly, K. 2002. Hermeneutics in action: empathy and interpretive research, in *Research in practice*, edited by M Terre Blanche and K Durrheim. Cape Town: UCT PRESS: 398-420.

Kelly, K. 2002. From encounter to text: data gathering in interpretive research, in *Research in practice*, edited by M Terre Blanche and K Durrheim. Cape Town: UCT PRESS:379-397.

Kendall, E & Buys, N. 1998. An integrated model of psychosocial adjustment following acquired disability. *Journal of Rehabilitation*,16-20. July/August/September.

Kendall, MB, Ungerer, G & Dorset, P. 2003. Bridging the gap: transitional rehabilitation services for people with spinal cord injury. *Disability and Rehabilitation*, 25(17):1008-1015.

Kendall, M, Booth, S, Fronek, P, Miller,D & Geraghty, T. 2003. The development of a scale to assess the training needs of professionals in providing sexuality rehabilitation following spinal cord injury. *Sexuality and Disability*, 21(1):49-64.

Kennedy, P, Evans, MJ, Berry, C & Mullin, J. 2003. Comparative analysis of goal achievement during rehabilitation for older and younger adults with spinal cord injury. *Spinal Cord*, 41:44-52.

Kim, SJ & Kang, KA. 2003. Meaning of life for adolescents with a physical disability in Korea. *Journal of Advanced Nursing*, 43(2):145-157.

Koch, T. 1999. An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, 6(3):20-34.

Koch, T & Harrington, A. 1998. Reconceptualizing rigour: the case for reflexivity. *Journal of Advanced Nursing*, 28(4):882-890.

Koch, T. 1995. Interpretive approaches in nursing research: the influence of Husserl and Heidegger. *Journal of Advanced Nursing*, 21:827-836.

Koch, T. 1996. Implementation of a hermeneutic inquiry into nursing: philosophy, rigour, and representation. *Journal of Advanced Nursing*, 24:174-184.

Kock, J. 1989. Life 'inside the shell': a needs analysis of spinal cord-injured wheelchair users in a Black South African township. *Disability, Handicap and Society*, 4(1):3-20.

Kosowski, MMR. 1995. Clinical learning experiences and professional nurse caring: a critical phenomenological study of female baccalaureate nursing students. *Journal of Nursing Education*, 34(5):235-241.

- Krause, JS. 1998. Dimensions of subjective well-being after SCI: an empirical analysis by gender, race, and ethnicity. *Archives of Physical Medicine and Rehabilitation*, 79: 900-909.
- Kreuter, M. 2000. Spinal cord and partner relationships. *Spinal Cord*, 38:2-6.
- Kvigne, K, Gjengedal, E & Kirkevold, M. 2002. Gaining access to the life-world of women suffering from stroke: methodological issues in empirical studies. *Journal of Advanced Nursing*, 40(1):61-68.
- Layder, D. 1993. *New strategies in social research*. Cambridge, MA: Polity Press.
- Lazarus, RS. 1993. Coping theory and research: past, present, and future. *Psychosomatic Medicine*, 55:234-247.
- Lazarus, RS & Folkman, S. 1984. *Stress, appraisal, and coping*. New York: Springer..
- Leonard, VW. 1994. A Heideggerian perspective on the concept of person, in *Interpretive Phenomenology* edited by P Benner. Thousand Oaks: Sage: 43-64.
- Liggett, H. 1988. Stars are no born: an interpretive approach to the politics of disability. *Disability, Handicap and Society*, 3(3):263-275.
- Lillesto, B. 1997. Violation in caring for the physically disabled. *Western Journal of Nursing Research*, 19(3):282-296.
- Lin, P, Wang, J, Chang, S & Yang, F. 2005. Effectiveness of a discharge-planning pilot program for orthopaedic patients in Taiwan. *International Journal of Nursing Studies*, 42:723-731.
- Lincoln, YS & Guba, EG. 1985. *Natural inquiry*. Newbury: Sage.
- Lincoln, YS. 1992. Sympathetic connections between qualitative methods and health research. *Qualitative Health Research*, 2(4):375-391.
- Lindgren, C & Oermann, MH. 1993. Effects of an educational intervention on students' attitudes toward the disabled. *Journal of Nursing Education*, 32:121-126.
- Lindsey, E. 1996. Health within illness: experiences of chronically ill/disabled people. *Journal of Advanced Nursing*, 24:465- 472.
- Livneh, R & Antonak, RF. 1997. *Psychosocial adaptation to chronic illness and disability*. Gaithersburg, MD: Aspen.
- LoBiondo-Wood, G & Haber, J. 2002. *Nursing research: methods, critical appraisal and utilization*. St Louis: Mosby.
- Lohne,V & Severinson, E. 2004. Hope during the first months after acute spinal cord injury. *Journal of Advanced Nursing*, 47(3):279-286.

Long, AF, Kneafsey, R, Ryan, J & Berry, J. 2002. The role of the nurse within the multi-professional rehabilitation team. *Journal of Advanced Nursing*, 37 (1):70-78.

Louw, D & Edwards, D. 1997. *Psychology: an introduction for students in Southern Africa*. 2nd edition. Johannesburg: Heinemann.

Lowenberg, JS. 1993. Interpretive research methodology. *Advances in Nursing Science*, 16(2):57-69.

Loy, DP, Dattilo, J & Kleiber, DA. 2003. Exploring the influence of leisure on adjustment: development of the leisure and spinal cord injury adjustment. *Leisure Sciences*, 25:231-255.

Lucke, KT. 1998. Ethical implications in rehabilitation. *Nursing Clinics of North America*, 33(3):253-264.

Lucke, KT. 1999. Outcomes of nurse as perceived by individuals with spinal cord injury during rehabilitation. *Rehabilitation Nursing*, 24(6):247-253

Lustig, DC. 2005. The adjustment process for individuals with spinal cord injury: the effect of perceived premorbid sense of coherence. *Rehabilitation Counselling Bulletin*, 48(3):146-156.

Mackey, S. 2005. Phenomenological nursing research: methodological insights derived from Heidegger's interpretive phenomenology. *International Journal of Nursing studies*, 42:179-186.

Madjar, I & Walton, J. 2001. What is problematic about evidence? In *The Nature of qualitative evidence*, edited by JM Morse, JM Swanson & AJ Kuzel. Thousand Oaks: Sage:28-67.

Madjar, I & Walton, J (eds). 1999. *Nursing and the experience of illness: phenomenology in practice*. St Leonards: Allen & Unwin.

Maggs-Rapport, F. 2000. Combining methodological approaches in research, ethnography and interpretive phenomenology. *Journal of Advanced Nursing*, 31(1):219-225.

Maggs-Rapport, F. 2001. 'Best research practice': in pursuit of methodological rigour. *Journal of Advanced Nursing*, 33(3):373-383.

Maheady, DC. 1999. Jumping through hoops, walking on egg-shells: the experience of nursing students with disabilities. *Journal of Nursing Education*, 38(4):162-170.

Manigandam, C, Saravan, B, Macaden, A, Gopalan, L & Bhattacharji, S. 2000. Psychological well-being among carers of people with spinal cord injury: a preliminary investigation from South India. *Spinal Cord*, 38:559-562.

Manns, PJ & Chad, KE. 2001. Components of quality of life for persons with a quadriplegic and paraplegic spinal cord injury. *Qualitative Health Research*, 11(6):795-811.

Marks, BA. 2000. Jumping through hoops and walking on egg shells or discrimination, hazing, and abuse of students with disabilities. *Journal of Nursing Education*, 39(5):205-210.

Mavundla, TR. 2000. Professional nurses' perception of nursing mentally ill people in a general hospital setting. *Journal of Advanced Nursing*, 32(6):1569-1578.

Mays, N & Pope, C. 1995. Rigour and qualitative research. *British Medical Journal*, 311:109-112.

McBrien, B. 2006. A concept analysis of spirituality. *British Journal of Nursing*, 15(1):42-45.

McColl, MA & Rosenthal, C. 1994. A model of resource needs of aging spinal cord injured men. *Paraplegia*, 32:261-270.

McColl, MA, & Skinner, H. 1995. Assessing inter- and innerpersonal resources: social support and coping among adults with a disability. *Disability and Rehabilitation*, 17:24-34.

McColl, MA, Bickenbach, J, Johnston, J, Nishimahama, S, Schumaker, M, Smith, K, Smith, M & Yealland, B. 2000. Spiritual issues associated with traumatic-onset disability. *Disability and Rehabilitation*, 22(12):555-564.

McDonald, H & Fish, W. 2002. Pain during spinal cord rehabilitation: Client perspective and staff attitudes. *Spinal Cord Injury Nursing*, 19 (30):125-131.

McGill, VR. 1998. *An investigation of certain demographic variables, coping behaviour, and social support*, (Dissertation Abstracts). http://biblioline.nisc.com/scripts/login.dll?Frame_Navigation=PRINT_FORMATS_PR... [accessed on 12-05-2004]

McGowan, MB & Roth, S 1987. Family functioning and functional independence in spinal cord injury adjustment. *Paraplegia*, 25(40):357-65.

McMillen, JC & Cook, CL. 2003. The positive by-products of spinal cord injury and their correlates. *Rehabilitation Psychology*, 48(2):77-85.

McNamara, MS. 2005. Knowing and doing phenomenology: the implications of the critique of 'nursing phenomenology' for a phenomenological inquiry: a discussion paper. *International Journal of Nursing Studies*, 42:695-704.

McNett, SC. 1985. Social support, threat, and coping responses and effectiveness in the functionally disabled. *Nursing Research*, 36:98-103.

Mitcho, K & Yanko, JR. 1999. Acute care management of spinal cord injuries. *Critical Care Quarterly*, 22(2):60-79.

Miklaucich, M. 1998. Limitations on life: women's lived experiences of angina. *Journal of Advanced Nursing*, 28(6):1207-1215.

- Montes-Sandoval, L. 1999. An analysis of the concept of pain. *Journal of Advanced Nursing*, 29(4):935-941.
- Moore, AD, Bombardier, CH, Brown, PB & Patterson, DR. 1994. Coping and emotional attributions following spinal cord injury. *International Journal of Rehabilitation and Research*, 17(1):39-48.
- Mouton, J & Marais, HC. 1992. *Basic concepts in the methodology of social sciences*. Pretoria: Human Sciences Research Council.
- Moran, D. 2000. *Introduction to phenomenology*. London: Routledge.
- Morgan, AK. 1994. Client education experiences in professional nursing practice: a phenomenological perspective. *Journal of Advanced Nursing*, 19:792-801.
- Morris, J. 1992. Personal and political: a feminist perspective on researching physical disability. *Disability, Handicap and Society*, 7(2):157-166.
- Morse, JM. 1994. *Critical issues in qualitative research methods*. Thousand Oaks: Sage.
- Morse, JM & O'Brien, B. 1995. Preserving self: from victim to patient, to disabled person. *Journal of Advanced Nursing*, 21:886-896.
- Morse, JM & Field, PA. 1995. *Qualitative research methods for health professionals*. 2nd edition. Thousand Oaks: Sage.
- Morse, JM, Swanson, JM., & Kuzel, AJ. 2001. *The nature of qualitative evidence*. Thousand Oaks: Sage.
- Morse, JM & Singleton, J. 2001. Exploring the technical aspects of "fit" in qualitative research. *Qualitative Health Research*, 11(6):841-847.
- Morse, JM. 1994. 'Emerging from the data': the cognitive processes of analysis in qualitative inquiry, in *Critical issues in qualitative research method*, edited by JM Morse. Thousand Oaks: Sage:23-43.
- Morse, JM & Penrod, J. 1999. Linking concepts of enduring, uncertainty, suffering, and hope. *Image: Journal of Nursing Scholarship*, 31(2):145-150.
- Mouton, J. 2001. *How to succeed in your master's and doctoral studies: a South African guide and resource book*. Pretoria: Van Schaik.
- Moyle, W & Clinton, M. 1997. Phenomenological description of memory loss. *Journal of Advanced Nursing*, 26:120-125.
- Mudzi, W. 2001. Spinal injured patients' knowledge of pressure sores. *SA Journal of Physiotherapy*, 57(4):9-13.

- Mulhall, A. 2003. In the field: notes on observation in qualitative research. *Journal of Advanced Nursing*, 41(3):306-311.
- Munhall, PL & Boyd, CA. 1993. *Nursing research: a qualitative perspective*. New York: National League for Nursing.
- Murphy, M. 1999. Traumatic spinal cord injury: an acute care rehabilitation perspective. *Critical Care Nursing Quarterly*, 22(2):51-59.
- National Institute of neurological Disorders and stroke. 2003. Available at http://www.ninds.nih.gov/health_and_medical/pubs/scireport.html. P 1-5. [assessed on 05-August 2003]
- National SCI Statistical Center. 2001. *Spinal cord injury: facts and figures at a glance*. Birmingham, AL:
Retrieved November 15, 2003, from
<http://www.spinalcord.uab.edu/show.asp?durki=21446>.
- Nelson, JP. 1996. Struggling to gain meaning: *living* with the uncertainty of breast cancer. *Advances in Nursing Science*, 18(3):59-63.
- Neuton, JJ & Rubinson, L. 1996. *Research techniques for the health sciences*. 2nd edition. Boston: Allyn and Bacon.
- Newell, RJ. 1999. Altered body image, a fear of avoidance model of psychosocial difficulties following disfigurement. *Journal of advanced Nursing*, 30(5):1230-1238.
- Nielson, WR & MacDonald, MR. 1988. Attribution of blame and coping following spinal cord injury: is self-blame adaptive? *Journal of Social and Clinical Psychology*, 4:163-175.
- Nolan, M & Nolan, J. 1999. Rehabilitation, chronic illness and disability: the missing elements in nurse education. *Journal of Advanced Nursing* 29(4):958-966.
- Nolan, M & Nolan, J. 1998. Rehabilitation following spinal injury: the nursing response. *British Journal of Nursing*, 2:97-104.
- Northway, R. 1997. Disability and oppression: some implications for nurses and nursing. *Journal of Advanced Nursing*, 26:736-743.
- Nystroom, AEM & Segesten, KM. 1994. On sources of powerlessness in nursing home life. *Journal of Advanced Nursing*, 19:124-133.
- Oliver, M, Zarb, G, Silver, J, Moore, M & Salisbury, V. 1988. *Walking into darkness: the experience of spinal cord injury*. London: Macmillan.
- Oliver, M & Hasler, F. 1987 Disability and self-help: a case study of spinal injuries association. *Disability, Handicap and Society*, 2 (2):113-125.

- Oiler, C. 1982. The phenomenological approach in nursing research. *Nursing Research* 31(3):178-181.
- Orne, RM, Fishman, SJ, Manka, M & Pagnozzi, ME. 2000. Living on edge: a phenomenological study of medically uninsured working Americans. *Research in Nursing & Health*, 23:204-212.
- Omery, A. 1983. Phenomenology; a method for nursing research. *Advances in Nursing Science*, 5(2):49-63.
- Parahoo, AK. 1997. *Nursing research principles, process and issues*. London: Macmillan.
- Parse, RR. 1995. Building knowledge through qualitative research: the road less travelled. *Nursing Science Quarterly*, 8(1):10-15.
- Parse, R, Coyne, R & Smith, M 1985. The lived experience of persisting change, in *Nursing Research Qualitative Methods*. Maryland: Bray Communications:39-68.
- Partridge, C. 1994. Spinal cord injuries: aspects of psychological care. *British Journal of Nursing*, 3(1):12-15.
- Pascoe, E. 1996. The value to nursing research of Gadamer's hermeneutic philosophy. *Journal of Advanced Nursing*, 24:1309-1314.
- Pateman, B & Johnson, M. 2000. Men's lived experiences following transurethral prostatectomy for benign prostatic hypertrophy. *Journal of Advanced Nursing*, 31 (1):51-58.
- Peat, M. 1991. Community based rehabilitation – development and structure: part 1. *Clinical Rehabilitation*, 5; 161-166.
- Peat, M. 1991. Community based rehabilitation – development and structure: part 2. *Clinical Rehabilitation*, 5; 231-239.
- Pellatt, GN. 2003. Perceptions of the nursing role in spinal injury rehabilitation. *British Journal of Nursing*, 12(5):292-299.
- Peyrovi, H, Yadavar-Nikraves, M, Oskouie, SF & Bertero, C. 2005. Iranian student nurses' experiences of clinical placement. *International Nursing Review*, 52: 134-141.
- Phillips, MJ. 1990. Damaged goods: oral narratives of the experience. *Social Science and Medicine*, 30:849-857.
- Pietila, AM. 1994. Factors associated with life control in young men. *Journal of Advanced Nursing*, 20:491-499.
- Plager, KA. 1994. Hermeneutic phenomenology. In *Interpretive phenomenology*, edited by P Benner. Thousand Oaks: Sage: 65-83.

Polit, DF & Beck, CT. 2004. *Nursing research principles and methods*. 7th edition. Philadelphia: Lippincott.

Polit, DF & Hungler, BP. 1999. *Nursing research: principles and methods*. 6th edition. Philadelphia: Lippincott.

Polit, DF, Beck, CT & Hungler, BP. 2001. *Nursing research: principles and methods*. 7th edition. Philadelphia: Lippincott.

Pollock, SC. 1993. Adaptation to chronic illness: a program for testing nursing theory. *Nursing Science Quarterly*, 6(2):86.

Porter, EJ. 1998. On "being inspired by Husserl's phenomenology; reflections on Omery's exposition of phenomenology as a method of nursing research. *Advances in Nursing Sciences*, 21(1):16-28.

Porter, CP & Villarruel, A. 1993. Nursing research with African-American and Hispanic people. *Nursing Outlook*, 59-63. March/April.

Post, MWM, van Asbeck, FWA, van Dijk, AJ & Schrijvers, AJP. 1997. Services for spinal cord injured: availability and satisfaction. *Spinal Cord*, 35:109-115.

Pound, B, Bury, M, Gompertz, P & Ebrahim, S. 1995. Stroke patients' views on their admission to hospital. *British Medical Journal*, 311:18-22.

Power, PW & Dell Orto, AE. 2004. *Families living with chronic illness disability*. 1st edition. New York: Springer.

Price, B. 1996. Illness careers: the chronic illness experience. *Journal of Advanced Nursing*, 24:275-279.

Price, B. 2002. Laddered questions and qualitative data research interviews. *Journal of Advanced Nursing*, 37(3):273-281.

Price, GL, Kendall, M, Amsters, DI & Pershouse, KJ. 2004. Perceived causes of change in function and quality of life for people living with long duration spinal cord injury. *Clinical Rehabilitation*, 18:164-171.

Price, C, Makintubee, S, Herndon, W & Istre, GR. 1994. Epidemiology of traumatic spinal cord injury and acute hospitalization and rehabilitation charges for spinal cord injuries in Oklahoma, 1988-1990. *American Journal of Epidemiology*, 139(1):37-47.

Quadruplegic Association of South Africa. *Spinal cord injury information & Links* Available at <http://quad.stormet.co.za.info.htm>. p.1-4 [accessed on 11 November, 2003].

Purdy, M. 1997. Humanist ideology and nurse education: limitations of humanist educational theory. *Nurse Education Today*, 17:196-202.

- Rawnsley, MM. 1998. Ontology, epistemology, and methodology: a clarification. *Nursing Science Quarterly*, 11(1):2-4.
- Ray, MA. 1994. The richness of phenomenology: philosophic, theoretic, and methodological concerns, in *Critical issues in qualitative research methods*, edited by J Morse. Thousand Oaks: Sage: 117-113.
- Ream, E & Richardson, A. 1996. Fatigue: a concept analysis. *International Journal of Nursing Studies*, 33(5): 519-529.
- Reed, J. 1994. Phenomenology without phenomenon: a discussion of the use of phenomenology to examine expertise in long-term care of elderly patients. *Journal of Advanced Nursing* 19:336-341.
- Rhodes, DL, & Bowles, CL. 2002. Heart failure and its impact on older women's lives. *Journal of Advanced Nursing*, 39 (5):441-449.
- Richardson, M. 1997. Addressing barriers: disabled rights and the implications for nursing of the social construct of disability. *Journal of Advanced Nursing*, 25:1269-1275.
- Richer, M & Ezer, H. 2000. Understanding beliefs and meanings in the experience of cancer: a concept analysis. *Journal of Advanced Nursing*, 32 (5):1108-1115.
- Ring, L & Danielson, E. 1997. Patients' experiences of long-term oxygen therapy. *Journal of Advanced Nursing*, 26:337-344.
- Rintala, DH, Hart, KA, Priebe, MM & Ballinger, DA. 1998. Racial and ethnic differences in community integration in a community-based sample of adults with spinal cord injury. *Top Spinal Cord Rehabilitation*, 80:1-7.
- Robley, LR. 1995. The ethics of qualitative nursing research. *Journal of Professional Nursing*, 11(1):45-48.
- Rodgers, BL & Cowles, KV. 1993. The qualitative research audit trail: a complex collection of documentation. *Research in Nursing and Health*, 16:219-226.
- Ronald, JS. 1999. Parental illness and disability: a family systems framework. *Journal of Family Therapy*, 21:242-266.
- Rooney, K (ed). 2001. *Encarta Concise English Dictionary*. London: Bloomsbury.
- Rose, P, Beeby, J & Parker, D. 1995. Academic rigour in the lived experience: researchers using phenomenological methods in nursing. *Journal of Advanced Nursing*, 21:1123-1129.
- Rosenstiel, AK & Roth, S. 1981 Relationship between cognitive activity and adjustment in four spinal-cord-injured individuals: a longitudinal investigation. *Journal of Human Stress*, 7:35-43.

Rumsey, A, Clarke, A, White, P, Wyn-Williams, M & Garlick, W. 2004. Altered body image: appearance-related concerns of people with visible disfigurement. *Journal of Advanced Nursing*, 48(5):443-453.

Ryles, SM. 1999. A conceptual analysis of empowerment its relationship to mental health nursing. *Journal of Advanced Nursing*, 29(3):600-607.

Sadala, MLA & Adorno, RCF. 2002. Phenomenology as a method to investigate the experience lived: a perspective from Husserl and Merleau Ponty's thought. *Journal of Advanced Nursing*, 37(3):282-293.

Sanford, LT & Donovan, ME. 1984. *Women and Self-esteem: understanding and improving the way we think and feel about ourselves*. New York: Anchor/Doubleday.

Sandelowski, M. 1993. Theory unmasked: the uses and guises of theory in qualitative research. *Research in Nursing and Health*, 16:213-218.

Sandelowski, M. 1994. Notes on transcription. *Research in Nursing & Health*, 17:311-314.

Sandelowski, M. 1994. The use of quotes in qualitative research. *Research in Nursing and Health*, 17:479-482.

Sandelowski, M. 1995. Qualitative analysis: what it is and how to begin. *Research in Nursing and Health*, 18:371-375.

Sandelowski, M. 1998. Writing a good read: strategies for re-presenting qualitative data. *Research in Nursing & Health*, 21:375-382.

Schonherr, JW, Groothoff, JW, Mulder, GA & Eisma, WH. 2000. Prediction of functional outcome after spinal cord injury: a task for the rehabilitation team and the patient. *Spinal Cord*, 38:185-191.

Schultz, R & Decker, S. 1985. Long-term adjustment to physical disability: the role of social support, perceived control, and self blame. *Journal of Personality and Social Psychology*, 48:1162-1172.

Schnyder, U, Buchi, S, Sensky, T & Klaghofer, R. 2000. Antonovsky's sense of coherence: trait or state? *Psychotherapy and Psychosomatics*, 69:296-302.

Schutz, SE. 1994. Exploring the benefits of a subjective approach in qualitative nursing approach. *Journal of Advanced Nursing*, 20:412-417.

Schwandt, TA. 2001. *Dictionary of qualitative inquiry*. 2nd edition. Thousand Oaks, CA: Sage.

Scullion, P. 1999. Conceptualizing disability in nursing: some evidence from students and their teachers. *Journal of Advanced Nursing*, 29(3): 648-657.

- Scullion, P. 2000. Equity of access for disabled people. *Disability Issues*, 15(10):667-670.
- Shakespeare, T. 1993. Disabled people's self-organization: a new social movement. *Disability, Handicap & Society*, 8(3):249-264.
- Sedler, F 1987. Life transition theory: the resolution of uncertainty. *Nursing and Health*, 10(8):437-451.
- Sholomskas, DE, Steil, JM & Plummer, JK. 1990. Spinal cord injured revisited: the relationship between self-blame, other-blame and coping. *Journal of Applied Social Psychology*, 20:548-574.
- Silverman, D (ed). 2002. *Qualitative research: theory, method and practice*. London: Sage.
- Sjolund, BJ. 2002. Pain and rehabilitation after spinal cord injury: a case of sensory spasticity? *Brain Research Reviews*, 40:250-256.
- Skelton, R. 1994. Nursing and empowerment: concepts and strategies. *Journal of Advanced Nursing*, 19:415-423.
- Smeltzer, SC & Bare, BG. 2004. *Textbook of medical and surgical nursing*. 10th edition. Philadelphia: Lippincott.
- Soder, M. 1990. Prejudice or ambivalence? Attitudes toward persons with disabilities. *Disability, Handicap & Society*, 5(3):227-240.
- Soeken, KL & Carson, VJ. 1987. Responding to the spiritual needs of the chronically ill. *Nursing Clinics of America*, 22(3):603-611.
- Sorrell, JM & Redmond, GM. 1995. Interviews in qualitative nursing research: differing approaches for ethnographic and phenomenological studies. *Journal of Advanced Nursing*, 21:1117-1122.
- Spooner, A. 1995. A personal perspective: the psychological needs of spine-injured patients. *Professional Nurse*, 10(6):359-366.
- Stanley, H. 2003. The journey to becoming a graduate nurse: a study of the lived experience of part-time post-registration students. *Nurse Education in Practice*, 3:62-71.
- Stew, G. 1996. New meanings: a qualitative study of change in nursing education. *Journal of Advanced Nursing*, 23:587-593.
- Stensman, R. 1994. Adjustment to traumatic spinal cord injury. A longitudinal study of self-reported quality of life. *Paraplegia*, 32:416-422.
- Stewart, JR. 1996. Applying Beck's cognitive therapy to Livneh's model of adaptation to disability. *Journal of Applied Rehabilitation Counselling*, 27 (20):40-45.

- Stiens, SA, Bergman, SB & Formal, CS. 1997. Spinal cord injury rehabilitation. 4. Individual experience, personal adaptation, and social perspective. *Archives of Physical Medicine and Rehabilitation*. 78:S65-S72.
- Stover, SL. 1995. Review of forty years of rehabilitation issues in spinal cord injury. *Journal of Spinal Cord Medicine*, 18(3):175-182.
- Strauss, A & Corbin, J. 1998. *Basics of qualitative research*. Thousand Oaks: Sage.
- Streubert, HJ & Carpenter, DR. 1999. *Qualitative research in nursing advancing the humanistic imperative*. 2nd edition. Philadelphia: Lippincott.
- Stuifbergen, AK, Becker, HA, Ingalsbe, K & Sands, D. 1990. Perceptions of health among disabled adults with disabilities. *Health Values*, 14(2):18-26.
- Sullivan, J. 1990. Individual and family responses to acute spinal cord injury. *Critical Care Nursing Clinics of North America*, 2(3):407-414.
- Sundin, K, Norberg, A & Jansson, L. 2001. The meaning of skilled care providers' relationships with stroke and aphasia patients. *Qualitative Health Research*, 308-321.
- Tanyi, RA. 2002. Towards clarification of the meaning of spirituality. *Journal of Advanced Nursing*, 39(5):500-509.
- Taylor, ES. Adjustment to threatening events: a theory of cognitive adaptation. *American Psychologist*, 38:1161-1173.
- Terch, R. 1990. *Qualitative research, analysis types and software tools*. New York: Falmer Press.
- Terre Blanche, M & Durrheim, K. (eds.). 2002. *Research in practice, applied methods for social sciences*. Cape Town: UCT PRESS.
- Thelan, LA, Urden, LD, Lough, ME & Stacy, KM. 1998. *Critical care nursing, diagnosis and management*. 3rd edition. St. Louis: Mosby.
- Thibodeau, J & MacRae, J. 1997. Breast cancer survival; a phenomenological study. *Advances in Nursing Sciences*, 19(4):65-74.
- Thomas, L & Mulhern, K. (eds.). 1994. *Link to life – spinal cord injury*. London: Box tree central.
- Thompson, SZ & Janigan, AS. 1988. Life schemes: a framework for understanding the search for meaning. *Journal of Social and Clinical Psychology*, 7(23):260-280.
- Thorne, SE 1991. Methodological orthodoxy in qualitative nursing research. *Qualitative Health Research*, 1(2):178-199.

- Thorne, S, Kirkham, SR & MacDonald-Emes, J. 1997. Interpretive description: a non-categorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20:169-177.
- Thorne, B, Dykes, A, Gunnars, B & Hallberg, IR. 2003. The experiences of older people living with cancer. *Cancer Nursing*, 26(2):85-96.
- Thorne, SE. 1999. The science of meaning in chronic illness. *International Journal of Nursing Studies*, 36:397- 404.
- Tooth, LR, Ottenbacher, KJ, Smith, PM, Illig, SB, Linn, RT & Granger, CV. 2004. Satisfaction with medical rehabilitation after spinal cord injury. *Spine*, 29(2):211-219.
- Tooth, L, McKenna, K & Geraghty, T. 2004. Rehabilitation outcomes in traumatic spinal cord injury in Australia: functional status, length of stay and discharge setting. *Spinal Cord*, 41:220-230.
- Trendall, J. 2000. Concept analysis: chronic fatigue. *Journal of Advanced Nursing*, 32(5):1126-1131.
- Triechmann, RB. 1980. *Spinal cord injuries: Psychological, social, and vocational adjustment*. California: Pergamon Press.
- Triechmann, RB. 1992. Psychosocial research in spinal cord injury: the state of the art. *Paraplegia*, 30:58-60.
- Vaarto, H & Leino-Kilpi, H. 2005. Nursing advocacy: a review of the empirical research 1990-2003. *International Journal of Nursing Studies*, 42:705-714.
- Van der Walt, D. 2004. *Assumptions*, paper presented at the Research Seminar, held at the University of South Africa, Pretoria, on 10-13 May 2004, p.1-10.
- Van der Zalm, JE & Bergum, V. 2000. Hermeneutic-phenomenology: providing living knowledge for nursing practice. *Journal of Advanced Nursing*, 31(10): 211-218.
- Valle, R. (ed). 1998. *Phenomenological inquiry in psychology: existential and transpersonal dimensions*. New York: Plenum Press.
- Van Manen, M. 1990. *Researching lived experience*. Albany, NY: University of New York Press.
- Van Niekerk, AS. 1995. Depressive symptomatology amongst South African youth with traumatic spinal cord injuries. (Dissertation Abstracts).
[http://biblioline.nisc.com/scripts/login.dll?Frame_Navigation=PRINT_FORMATS_PR...\[accessed on 12-05-2004\]](http://biblioline.nisc.com/scripts/login.dll?Frame_Navigation=PRINT_FORMATS_PR...[accessed on 12-05-2004])
- Vithal, R & Jansen, J. 2002. *Designing your first research proposal*. Cape Town: Juta.

- Wallerstein, N. 1992. Powerlessness, empowerment, and health: implications for health promotion program. *American Journal of Health Promotion*, 6 (3):197-205.
- Walters, AJ. 1995. The phenomenological movement: implications for nursing research. *Journal of Advanced Nursing*, 22(4):791-799.
- Walters AJ. 1994. The comforting role in critical care nursing practice: a phenomenological interpretation. *International Journal of Nursing Studies*, 31(6):607-616.
- Walter, S. 2001. *The phenomenological experience of sexuality of males with spinal cord injury*. (Dissertation Abstracts).
http://biblioline.nisc.com/scripts/login.dll?Frame_Navigation=PRINT_FORMATS_PR... [accessed on 12-05-2004].
- Waters, RL, Sie, IH & Adkins, R. 1995. Rehabilitation of the patient with a spinal cord injury. *Orthopedic Clinics of North America*, 26(1):117-122.
- Waters, JD. 1987. Learning needs of spinal cord-injured patients. *Rehabilitation Nursing*, 12(6):309-312.
- Wheeler, S & Lord, L. 1999. Denial: a conceptual analysis. *Archives of Psychiatric Nursing* XIII (6):311-320.
- Wehmeier, S (ed). 2001. *Oxford Advanced Learner's Dictionary*. Oxford: Oxford University Press.
- Wellard, S. 1998. Construction of chronic illness. *International journal of Nursing Studies*, 35:49-5.
- Whitehead, D. 2002. The academic writing experiences of a group of student nurses: a phenomenological study. *Journal of Advanced Nursing*, 38(5): 498-506.
- Whittemore, R, Chase, SK & Mandle, CL. 2001. Validity in qualitative research. *Qualitative Health Research*, 11(4):522-537.
- Wilde, V. 1992. Controversial hypotheses on the relationship between researcher and informant in qualitative research. *Journal of Advanced Nursing*, 17:234-242.
- Wilson, HS. 1989. *Research in nursing*. 2nd edition. New York: Addison-Wesley
- Wilson, HS & Hutchinson, SA. 1991. Triangulation of qualitative methods: Heideggerian hermeneutics and grounded theory. *Qualitative Health Research*, 1(2):263-276.
- Wimpenny, YP & Gass, J. 2000. Interviewing in phenomenology and grounded theory: is there a difference ? *Journal of Advanced Nursing*, 31(6):1485-1492.

- Wineman, NM, Durand, EJ & Steiner, RP. 1994. A comparative analysis of coping behaviours in persons with multiple sclerosis or a spinal cord injury. *Research in Nursing and Health*, 17:185-194.
- Winter, PL & Keith, RA. 1988. A model of outpatient satisfaction in rehabilitation. *Rehabilitation Psychology*, 33(3):131-142.
- Wirtz, KM, LaFavor, KM & Ang, R. 1996. Managing chronic spinal cord injury: issues in critical care. *Critical Care Nurse*, 16(4):24-35.
- Woelk, GB. 1992. Cultural and structural influences in the creation of and participation in community health programs. *Social Science Medicine*, 35(4):419-424.
- Womble, DM. 2004. *Introductory mental health nursing*. 1st edition. Philadelphia: Lippincott, Williams & Wilkins.
- Wortman, CB & Silver, RC. 1989. The myths of coping with loss. *Journal of Consulting and Clinical Psychology*, 57(3):349-357.
- Yamashita, M. 1993. Spousal separation and its impact on women's mental health: a study of Japanese corporate transfers. *Journal of Advanced Nursing*, 18:1515-1523.
- Yarkony, GM, Bass, M, Keenan, V & Meyer, JR. 1985. Contractures: complicating spinal cord injury. Comparison between spinal cord centre and general hospital acute care. *Paraplegia*, 23:265-271.
- Yarkony, GM, Formal, CS & Cawley, MF. 1997. Spinal cord injury rehabilitation.1. Assessment and management during acute care. *Archives of Physical Medicine and Rehabilitation*, 78:S46-S52.
- Yegdich, T. 2000. In the name of Husserl: nursing in nursing of pursuit of the things-in-themselves. *Nursing Inquiry*, 7:29-40.
- Yazictoglu, K, Gunduz, S, Ozgul, A, Alaca, R & Arpacioğlu, O. 2001. Nursing care in spinal cord injuries in Turkey. *Spinal Cord*, 39:47-50.
- Yerxa, EJ & Locker, SB. 1990. Quality time use by adults with spinal cord injuries. *The American Journal of Occupational Therapy*, 44(4):318-326.
- Yoshida, KK. 1993. The reshaping of self: a pendular reconstruction of the identity among individuals with traumatic spinal cord injury. *Sociology of Health and Illness*, 15:217-245.
- Yoshida, KK. 1994. Institutional impact on self concept among persons with spinal cord injury. *International Journal of Rehabilitation Research*, 17:95-107.
- Young, E. 1999. *Gunshot-Induced Spinal Cord Injury*. Part 1 Care, cure, community. New Jersey: W.M Keck center for Collaborative Neuroscience. Available at http://carecure.rutgers.edu/spinewire/Archives/gunshot_1.html. P. 1-6. [Accessed on 20-11 2003]

Young, A, Taylor, SB & Mclaughlin-Renpenning, K. 1996. *Connections: nursing research, theory, and practice*. St Louis. Mosby.

Younger, JB. 1995. The alienation of the sufferer. *Advances in Nursing Science*, 17(4):53-72.

Zarb, G. 1992. On the road to Damascus: first steps towards changing the relations of disability research. *Disability, Handicap & Society*, 7(2):125-138.

Zimmerman, MA & Rappaport, J. 1988. Citizen participation, perceived control, and psychological empowerment. *American Journal of Community Psychology*, 16(5) 725-750.

Appendix 1 (a)

University of Fort Hare
Nursing Sciences
PO Box 1054
East London
5200
27 May 2004

The Member of the Executive Council
Department of Health
Private Bag X 0038
Bisho
5608

Attention: The Superintendent General

Dear Sir

REQUEST TO CONDUCT RESEARCH

I wish to request permission to conduct a research study in the Eastern Cape Province. The area of interest is rehabilitation of spinal cord injuries. The title of my study is: *The individuals' experiences of traumatic spinal cord injuries*.

The purpose of the study is to allow the research participants to tell their 'stories' so that a model of support can be developed. I intend collecting data through research interviews, at the participants' homes. I will also need access to hospital records in order to trace where possible participants could be found initially. After collection of data, access to records will be needed only for those who actually took part in the study, so as to get information about the level of injury, date and time of injury.

The study will not influence the medical care of the participants. The participant will be assured of voluntary participation, confidentiality, and that they would retain the right to terminate their involvement in the study at any time should they so wish.

I also request any available guidelines on ethical requirements for conducting research in the province. A research report will be made available to the Eastern Cape Department of Health.

I trust that my request will be considered favourably.

Yours truly

Nkosazana Magenuka
Doctoral student: University of South Africa

Appendix 2 (a)

Department of Nursing
University of Transkei
Private Bag X1
Unitra
5117

25-06-2005

The Head
Bedford Orthopaedic Hospital
Mthatha

Dear Professor McConnachie

PERMISSION TO CONDUCT A STUDY IN THE INSTITUTION

I am conducting a study on spinal cord injured people, after they have been discharged from hospital, following the initial admission after the accident. The purpose of the study is to give them an opportunity to tell their experiences pertaining to living with a spinal cord injury, using a wheelchair in the community.

There are three categories of such individuals within the institution:

1. those who are working
2. those who attend physiotherapy coming from home
3. those who have come back and been re-admitted

The study has been approved by the Provincial Ethics Committee. I am bound to abide by the ethical principles, when conducting the study. I refer particularly to the issue of protection of the rights of those who might participate or actually participate in the study.

Thank you in anticipation

N Magenuka

APPENDIX 3

**UNIVERSITY OF SOUTH AFRICA
Health Studies Research & Ethics Committee
(HSREC)
College of Human Sciences
CLEARANCE CERTIFICATE**

Date of meeting: **17 September 2004** Project No: **301-756-7**

Project Title: **The lived experiences of spinal cord injured (SCI) people**

Researcher: **Ms SN Magenuka**

Supervisor/Promoter: **Prof TR Mavundla**

Joint Supervisor/Joint Promoter:

Department: **Health Studies**

Degree: **D Litt et Phil (Health Studies)**

DECISION OF COMMITTEE

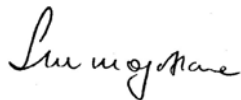
Approved

Conditionally Approved

Date:



**Prof TR Mavundla
RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**



**Prof SM Mogotlane
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

PRESUPPOSITIONS

Before embarking on a project Valle and King (1978 (55) advise phenomenologists to ask themselves or interrogate their presuppositions. Questions that one may use for the interrogation are suggested and were used in preparation for this study. My responses are recorded below as on 17 June 2004.

Question: Why am I involved with this phenomenon?

Response: - Because of my experiences – negative ones at that; and
- the feeling that provision of resources to rehabilitate them are inadequate.

Q: How might the constituents of my personal personality condition my selection of this particular phenomenon?

R: I am a very empathic person

Q: How might my personal inclinations and predisposition as a researcher influence or even bias what I investigate?

R: I could choose participants who are worse off than others (indeed, my choice of rural persons).

Q: What are the hidden gains I might acquire in investigating it in this way?

R: - Personal gain and prestige (obtain a higher qualification).
- Unpack the moral, ethical, religious, political and economic issues involved in their lives.

My presuppositions based on previous experience with spinal cord injuries (what I had seen and read) that I bring to the research are: if I were to sustain an SCI I would probably:

- find someone to blame for the accident
- have problems with activities of daily living

- feel hopeless; my dreams had been shattered, not able to lead a life I had hoped for
- perhaps not want to meet old friends/mixed feelings, jealousy, envy that they can go wherever they like and do things I could no longer engage in,
- feel there is no light at the end of the tunnel
- find resources inadequate
- be grateful to the medical/health professionals for saving my life
- be bothered about the vigilance I have to keep – physical condition, skin, contractures, etc

SPECIFIC STORIES RELATED TO PEOPLE LIVING WITH AN SCI

For the purposes of this study, I picked two that left an everlasting impression on me.

I will refer to the first one as ***James' story***.

It started late one afternoon when a client who was due to be taken to a specialised orthopaedic centre for a “check up” the following day had not arrived at the small mission hospital I was working at. It had not been explained to me how he should have come. For some reason, the person in charge of the Outpatients Department asked me to go with the ambulance driver and fetch the gentleman from home. The first thing that struck me was that the home was perched on a sloping hillside, with no road leading to the home except an insignificant footpath. We stopped in front of a hut, and by that time it was dusk and the only occupant was our man, who was very pleased to see us. He had been sitting in the wheelchair for the whole day with nobody else at home as they had gone to a cultural ceremony (*umgidi*) somewhere in the village. In his words, no one had been prepared to miss the occasion “for the sake of a cripple”. For the whole day he had had only porridge as a meal in the morning as was evident from the plate that was still there next to him, no water, nothing. No wonder he had developed pressure sores and a urinary infection. There was an unpleasant smell. What hurt me most was that James would most likely have remained in that malfunctioning wheelchair until the next morning, with the door wide open, as he was unable to wheel himself. Worse still, he would have missed his appointment and an opportunity of getting another wheelchair.

The second one is ***Gladys and John's story***.

This time I was more senior, and was in charge of the afternoon-evening shift. An obviously disgusted enrolled nurse came to report that there was a mother who was refusing to stay overnight, as was the practice, while her child was being kept for re-hydration and observation. The nurse added, "*Akamfuni lomntana*" ("she does not want this child"). The mother was brought and did not appear to "hate" the child but displayed extreme anxiety. "Ma'am, I cannot stay under any circumstances because my husband will spend the night outside — he is paralysed." So the story unfolded that the man was entirely dependent on her for everything. She had to carry him each time. For example, every morning so that he could get some air, and bring him in when the weather changed or carry him to another spot that provided some shelter. John did not have a wheelchair; had never had one and did not even receive a disability grant. He had previously been a farm labourer who had sustained his injuries by falling off the back of a lorry, perched on top of wooden blocks.

I have taken this opportunity to tell their stories, and what it means for them to live with an SCI in a rural setting.

Classification of Spinal Cord Injuries (SCI)

The classification is based on sacral sparing definition, which is said to be present if motor function or sensation is considered to be present at the anal mucocutaneous junction when a rectal examination is performed (Yarkony, Formal & Cawley 1997:S48). Spinal cord injuries are classified as either complete or incomplete.

Complete spinal cord lesion

A spinal cord 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 2003:39). The patient lacks sensory function, position sense and voluntary activity below the lesion. These patients have the worst prognosis for recovering neurologic function (Burns & Ditumo 2001:S138; Laskowski-Jones 1993:2).

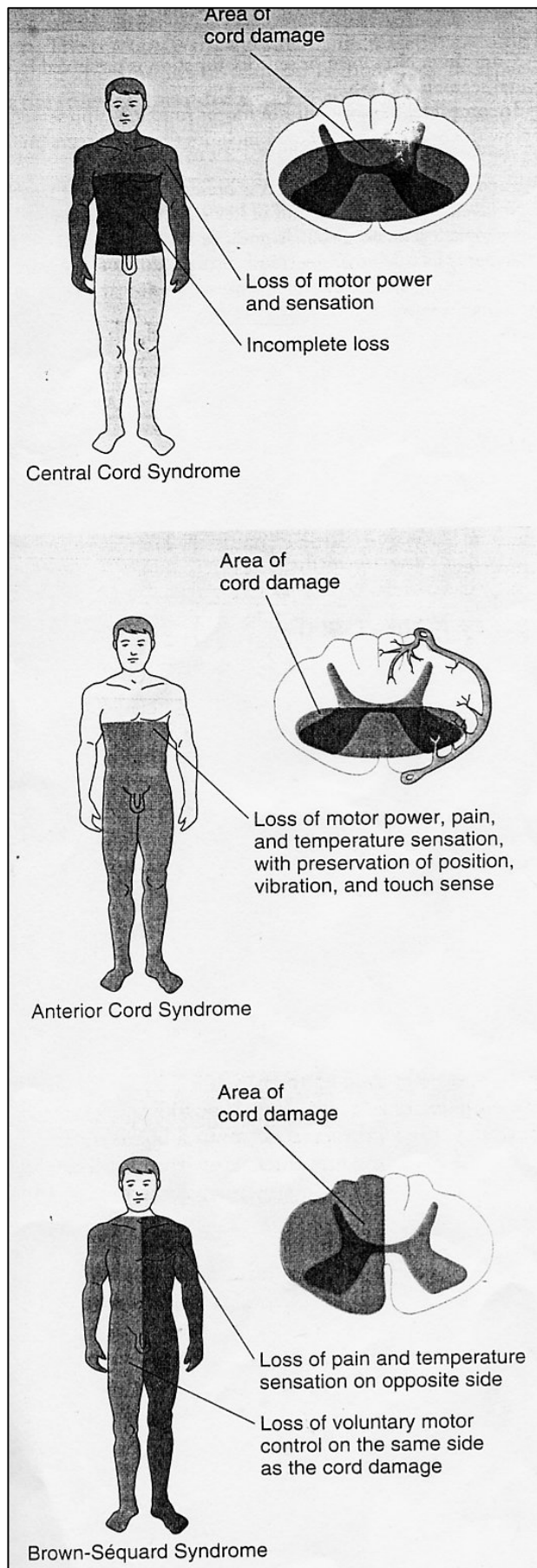
An incomplete SCI means that parts of the spinal cord at the level of the lesion are intact, some sensory, proprioceptive (position sense) or motor impulses can still travel up and down the cord. How much sensory/motor function is lost depends on the size and location of the spinal cord lesion. A combination 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 syndromes of the SCIs. Examples of incomplete spinal cord lesions include:

Central cord syndrome is due to a lesion or oedema of the central cord, almost exclusively in the cervical area. Motor deficits and sensory loss are more pronounced in the upper extremities compared to the lower sensory extremities. According to Burns and Ditumo (2001:S140), 57% to 86% of patients with this syndrome will independently ambulate.

Anterior cord syndrome. This is the most common form of incomplete lesion and is characterized by loss of pain, temperature, and motor function noted below the level of the lesion; light touch, position and vibration sensation remain intact. This may occur as a result of hyperflexion of the cord and the involvement of the anterior spinal artery, spinothalamic and corticospinal tracts, while sparing the posterior columns. It occurs

after a high-velocity impact trauma (Hughes 2003:39). Motor recovery is thought to be significantly less in these patients in comparison with other patients who have incomplete SCI (Burns & Ditumo 2001:S140).

Brown-Sequard syndrome (lateral cord syndrome) is characterized by ipsilateral paralysis, together with ipsilateral loss of touch, pressure, and vibration as well as contralateral loss of pain and temperature. The prognosis is also favourable with this syndrome, and almost all patients will ambulate successfully (Burns & Ditumo 2001:S140). Commonly seen in stabbing or gunshot injuries (Hughes 2003:39). Figure: Appendix 6, on page 3, showing the areas of damage incomplete SCI.



Incomplete SCI

Source: Smeltzer & Bare (2004:1927).

Interview

I= Researcher

P= Participant

I: *Ndiyabulela ngokuba undinika elithuba lokuba sincokole [ewe,ewe]. Ndicela ukuba ukhe undixelele ukuba kunjani ukuba ngumntu okhubazeke ngolohlobo apha ekuhlaleni?*

Thank you for giving me your time so that we can sit and talk (yes, yes). Can you explain to me what it means to live with a spinal cord injury in the community?

P: *Mama ubom nje ngoba ndaba kule meko, eh, eh ndibuva bungcono kakhulu ngoku. Kodwa (voice louder) ---- ukwehlelwa kwam yile ngozi! (long pause), zange ndiyamkele, ibe zange ndiyicinge nokuyicinga uba ndinganje (silence). Kwathi ke ngenxa yentshumayelo yabantu benkonzo, ndakwamkela ukuhlala esitulweni.(cwaka ithuba elide, ngathi uyacinga). Eh ... ukuhlala esitulweni, eh, yenye yezinto ezibuhlungu kakhulu, akululanga ngoba xa usestulweni ukhangeleka ungabalulekanga ebantwini. Zizinto ezidala ukuba abanye abantu ke ba ngayamkeli. Ngakumbi xa ubuhamba ngenyawo usuke ubone se uhleli phantsi, yenye yezinto ebethayo ebomini bakho, ngoba unendawo ofuna ukufikelela kuzo, ukule meko ke ngoku----iyabetha lo nto. Kodwa ndathi mna ndakuba kule meko ndafumanisa ukuba ndiye ndakhula kwilizwi lika Thixo. Ndiye ndithi noba ndisengxingweni enzima ndi qonde ukuba ngomnye umhla ndakuba semekweni entle kuba ubomi endibu chithe kule-wheelchair andisakubu phila kwixesha elizayo (wathi cwaka esezingcingeni, ngathi kutha qatha loo mihla yobu nzima ebekhe ayifumane).*

Ma'am, life --- since I became like this, eh, eh, I see it now as much better. But (voice louder) when the accident happened (pause), I never accepted it nor expected it could be like this (silence). I had not accepted this ... but with sermons, I accepted being in a wheelchair. Church members kept on preaching to me, and I grew in God's Word (long silence, as though deep in thought).

Being in a wheelchair is one of the most hurtful experiences, it is not always easy, like people look down upon you, you are not treated with respect --- eh --- that is why other people never accept this situation, especially that you were walking the next thing you

find yourself sitting in this chair --- this hits hard, as there are places you would like to get to, here you are now like this, it is really hard. Growing in God's Word helps me a lot, even if I am in a difficult situation, sitting in a dark corner, I do realize that it won't be like this after this life, I will be in a better place, as the life as I experience now in this wheelchair will not be the same... (long pause, looking down, as if reliving the situation when he drew strength from his faith, in order to cope with living with a spinal cord injury).

I: *mh,mh, ifamily yakho ----*

Mh, mh, what about your family?

P: *Abazali bam abasekho, ndino brother wam otshatileyo ohlala kwenye indawo. Ndiya-renta apha lom khukhu.*

My parents have both passed on, I have a married brother who lives elsewhere, it is difficult to visit him. I am renting this place – a shack (silence).

I: If you were to meet someone who has just experienced the injury what would you tell them?

P: I would encourage them to be strong and trust God, have confidence in themselves not to pity themselves, even when people are feeling sorry for them, they should not be lazy just because they are unable to walk, ... even from a wheelchair, there are many things that one can do, using their hands, the problem is just walking, your mind is working. I mean I support people that they should be strong and move on and not give up because they think their life has ended just because they can not walk, eh, there is nothing much, it's no big deal, eh, I attend conventions, and do other things, eh, yes, yes [emphasizing] for instance standing over the grave and conduct a burial and preach just like other people. I am a person like other people, I am just like you [laughs] I am gifted with my hands I even repaired a wheelchair for one of us [long pause], that one is neglected by her family...it is very sad ... silence.

I: Earlier you mentioned that you are undermined by other people, is there a story that you can perhaps relate?

P: Yes! I have stories about persons using wheelchairs, we are indeed undermined, we can't even move freely, in town people think we have no right to be there, they say 'these people are a nuisance' they will not step aside for us, I have even inserted a bell in mine (activated the bell) so as to warn them. Even then they are talking, 'we are tired of these people'. Taxis! they don't pick us, that is why we travel on foot, they say we waste their time --- those things hurt us---things like that

I: mh mh (encouraging)

P: Another problem we are facing --- our dwellings we can not get in because of these wheelchairs, such that at times you find yourself thinking, hey! If only God had taken me from this world, I would not be facing this, [silence].

Yet, one can say these are things that make us strong. Another concern – we do not have a place to live, eh, that is, we have no accommodation, and the problem is even if we are trying to raise the issue in a meeting, nobody listens, they talk over our heads, because we don't jump up and down like others when they are making their contributions so with us it is just, 'forget about those' and that will be it. Even the little that the government gives us, you see, some are never taken out because the door is like this (demonstrating a steep) and what they do will take them out only to go and receive the disability grant, and then they take the money for themselves, and do what ever, even by alcohol, the disabled person does not enjoy his money- don't even buy him food – not benefiting anything. It hurts us very much – these are the things that government needs to follow up closely on physically challenged people---because we have a huge problem like that ... I have tried ...

There is a gentleman like this here at (mentions area) who is treated like that, his money is taken --- look, even now he has been put in a place to rent --- so much money --- just imagine such an amount --- renting and the rest is taken away. I want to stress this to the government as you are already involved, I must say we appreciate this effort, it is like a new beginning, there is a need to keep in touch with us, and see for yourself our circumstances and how some of us are abused by their own people (looks at me with sadness in his eyes – I am overwhelmed)

I am prepared to get my friends who are sitting at home with nothing to do, then we can make a lot of things and make money so that we do not depend on the grant. I wish the government could support us as a group. We should be given accommodation, and not put away – we should also be given sites and live within the community, I am saying that we should not be put aside as if we are --- eh, lepers or certain kinds of diseases --- eh – yes, we should be with other people, it must be understood that maybe I want something --- for instance I want to climb up here (pointing at a steep slope in front of his shack), then I can call, “Young man, can you please help me?” Those are the things we want to be within communities and get used to other people --- we really need accommodation, so that we don’t stay in hospitals or in hospices – you name it, where physically challenged people are kept, we want to get used to the living conditions of the outside world, live independently.

I: If you were to summarise your life what would you say?

P: Yes --- my life – eh, since I got bound to this chair, --- there are many things that I notice and I am grateful for in my life, because, eh, God heard my plea, I have my helper, my other half, my wife, eh getting a wife while using a wheelchair is not easy, one of the most difficult things, my first wife left me. I am able to --- something I --- I --- (could not get the right word) – the support I get from the government I try to live within I don’t do anything beyond my monthly allowance - -- eh, I --- if in life, I would find a place to stay, I think, --- I would have a better life, I could feel like a person --- yes a strong one --- in my life ...

I: Thank you for your time. (Tape turned off.)