

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

In Chapter 1, the background and problem, purpose, objectives, research approach and significance of the study were described. As part of the discussion of the background to the problem, the researcher referred to literature regarding the rehabilitation of PLWSC, the impact of disability as a result of SCI and the challenging reality of reintegrating PLWSC into their communities. In this chapter the literature on community participation by PLWSC is reviewed in order to provide an overview of factors influencing the process of renewed participation.

An electronic and manual literature search was conducted to identify the literature available on the various facets of the topic and to select relevant resources for the review. The search was performed using various electronic databases: Medline, Cinahl, Science direct, PEDro, and Pubmed. The Google scholar search engine was also utilised. Keywords used included spinal cord injury, rehabilitation outcome, community participation, functional outcome, disability and outcomes research. The search was limited to resources in the English language and was conducted over the period January 1988 to July 2009. The researcher also searched the reference lists of relevant articles, and particular resources were subsequently found on-line, through an inter-library loan and/or in the archives of the health science library of the University of Pretoria. The search strategy is illustrated in Table 2.1.

Table 2.1: Literature search strategy

Database(s)	Keywords	Cut-off date of articles included in the search	Limitation (e.g. language, human)
- Science Direct - Ovid - PubMed - Medline, - Cinahl, - PEDro, - Google Scholar	- spinal cord injury, - rehabilitation outcome, - community participation, - functional outcome, - disability and - outcomes	January 1988 to July 2009	- English language - Human subject

This literature review begins with an overview of the epidemiology of SCI, indicating the global nature of the problem. The overview is followed by a discussion of the International Classification of Functioning Disability and Health (ICF) (WHO, 2001a) as the disablement model underpinning the conceptual framework of this study. Factors influencing community participation are discussed within the theoretical framework and the various tools used for measuring community participation are presented using the same framework. The literature review is presented according to the following non-exhaustive sub-topics that are derived from the research objectives, and which encapsulate the essence of the study:

- Epidemiology of SCI
- Background to the conceptual framework of this study
- Factors influencing the community participation by PLWSCI
- A review of the measures of community participation following SCI.

The outline of the literature review is presented schematically in Figure 2.1.

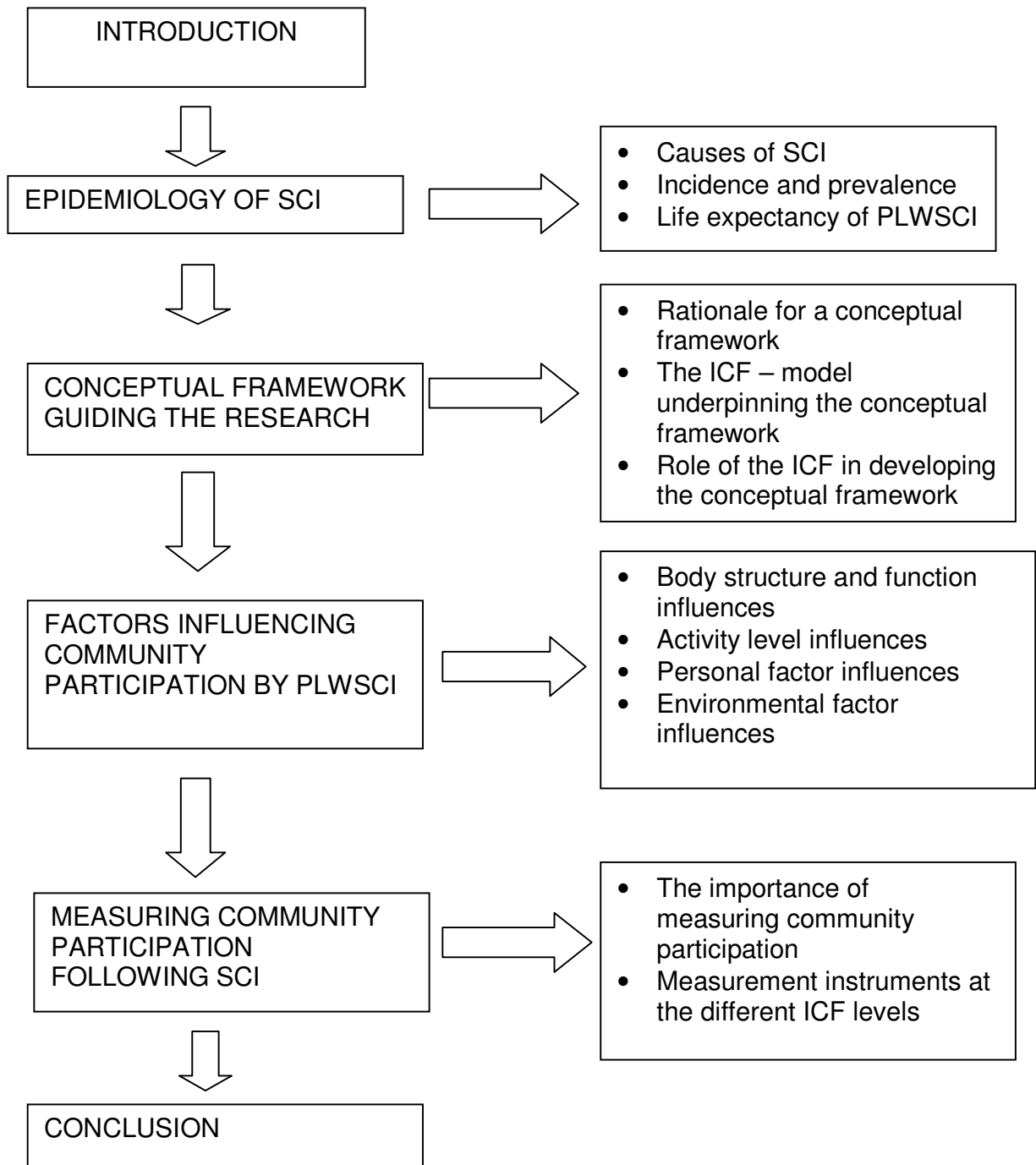


Figure 2.1: Outline of aspects of the literature review

2.2 EPIDEMIOLOGY OF SPINAL CORD INJURY

A spinal cord injury has been reported as a low-incidence type of injury, yet it is a high cost, disabling condition that results in tremendous change a person's life (Yarkony, Formal & Cawley, 1997). SCI causes high personal and bio-psychological impacts and significant socio-economic consequences, making it important to establish its incidence and prevalence. Incidence rates are important because they reflect the level of control of the various causes of SCI and the need for improved prevention strategies. Equally important are prevalence rates, because high prevalence rates have a huge impact on healthcare and on social resources (Wyndaele & Wyndaele, 2006), and eventually affect the tax payer.

2.2.1 Incidence and prevalence of SCI

There are no official statistics on the incidence or prevalence of SCI in South Africa. However, a report by the Department of Health estimated that about 2000 patients per annum are treated for SCI in public and private hospitals nationally. This estimated number implies an incidence of fifty people per million members of the population (Department of Health, 2003). On the other hand, the QuadPara Association of South Africa suggests that about 650 people sustain SCIs in the country annually and that there are over 50 000 PLWSCI in South Africa (Sereilis, 2009). QASA's figures are an underestimation compared to the estimates provided by the Department of Health. This discrepancy highlights the need for better epidemiological information, something which could be achieved by keeping a national SCI database.

A recent review of the global literature on the prevalence of SCI by Wyndaele and Wyndaele (2006) yielded surprisingly few articles on the topic. The review revealed that in the USA, an estimated 250 000 persons were living with SCI in

2005, converting to a prevalence of about 755 per million of the population. Other countries reviewed included Sweden with 223/million, Finland with a prevalence of 280/million and Australia with a prevalence of 681/million (op. cit.). However, the prevalence reported in these countries is a reflection of the prevalence of SCI in developed countries, and may not be applicable to developing countries. Countries that have centralised healthcare and record keeping systems like the United States with their National Model Spinal Cord Injury Systems Database, have population-based estimates of the incidence and prevalence of SCI (Eastwood et Al., 1999). Unfortunately, such systems have not yet been developed in South Africa, hence the lack of reliable data. This further highlights the need for improved reporting and publishing of SCI and the need for publication of SCI research findings in both developing and some developed countries.

2.2.2 Aetiology of Spinal Cord Injury

The aetiology of SCI varies throughout the world. A review of the literature on SCI epidemiology by Ackery, Tator and Krassioukov (2004) indicated that countries with similar market economies display similar aetiological trends, age distributions and male-to-female ratios for SCI. The age of individuals at the time of SCI was found to be higher in developed countries, possibly because of longer life expectancies in those countries. The male-to-female ratio was found to be higher in less developed countries, and this is possibly because of the predominant manual labour and risk-taking behaviour characteristic of men in these countries (Tator & Krassioukov, 2004).

The causes of SCI include trauma, disease and congenital defects (Hulsebosch, 2002). In most cases, an SCI occurs suddenly due to trauma and as such mainly affects young males in the prime of their lives (Hampton & Marshall, 2000; Morris & Marshall, 1997). The most common traumatic causes of spinal cord injury globally are motor vehicle accidents (MVA), falls, sports-

related injuries and violence related injuries including gunshot wounds and stab wounds (Hulsebosch, 2002; QASA, 2009). In South Africa, both gunshot injuries and motor vehicle accidents (MVA) have been reported as the leading causes of the injury (Hart & Williams, 1994; Mothabeng, 1999). Geographic location and the time of the year play a role in the aetiology of SCI in South Africa. More violence related injuries (gunshots) are seen in the major cities, and many of the MVA-related injuries occur during festive periods around Easter and Christmas time (Bradshaw et al., 2003; Magenuka, 2007).

However, over the past two decades, a significant new feature in the epidemiology of SCI in South Africa has been observed. While traumatic causes remain the major cause of SCI, a new picture in the gallery of causes is emerging. A number of people sustain SCI as a result of HIV-related diseases like tuberculosis of the spine (TB Spine) while other patients with traumatic SCI only discover that they have HIV after sustaining the spinal injury (Mothabeng, 2006).

2.2.3 Life expectancy of people living with Spinal Cord Injury

The management of spinal cord injuries (SCI) has progressed dramatically from the days of the ancient Egyptians, where it is documented in the Edwin Smith papyrus that an SCI “was an ailment not to be treated” (Hughes, 1988). Until the late 20th century, the life of a PLWSCI was cut short as a result of this nihilistic approach to patient care and by various medical complications that went mismanaged. Due to advances in healthcare and assistive technologies, the life expectancy of persons with SCI has increased, unlike a few decades ago when death was certain, due to secondary complications after injury (Chan, Lee & Lieh-Mak, 2000; Norrbrink, Budh & O’Steraker, 2007; Post et al., 2005).

The survival rate of PLWSCI is highest among persons in their teens and twenties (Norrbrink et al., 2007). In the USA, the rate of surviving an SCI has improved to approximately 88% in the first twelve years following an injury, with even better survival rates among young adults (De Vivo, Richards, Stover & Go, 1991). In Australia, O'Connor (2005) reported a survival rate of 86% at 10 years post injury. There are no published statistics on the survival rate for PLWSCI in South Africa. The only available statistics on the African continent are from Zimbabwe: Levy, Makarawo, Madzivire and Bhebhe (1998) reported a one-year survival rate of at least 51% based on a study they conducted over three years. This lack of statistics on the survival of PLWSCI further supports the previously indicated need for more research in South Africa and Africa, as well as globally.

2.3 BACKGROUND TO THE CONCEPTUAL FRAMEWORK

Having outlined the global impact of SCI in terms of its epidemiology, this section discusses the background to the framework within which the community participation of PLWSCI is to be studied.

In Chapter 1 (section 1. 6) it was pointed out that the ICF (WHO, 2001) is the selected disablement model of choice underpinning the conceptual framework for this study. Disablement models provide a framework for understanding the effects of injury and/disease on human functioning (Snyder et al., 2008) and are therefore a foundation for outcomes assessment.

The first disablement model was proposed by Nagi (1961), a sociologist employed by the United States Social Security Agency. Numerous other models have been developed since, including but not limited to the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO 1980), the National Centre for Medical Rehabilitation Research (NCMRR) (1992), the Disability Creation Process (Fougeyrollas, 1998) and the World Health Organisation's International

Classification of Functioning Disability and Health (ICF) (WHO, 2001). In this section, the historical evolution and theoretical background of the ICF as the model underpinning the conceptual framework of this study is presented.

2.3.1 Evolution of the World Health Organisation's model - International Classification of Functioning Disability and Health (ICF)

The first disablement model of the World Health Organisation, the International Classification of Impairments, Disabilities and Handicaps (ICIDH), was developed by Dr Philip Wood in the UK in the early 1970s. In 1972, the World Health Organisation recognised the need for better methods to evaluate healthcare, and commissioned an investigation into a model that could describe the consequences of injury and/or diseases, particularly chronic and progressive or irreversible disorders, for human functioning. A manual of classification relating to the consequences of disease, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published in 1980 and has undergone several revisions since.

Secondary to numerous revisions of the ICIDH, a new model incorporating all factors that impact on disability and affect functioning, namely the International Classification of Functioning Disability and Health (ICF), was adopted in 2001. One major change in the ICF was to remove the negative connotations associated with disability by using more positive terms to describe its characteristics. For instance, reference is made to a patient's "functional abilities" rather than "handicaps".

The development of the ICF started as a revision of the ICIDH, to correct inappropriate terminology and to reflect the interactive nature of the components by moving away from a linear model. One of the criticisms levelled against the ICIDH was its lack of explicit recognition of the role of the

environment in the disablement process. However, the ICIDH does refer to the environment by stating that “handicaps reflect interaction with and adaptation to the individual’s surroundings” (Whiteneck, 2005).

The evolution of the WHO model from ICIDH to ICF is illustrated in Figure 2.2 below:

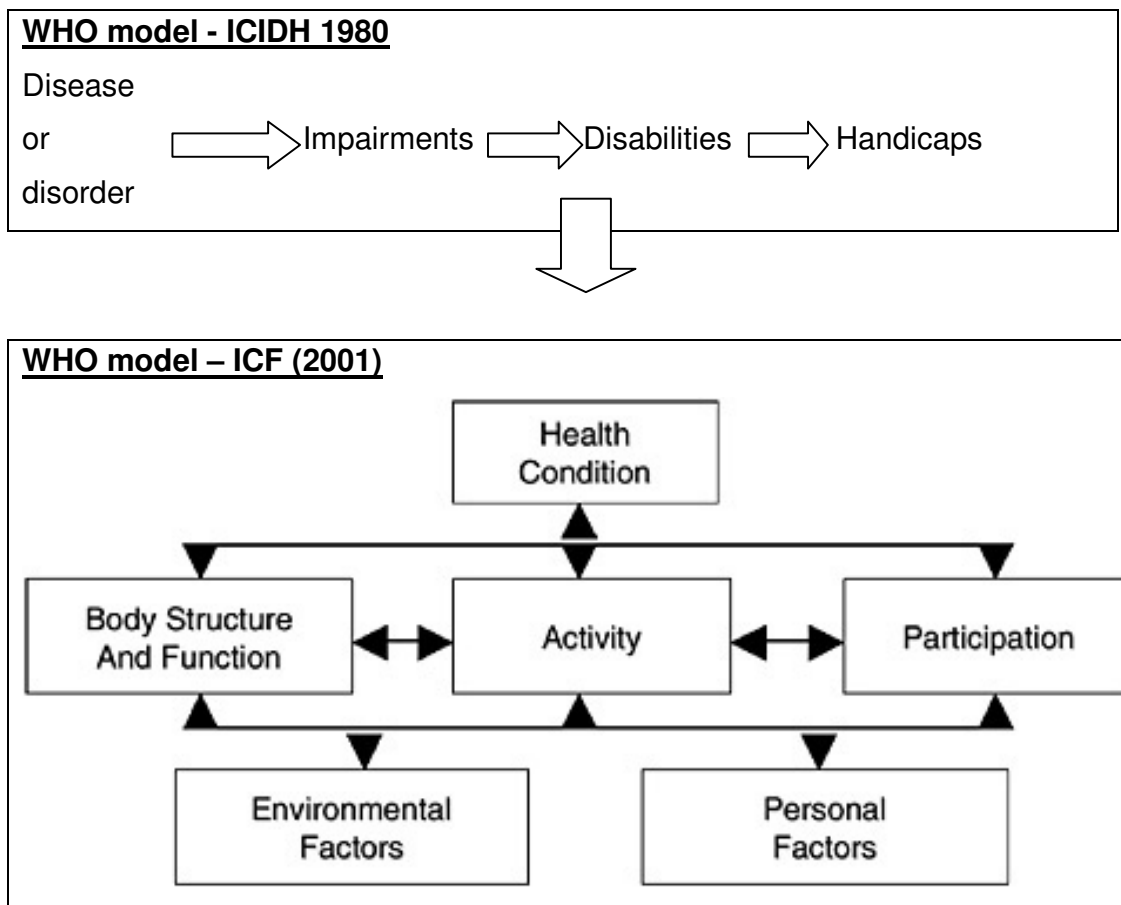


Figure 2.2: Evolution of the WHO model – from ICIDH to ICF

The ICF is a disablement model used to describe functioning and disability in relation to a health condition. Based on a bio-psychological model, the ICF integrates elements of both the medical and social models of disability. The ICF places the functioning of a person living with a disability in a context that acknowledges the interactions between a person's health, the environment, and social and personal factors. According to Jette (2005), the ICF looks

beyond mortality and disease to focus on how people live with their conditions. The ICF is thus a very useful framework for assessing how health conditions affect the functioning of individuals (Schneider, Hurst, Miller & Ustun, 2003; World Health Organization, 2001).

2.3.2 Components of the ICF

As illustrated in Figure 2.2, the ICF conceptualises disability as having a medical or health condition as one of its core components. The health condition in the case of this study is a spinal cord injury (SCI), which occurs as a result of either trauma or disease. In the ICF disablement model, disability occurs when a health condition leads to dysfunction at the domain levels (body functions and structures and activities and participation) resulting in impairments of body functions and structures, activity limitations or participation restrictions as mediated by both environmental and personal contextual factors.

The ICF is arranged in two parts. Part 1 of the ICF is termed Functioning and Disability while part 2 is Contextual Factors (WHO, 2001a).

2.3.2.1 Part 1 of the ICF: Functioning and Disability

This part of the ICF encompasses three levels of human functioning, namely body functions and structures, activities and participation (Boerman, 2004; WHO, 2001). The following sections discuss the application of the ICF to PLWSCI.

a) Body structure and function component level

The body functions and structures level of the ICF includes both mental and physical aspects of health. Body functions refer the physiological functions of the body and body structures entail the anatomical parts (i.e., sensory organs, limbs). Changes or deviations from normal function at this level are referred to

as impairments. Impairments due to SCI include loss of muscle strength and sensation below the lesion, and incontinence of bladder and bowel function.

b) Activities level

The activities level of the ICF entails personal functional activities such as walking, communication, learning, playing and interacting with others (Bornman, 2004; WHO, 2001). When a PLWSCI has difficulty performing one or more functional activities, as determined through a physical evaluation or observation by a rehabilitation professional, or as reported by the PLWSCI him or herself, this problem is called an activity limitation. Depending on the level and completeness of the SCI, a PLWSCI may present with limitations to activities of daily living, mobility and self-care.

c) Participation level

The participation level refers to involvement in life situations; including being autonomous and able to control one's own life, even if one is not actually doing things oneself. The presence of one or more activity limitations places a PLWSCI at risk of being excluded from participating in a range of life situations. The extent to which a PLWSCI is able or unable to participate in certain situations (e.g. work, school, social events etc.) will contribute to the extent and type of disadvantage he or she experiences. For example, a young PLWSCI who does not participate in learning will experience a disadvantage on the level of educational attainment whilst another who does not participate in social events or activities will experience the disadvantage of social exclusion.

2.3.2.2 Part 2 of the ICF model - Contextual Factors

Contextual factors are those factors that represent the background of an individual's life and living (Bornman, 2004). Contextual factors are particularly important because they address the significant effect of environmental as well as personal factors on the person's overall level of functioning. Contextual

factors are divided into two components in the ICF, namely environmental factors and personal factors, discussed in the following sections:

a) Environmental Factors

Environmental factors include those in the physical environment (including buildings and roads), the social environment (including family and friends) and the attitudinal environment (including the attitudes of people in the community). The impact of environmental factors is critical to the participation of PLWSCI in their communities. The environment may be either one that facilitates or presents obstacles to participation.

If the environment is facilitating, a PLWSCI may, despite significant activity limitations, still be able to participate in daily life situations and activities such as going to work or enjoying quality time with family and friends. For example, a PLWSCI who is unable to walk may be able to move around effectively in a wheelchair if the physical environment is accessible for wheelchair users. Another person may be totally dependent on others for function but if family and friends are supportive this person may experience few of the disadvantages of exclusion. However, if the environment presents many obstacles, the same two PLWSCI could face significant disadvantages because of an inaccessible physical environment or a stressful and unsupportive social network.

b) Personal Factors

Personal factors include features of an individual that are not part of a health condition, such as age, motivation, educational level and experience of living with the health condition (Bornman, 2004). Personal factors can also act as barriers to or facilitators of community participation. For example, a very motivated PLWSCI may have a high lesion with limited physical abilities, but may achieve a better participation level than someone with a low lesion who is not motivated. On the other hand, a young and educated PLWSCI may find it

easier to reintegrate into society and to participate in various meaningful activities than an older, uneducated person.

2.3.3 Summary – background to the conceptual framework

In this section, the historical background of the ICF, which underpins the conceptual framework of this study, was presented. From this background, four main elements which influence community participation, namely body structures and function, functional activities, personal factors and environmental factors, were identified (as illustrated in the conceptual framework in figure 1.4). In the next section, the review of literature illustrating the influence of these factors on participation is presented.

2.4 FACTORS INFLUENCING THE COMMUNITY PARTICIPATION OF PEOPLE LIVING WITH SPINAL CORD INJURY

Despite the intensive efforts of rehabilitation through education and functional skills training, PLWSCI experience a range of physical and psychosocial difficulties once they return to the community (Kendall, Ungerer & Dorsett, 2003). Even those individuals who make significant gains in rehabilitation may experience difficulties when attempting to participate in various roles as members of their communities. An SCI impacts on many facets of an individual's life, including social roles, personal goals and future life expectations (Conroy & McKenna, 1999; Wood-Dauphinee et al., 2002). The ensuing sections discuss the literature on factors affecting participation as outlined in the framework in section 2.3.4.

2.4.1 The influence of factors in the 'body structure and function' component on community participation

An injury to the spinal cord as a result of trauma or disease causes a circumscribed spinal cord lesion resulting in functional deficits owing to the disconnection of efferent motor and afferent sensory pathways between that part of the body and brain centres (Curt, Bruehlmeier, Leenders, Roelke, Dietz, 2002). The injured person presents with paralysis and loss of sensory function below the level of the injury, as well as loss of bowel and bladder control (Dorsett, 2001). Voluntary movement above the lesion is maintained although changed due to inevitable adaptation of the body's balance mechanisms and loss of spontaneous whole body movement.

Following an SCI, the patient can present with one of two main injury levels, namely paraplegia or quadriplegia (also known as tetraplegia). Quadriplegia is the result of an injury above the first thoracic vertebra and is characterised by paralysis of the trunk and lower limbs, and partial paralysis of the upper limbs (total paralysis of the upper limbs occurs in injuries above the fourth cervical vertebra, C4). A lesion above the C4 neurological level results in paralysis of the diaphragm. In addition to upper and lower limb paralysis, the muscles of the thorax and trunk are also paralysed to an extent that is determined by the level of the lesion. This results in respiratory problems that include low tidal volume and the inability to cough effectively and clear the chest of secretions.

In the case of paraplegia, the injury occurs below the first thoracic spinal nerve, resulting in loss of sensation or motor function in the lower limbs and lower part of the thorax or trunk (Dorsett, 2001). The PLWSCI loses bladder and bowel function and the ability to walk. The influence of body structure and function impairments on the participation of PLWSCI in the community is determined by the neurological level of the injury (NLOI), the completeness of the injury, the

presence of medical complications and the psychological status of the individual (Marino, et al., 2003).

2.4.1.1 Type and level of the lesion

Depending on the nature and level of the lesion incurred, injuries to the spinal cord usually result in some degree of cord-related motor and sensory impairment that may be complete or incomplete, temporary or permanent. Many individuals are left with serious residual disability which often leads to severe body changes and the inability to perform functional activities, including mobility and activities of daily living (Wood-Dauphinee & Exner, 2002).

The NLOI is defined as the most caudal (i.e. lowest) level of the spinal cord that has normal motor and sensory functions (Ditunno, Young, Donovan & Greasey, 1994). Motor function is determined by manually testing key muscle groups on both sides of the body. These muscle groups represent neurological levels, and findings are graded 0-5. Sensory function is determined by examining 28 key sensory points on both sides of the body.

The completeness of the SCI is determined using the American Spinal Injury Association (ASIA) Impairment Scale (American Spinal Injury Association, 2002). The ASIA scale classifies the completeness of SCI on a scale from A to E, as follows:

- *A - Complete = No sacral motor or sensory sensation in segments S4-5.*
- *B - Sensory incomplete = Preservation of sensation below the level of injury extending through sacral segments S4-5.*
- *C - Motor incomplete = Voluntary anal sphincter contraction or sensory sacral sparing with sparing of motor function below the motor level of injury, with the majority of key muscles having a strength grade of less than 3.*
- *D - Motor incomplete = Voluntary anal sphincter contraction or sensory sacral sparing with sparing of motor function below the motor level of injury, with the majority of key muscles having a strength grade of 3 or greater.*

- *E - Normal = Normal motor and sensory recovery.*

The neurological level and completeness of the injury are important factors that assist in predicting functional outcomes after SCI (American Spinal Injury Association 2002; Ditunno et al., 1994; Eastwood et al., 1999). The main factor that determines functional activity is the motor level of the lesion. A patient with a complete and high SCI level (i.e. tetraplegia) will have fewer innervated muscles with which to perform physical functions than a PLWSCI with a low level injury (e.g. low paraplegia). On the other hand, if the lesion is incomplete, the potential for neurological recovery is greater, and it will be easier to perform physical functional activities and to reintegrate into society.

2.4.1.2 Health-related complications

A variety of complications can occur during both the acute and chronic stages of the SCI despite advances in prevention and treatment of spinal cord injuries (SCI) (Chen, Apple, Hudson, & Bode, 1999). The presence of medical complications has a direct impact on a person's functional ability, feeling of well-being and ultimately on his or her participation in society. The three most common complications that affect PLWSCI are pressure ulcers (PU), urinary tract infections, and respiratory infections.

a) Pressure sores

Pressure ulcers are the most serious of secondary complications that a patient with SCI can develop, with potentially fatal consequences. They usually occur over bony prominences and are classified in stages by the degree of tissue damage observed. Pressure ulcers are defined as lesions caused by unrelieved pressure, resulting in damage to the underlying tissue (Garber & Rintala, 2003). Pressure sores occur in 25%-85% of permanent wheelchair users and are the cause of 8% of deaths amongst PLWSCI (Basson et al., 2006). PLWSCI have a higher risk of developing PU than other people living with a disability because of their impaired sensation and immobility. The

presence of pressure ulcers will confine a PLWSCI to bed, thus limiting the postures and activities that s/he will be able to adopt and/or perform. These limited activities will also limit or prevent the PLWSCI from participating in the community.

The aetiology of the pressure sore is multi-dimensional. Pressure, sheer friction and poor nutrition contribute directly to the physiological aetiology of pressure sores (Garber & Rintala, 2003). Other factors associated with the development of these sores include immobility and psychosocial factors such as inadequate personal and financial resources as well as non-compliance with preventative behaviour (Garber & Rintala, 2003). Krause (1998) explored correlations between secondary conditions including pressure sores and subjective well-being and found that pressure sores were most highly related to emotional distress, decreased financial well-being and poor living circumstances. The various factors contributing to development of PS are reflected in Figure 2.3 (Britz et al., 2007).

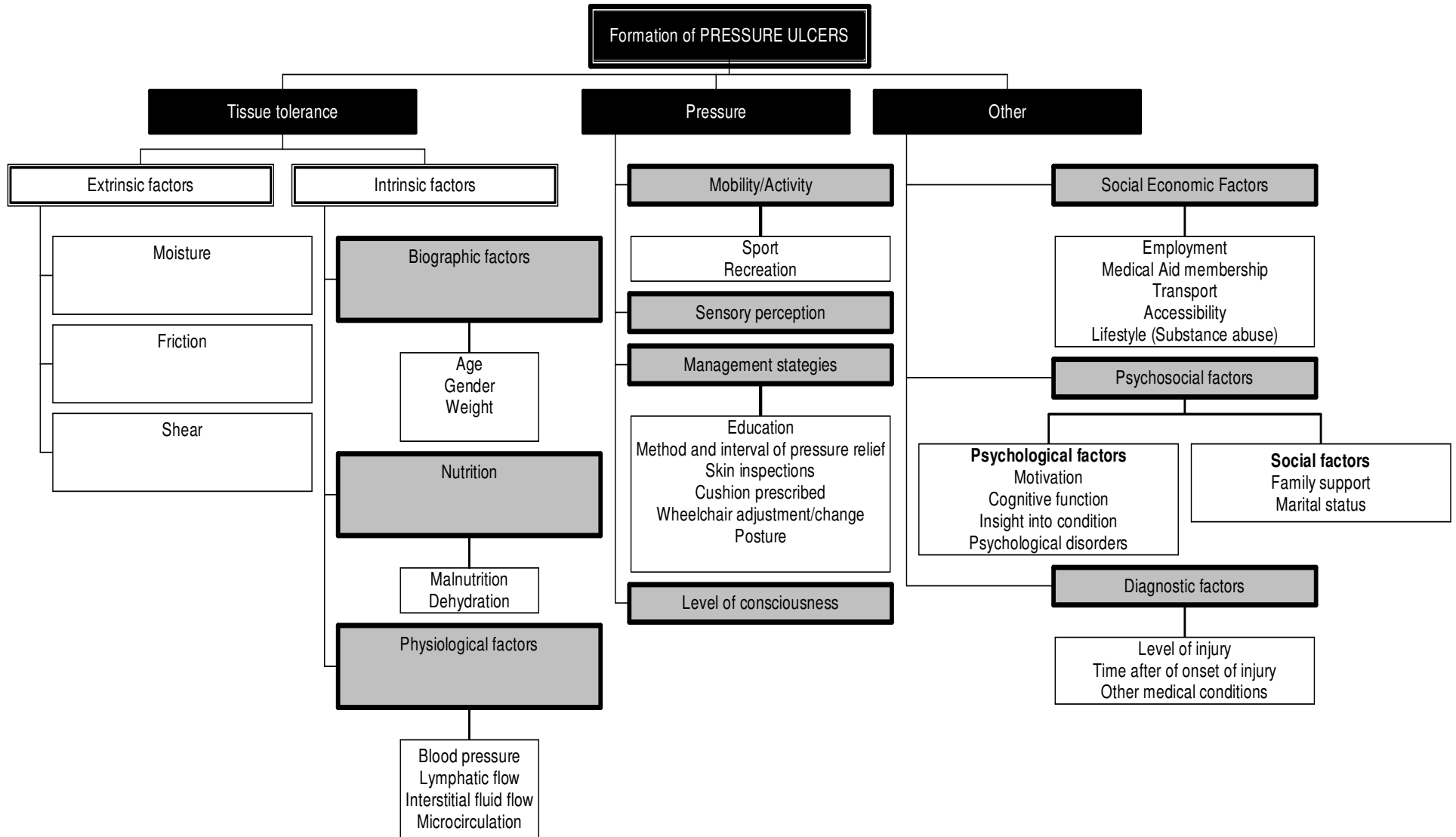


Figure 2.3 Risk factors for pressure ulcer development

b) Urinary tract infection (UTI)

Asymptomatic bacteruria is common among SCI patients who use self-catheterisation, with urinary tract infection (UTI) being the most frequent complication (Montegomerie, 1997). The factors increasing the risk of infection include over-distension of the bladder, vesico-ureteric reflux, high pressure voiding, large post-void residuals and stones in the urinary tract (Salomon, Denys, Merle, Chartier-Kastler, Perronne, Gaillard & Bernard, 2006). Savic, Short, Weitzenkamp, Charlifue and Gardner (2000) postulate that urinary and skin complications are the principle reasons for readmission of individuals with spinal cord injury after being discharged.

c) Respiratory infections

Respiratory complications are the leading cause of morbidity and mortality following SCI (Cardozo, 2007; Smith, Evans, Kurich, Jibby, Waever, Nayna Patel & Burns, 2007; Werhagen, 2008). Respiratory infections occur as a result of reduced inspiration and expiration ability, decreased tidal volumes and an inability to cough out secretions (Soden, Walsh, Middleton, Craven, Ruthkowski & Yeo, 2000).

Davies and McColl (2002) conducted a study on the incidence of lifestyle risks for three disease outcomes, namely cardiovascular disease, respiratory infection and urinary tract infections, in PLWSCI. These authors found that people with tetraplegia were at greater risk of developing respiratory infections than those with paraplegia. This was attributed to their impaired ability to clear the respiratory tract of secretions by coughing, leading to retention of respiratory tract secretions and respiratory infections. The authors further found that the number of cigarettes smoked per day increased the risk of respiratory infection.

d) Gastrointestinal complications

Spinal cord injury (SCI) has an impact on multiple organs in PLWSCI, including bowel function (Hass, Geng, Evers & Knecht, 2005). Signs and symptoms of bowel dysfunction as well as complications reported in the literature include prolonged colonic transit time, faecal impaction, abdominal distension and colonic dilatation (Haas et al., 2005). Changes in bowel motility, sphincter control, and decreased gross motor dexterity interact to make bowel management a major lifestyle problem and one which limits quality of life (Lynch et al., 200; 1Ayas, Leblebici, Sozay, Bayramoglu & Niron, 2006).

Bowel dysfunction following spinal cord injury (SCI) is increasingly recognised as an area of major physical and psychological discomfort for PLWSCI (Lynch, Antony, Dobbs & Frizelle, 2001). Problems of bowel dysfunction also increase the level of dependency among PLWSCI (Kanisto & Rintala, 1995; Ayas et al., 2006).

Bowel dysfunction is more common in people with higher injuries (tetraplegia) than in those with lower injuries (paraplegia) and it has a major impact on the lifestyle of PLWSCI. Ayas et al. (2006) also found that the majority of male paraplegics (80%) and tetraplegics (46%) ranked bladder and bowel dysfunction as their greatest functional loss, second only to loss of mobility. The more complete the SCI, the greater the effect on bowel function as a result of the greater difficulty associated with toileting and the need for assistance (Stone, Nino-Murcia, Wolfe & Perlash, 1990). The biggest problem associated with bowel dysfunction is "*having a bowel accident*", which is socially unacceptable to a PLWSCI. This leads to problems of social isolation, as the PLWSCI chooses to stay away from the public for fear of embarrassment.

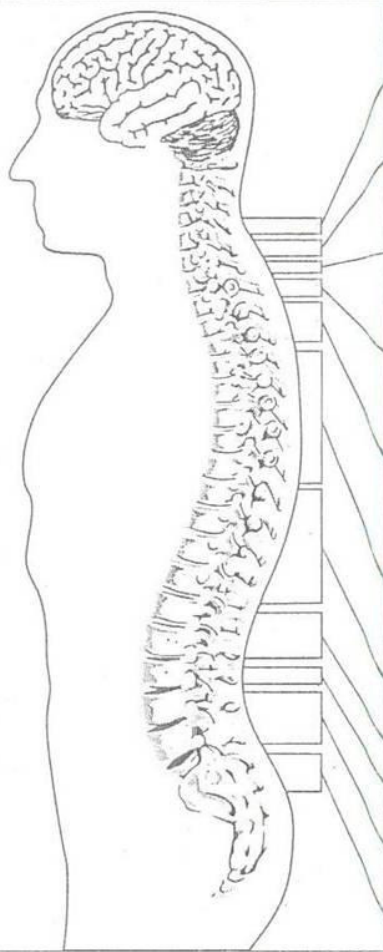
e) Psychological status

The psychosocial consequences of SCI stem mainly from the resultant marked changes in body image after a spinal cord injury (Brown, Bell, Maynard, Richardson, & Wagner, 1999; North, 1999). Adapting to these changes can be a significant psychological challenge for some individuals, leading to depression and anxiety. Other psychological challenges include fear of rejection by partners or peers, poor coping skills and a struggle with self-identity (Carpenter, 1994; Brown, et al., 1999; Craig et al., 1999; Levins et al., 2004). The ability of the PLWSCI to adapt their socio-emotional behaviour to their changed functional ability in all spheres of life is also crucial to successful community participation.

2.4.2 The influence of functional activities on community participation

Activity as defined in the International Classification of Function, Health and Disability (WHO 2001) is the execution of a task or action. Activities of daily living and mobility are the functional outcomes expected from people with SCI (Catz et al., 1997). Skills of self-care and mobility are basic to higher levels of functioning, and improvement in these abilities is likely to have considerable impact on the ability of the PLWSCI to participate in community life, and eventually on his/her quality of life (Catz et al., 1997). A study on the functional outcome of patients with SCI found that the ability of patients to perform functional activities was closely associated with the neurological level of the lesion and the presence of medical complications (Vogel, Klaas, Lubicky & Anderson, 1998). Depending on the level and completeness of the injury, a PLWSCI may not be able to perform certain basic functions as illustrated in Table 2.2.

Table 2.2 Functional abilities of PLWSCI



LEVEL	MUSCLE FUNCTION	ABILITIES
C3	None to little diaphragm Neck control.	Special adapted wheelchair, portable ventilating system. Mouth-stick communication.
C4	Neck control, Some shoulder function.	Can manipulate electric wheelchair with special devices. Mouth-Stick communication.
C5	Partial shoulder control. Partial elbow flexion.	Able to eat with special devices. Can propel a wheelchair with assistive devices. Can swim and bowl with adaptive equipment.
C6	Shoulder control, elbow flexion and can move wrist.	Can dress independently with special equipment. Can transfer in bed or car independently. Can drive with adaptive equipment.
C7-8	Shoulder control, elbow extension, some hand function.	Can completely dress with special equipment. Able to shower. Able to work in a building free from architectural barriers.
T1-5	Normal upper extremity muscle function.	Total wheelchair independence. Can move from wheelchair to floor and back. Can stand with assistance. Can compete in all wheelchair sports. Has fine motor coordination in fingers.
T6-10	Partial trunk stability.	Can walk with long braces and crutches in the home.
T11-L1	Trunk stability.	Can possibly walk to do some household activities.
L2	Hip flexion.	Can walk within the confines of the house.
L3-4	Knee extension.	Can walk in the community with leg braces and crutches or cane.
L5-S2	Leg and ankle control.	Can possibly walk without any special devices.

Eareckson Tada et al (Joni and Friends) : 1980, p.21

2.4.3 The influence of personal factors on community participation

Personal factors include features of an individual that are not part of a health condition such as age, motivation, educational level, experience of living with the health condition, to mention but a few. The presence of certain personal characteristics has been found to have either a negative or a positive influence on community participation. In the following sections, the influence of the demographic characteristics and rehabilitation experience of the PLWSCI are discussed.

2.4.3.1 Demographic influences on participation

The age, ethnicity and level of education of PLWSCI have been reported as having an influence on community participation (Krause 1996, 1997; Krause, Sternberg, Lottes & Maides, 1997). These authors found that PLWSCI who were younger, of Caucasian ethnicity and with better education participated more actively in society and demonstrated higher levels of participation in their communities. Similar findings were reported by Whiteneck, Tate and Charlifue (1999) in a study to identify factors predicting community participation after SCI. These authors found that gender was also related to community participation, with males participating better than females. A study on the quality of life of African Americans with SCI found that the male gender had a positive influence on community participation (Charlifue & Gehart, 2004). Regarding the number of years post injury, the reviewed literature suggests that the longer the period post injury, the better the community participation (Charlifue & Gehart, 2004; Pentland et al., 1995).

All the above personal factors have been built into the methodology of this study, as they are important in a developing country like South Africa, where demographic issues (especially gender) still influence the socioeconomic status of individuals (Bradshaw et al., 2004). The influence of some of the demographic factors is illustrated in Table 2.4 below.

Table 2.3 The effects of demographic factors on community participation

Demographic factor	Impact (positive or negative)	Reference
Male gender	Positive Positive Negative	Tomassen et al. 2000 Krause 2003 Ville & Ravaud 1996 Anderson & Vogel 2002
High level of injury (Cervical or tetraplegia)	Negative Negative Negative Negative Negative Negative Negative	Krause 2003 Krause 1996 Anderson & Vogel 2002 Krause & Anson 1996 Noreau et al. 1999 Young & Murphy 2002 Castle 1994 Tate et al. 1993
Years of injury	Positive (more yrs) Positive (more yrs)	Meade et al. 2004 Crewe & Krause 1990
Employment	Positive	Mackenzie et al. 1986
Age at time of injury	Positive (younger) Positive	Noreau et al. 1999 Ville & Ravaud 1996
Higher education pre-injury	Positive Positive Positive Positive Positive Positive Positive	Tomassen et al. 2000 Krause 2003 Krause & Anson 1996 MacKenzie et al. 1986 Goldberg & Freed 1982 Ville & Ravaud 1996 Noreau et al. 1999 Castle 1994
Education & training post injury	Positive +	Tomassen et al. 2000 Krause 2003
Private insurance	Positive	Tate et al. 1993
Racial & ethnic minorities	Negative	Meade et al. 2004

2.4.3.2 The influence of rehabilitation on community participation

The focus of rehabilitation for chronic disabling conditions like SCI has shifted from a biomedical to a bio-psycho-social model, with increasing emphasis on a client-centred approach to rehabilitation (Cardol et al., 2002; Kennedy 2007; Pimentel 2008). Rehabilitation programmes aim to enhance the adjustment to life following spinal cord injury by equipping the individual with the skills and resources required for community participation (Conroy & McKenna, 1999). The objectives of rehabilitation are to maximise functional independence, prevent secondary complications, optimise physical functioning and facilitate renewed participation in the community (Ada, Mackery, Heard & Adams, 1999; Chappell et al., 2003; Rimmer, 1999). After the inpatient rehabilitation phase has been completed, the PLWSCI is discharged into the community to resume his/her social life roles. It is during this period that PLWSCI face obstacles associated with their return into the community

The experience of PLWSCI during institutionalised rehabilitation has a bearing on their outcome following discharge. Cott (2004) interviewed people with long-term physical disabilities, including SCI, on the role of rehabilitation in preparing them for community living. Participants in their study reported that they felt ill prepared for community living with respect to practical skills and dealing with the emotional challenges of living with a chronic disabling condition. Similar findings were reported by Magenuka (2006) in a study of the experience of South Africans living with SCI in rural areas. In both studies, participants felt that rehabilitation professionals only addressed impairments and activity limitations, and not participation in social relationships, home life, education, work and economic life. Therefore the transition from being a rehabilitation “patient” to becoming a community-dwelling person with a disability was particularly challenging for the participants once they were discharged from rehabilitation (op. cit.).

These findings were confirmed by Cott, Wiles and Devitt (2007) in their review of the literature on preparing clients for life in the community after their rehabilitation. A key finding from this review was that clients “*found discharge from rehabilitation services distressing in that they feel they have received inadequate information about their expected outcome, ill-prepared for life in the community and unable to participate in life in the ways that they find fulfilling*”. Rehabilitation needs to address bio-medical needs, as well as the psycho-social and environmental contexts of PLWSCI. That is why this study asks whether our rehabilitation programmes have effectively prepared PLWSCI for life in the community.

Nolan (2008) conducted a literature review of patients’ experiences of rehabilitation in order to gain an understanding of these experiences and to outline implications for the practice of rehabilitation. The review revealed that the attitude of rehabilitation staff is a very strong and significant factor influencing the experience of PLWSCI. Similar findings were reported by Mothabeng, Malinga, Van der Merwe, Qhomane and Motjotji (2007) in their study on the views patients with spinal cord injuries had about their rehabilitation experiences. Hammell (2007) concurred that rehabilitation staff “*hold the power to facilitate or to thwart the process of reconstructing life*” owing to their intimate involvement in the early stages when a PLWSCI forms a new identity as a PWD. The attitude of rehabilitation staff can therefore be a facilitator or an obstacle to the preparation of community participation by the PLWSCI.

2.4.4 The influence of environmental factors on community participation

Environmental factors are part of contextual factors, those factors that represent the background of an individual’s life and living (Bornman, 2004). Environmental factors include the cultural (e.g. attitudes, beliefs), physical (e.g. architecture) and social (e.g. family and friends) aspects that surround the

individual (Law et al., 1997). The environment is therefore the situational context that shapes what PLWSCI can do by either supporting or constraining them in their performance of activities and thus affecting community participation.

Environmental factors can act as impediments or facilitators of community participation.

2.4.4.1 The physical environment

The physical environment can also act as an impediment to or facilitator of participation of PLWSCI in society. The physical factors include geographic, architectural and transportation issues and have been identified as accessibility problems that spinal cord injured individuals encounter once back in the community (Anderson & Vogel, 2002; Levins, Redenbach & Dyck, 2004). These factors may cause the social isolation of the person living with SCI, limiting the extent to which the individual is able to integrate fully into and participate in society.

The geographic area around the home of the PLWSCI can be a barrier if it is not conducive to wheelchair use. This may mean that the PLWSCI is unable to leave the house, limiting his/her participation in society. Examples of architectural barriers are inaccessible buildings and community centres where there may be stairs but no lifts or ramps for wheelchair users. Transportation issues include the lack of affordable and disability-friendly public transport.

Whiteneck, Meade, Dijkers, Tate, Bushnik and Forchheimer (2004) conducted a survey of the role of environmental factors on the participation of 2762 PLWSCI in the USA, who had been living with SCI for between one and 25 years. The results of the survey revealed that the perceived top five environmental barriers were those in the natural environment, transportation, help at home, healthcare and government policy, as reported using the Craig Hospital Inventory of Environmental Factors (CHIEF) instrument. Significant

predictors of higher CHIEF total scores (i.e. more perceived environmental barriers) were mid-age range at time of injury, female, minority ethnicity, more recent injury, more severe injury, and higher degree of activity limitations (all at $p < 0.05$).

2.4.4.2 The social environment

Social support is an important factor in enhancing the participation of PLWSCI in rehabilitation (Larson Lund et al., 2005), and eventually in their communities. Larson Lund et al. (2005) suggest that it is important to focus on factors related to social support during rehabilitation, as this will facilitate positive community participation. This is why it is common practice in spinal rehabilitation facilities for PLWSCI to have weekend passes and to experience the realities of the social environment by interacting with family, friends and the community in the natural environment in preparation of participation after discharge from the rehabilitation facility. Hampton (2001) found social support from family and friends to have a positive influence on the quality of life of young Chinese adults living with SCI.

Social support from peers with SCI is another important resource for PLWSCI. Peer support is crucial in helping a new PLWSCI to “accept his/her condition”, as a source of motivation and encouragement. Support groups have been reported to have a positive influence on self-reliance and group participation in a South African case study of people with physical disabilities, including PLWSCI (Stewart & Bhagwanjee, 1999). Similarly, an investigation of the social support needs of PLWSCI in Virginia by Mead et al. (2006) found that the greatest need was to network with other people with SCI in a support group.

2.4.5 Summary – factors influencing community participation

From the discussion in the preceding sections, it emerges that the ability of PLWSCI to participate in their communities depends on their personal characteristics and experiences, the accessibility of the physical environment and the support in the social environment. As indicated in the justification of the study in chapter 1, there is very limited research on community participation by PLWSCI in South Africa. In the next section, a brief review of what South African literature there is on the topic is presented.

2.5 SOUTH AFRICAN RESEARCH ON THE COMMUNITY PARTICIPATION OF PLWSCI

The existing literature on community participation has been growing in the past two decades; however, limited research has been conducted on this topic in the South African context. As indicated in chapter 1, very few articles on the topic have been published in this context. The few South African studies that do exist lend support to the international literature as far as the personal and environmental factors influencing community participation are concerned. Table 2.5 below reflects South African studies related to the participation of PLWSCI (personal and environmental factors in italics and underlined).

Table 2.4 South African studies on the community participation of PLWSCI

Publication	Aim of study	Main findings
Cock (1989) (Disability and Society Journal)	To determine the needs of PLWSCI in Soweto	Lives of PLWSCI in Soweto are characterised by <u>poverty and isolation</u>
Leshilo (2005) (MA Social Work thesis, University of Pretoria)	The feelings of people with physical disabilities regarding discrimination in Tembisa	PWD feel <u>isolated, rejected, marginalised and stigmatised</u> in their own community
Magenuka (2006) (PhD Nursing (rehabilitation) thesis, University of South Africa)	To explore the experiences of people living with SCI in the Eastern Cape	PLWSCI live in <u>isolation</u> and have a limited social life. They feel <u>ill-prepared for life in the community</u> and are poorly integrated into the community
Njoki et al. (2007) (South African Journal of Physiotherapy)	The impact of SCI on South African youth in the Western Cape	<u>Social identity, intra and interpersonal factors, social support and employment</u> are major challenges for youth with SCI once back in the community.
Monageng (2007) (MA Social Work thesis, University of Pretoria)	Psychosocial problems encountered by black tetraplegics once discharged from hospital	Psycho-social challenges included <u>disturbed family relations, negative self esteem, lack of self confidence, lack of transport and stigmatisation</u> by the community.
Vosloo (2009) (Disability and Rehabilitation Journal)	To evaluate the functioning of primary school children living with paraplegia in the Western Cape	The children were restricted in cognitive independence and mobility. Physical and educational <u>resources, social support and equity</u> are needed to facilitate the inclusion of these children

2.6 MEASURING COMMUNITY PARTICIPATION FOLLOWING SCI

Community participation is an important outcome to evaluate following the rehabilitation of persons with disabilities, including those with spinal cord injury (SCI), because participation is closely related to quality of life (Dijkers, 1997). Section 2.5 presented the various factors affecting the community participation of PLWSCI. In this section, the literature on instruments for measuring community participation and related factors is reviewed in order to select instruments for implementation in this study (Chapter 3).

There are very few instruments specifically developed for measuring community participation by PLWSCI. Most instruments used with this population are generic and have been developed for use with the general population living with physical disabilities. As indicated in the framework in chapter 1, the community participation of PLWSCI is influenced by factors related to body structure and functions, activities, personal and environmental factors. All these factors must be taken into cognisance when measuring participation. Therefore the description of instruments in this section includes all factors, and is not limited to instruments that measure participation only.

2.6.1 Measurement instruments at body structure and function level

Problems of body structure and function are called impairments (Bornman, 2004). The major impairments following SCI are motor and sensory loss, and these are used to determine the Neurological Level of Injury (NLOI). The NLOI is determined using the International Standards for Neurological and Functional Classification of Spinal Cord Injury (ISCS-CI-92), initially published by the American Spinal Injury Association (ASIA) in 1982, and adopted by the International Spinal Cord Association (ISCOS) in 1992. The international standard (hereafter referred to as the ASIA scale) tests the NLOI using motor and sensory testing.

The ASIA scale will not be used as a measuring instrument in this study, as it is not the intention to diagnose the participants by determining the level of their lesions. The study participants are all living with chronic SCI (for more than two years), and therefore their diagnoses are well established. During the study, the level of the lesion will be established by asking the participants questions using the socio-demographic and injury profile (SDIP) (Appendix H) designed by the researcher.

The socio-demographic and injury profile (SDIP) will be used to collect information on participants' personal data, and SCI and general health data: injury data, including the cause of the SCI, **level of the SCI**, date of injury, **completeness of injury**, current **complications of the SCI and any related health problems**. By the time PLWSCI are discharged from rehabilitation, they are educated regarding the level and completeness of their lesion, and whether their injury is complete or not. The researcher will also be able to verify the participants' responses by checking the recorded level and completeness on the database.

2.6.2 Measurement instruments at activity level

A number of instruments exist for measuring the functional activities of PLWSCI. These include instruments for measuring activities of daily living and/or mobility. Some measurement instruments have been specifically developed for PLWSCI, while others are generic for use with all people with disabilities. Table 2.6 provides a summary of the instruments measuring the activity levels applicable to PLWSCI.

Table 2.5 Instruments for measuring the activity level outcomes for PLWSCI

Instrument and reference	Purpose of instrument	Validity and reliability	Comments
Barthel Index (BI) (Mahoney and Barthel, 1955)	To assess the severity of disability or independence in personal care and mobility	Good validity and reliability	Oldest measure of functional ability. Has been used on PLWSCI but has floor and ceiling effects. Not sensitive to changes in function of PLWSCI.
Functional Independence Measure (FIM) (Granger et al., 1986)	To assess the functional ability of PWD in terms of physical and cognitive disability	Excellent validity and reliability	The FIM is considered a gold standard routinely used in most rehabilitation institutions for assessing ADL, in PWD, and has been used in PLWSCI. A major limitation is lack of sensitivity to small functional changes in PLWSCI.
Quadriplegic Index of Function (QIF) (Gresham et al., 1986)	To measure functional improvements in people with quadriplegia during rehabilitation	Excellent validity and reliability	Designed to measure functional activity in PLWSCI who are still in rehabilitation. Specifically designed for people with quadriplegia.
Spinal Cord Independence Measure (SCIM) (Catz et al., 1997)	To measure functional ability of PLWSCI in terms of self-care, respiration, sphincter management and mobility	Excellent reliability and validity. Validated in a multicentre trial in 13 countries.	Developed specifically for PLWSCI, to counter the shortcomings of sensitivity in other tools.

From the instruments presented in Table 2.6, the SCIM was selected as the instrument of choice for measuring the functional abilities of PLWSCI for the following reasons:

- The SCIM is the only instrument designed specifically to measure functional ability in PLWSCI. The SCIM was developed in Israel by Katz and Itzkovich (1997) because previous measures of functional ability were found not to be sensitive to changes in the functional status of people with SCI (Allan et al., 2000). The SCIM was revised by the developers in 2001, and SCIM II was developed. The SCIM II (Appendix J) is the validated version which was used in this study.
- The validity of the SCIM II is supported by several studies including a recent multi-centre study of 13 centres in six countries. The results suggest strong validity and reliability (Katz et al., 2007) and better sensitivity to change, compared to the Functional Independence Measure (Katz et al., 1997). The SCIM is widely used as a preferred research instrument in SCI rehabilitation (Grijalva et al., 2003; Itzkovich et al., 2002, 2006; Katz et al., 1997; Katz et al., 2001b; Katz et al., 2002; Katz et al., 2004; Katz et al., 2006; McKinley et al., 2001; Morganti et al., 2005; Popovic et al., 2006; Ronen et al., 2004; Scivoletto et al., 2003).
- The SCIM II has been used before on South African patients with spinal cord injury, but the psychometric properties of the instrument were not reported (Mothabeng et al., 2005). This study will therefore establish its psychometric properties.

2.7.3 Measurement instruments at participation level

There has been tremendous progress over the past three decades in understanding how individuals resume participating in life activities following a health condition. The interest of rehabilitation professionals in measuring participation has evolved in line with the development of disablement models.

The measurement of participation is the most meaningful outcome of rehabilitation, as it measures outcomes in relation to real life issues in the community (Cicerone, 2004). There are many factors that contribute to a person's level of participation, making it the most challenging variable to measure.

Community participation is “the experience of being a part of the community, being accepted, and not being unduly disadvantaged because of the disability” (McColl, 2001, 215). Participation is important to people with disabilities, disability policy, rehabilitation research, and clinical practice, because it is the real life outcome of SCI rehabilitation. Therefore, it is imperative that clinicians and researchers interested in community participation have access to instruments that accurately measure participation in ways that are both conceptually and psychometrically sound (Magasi, Heinemann & Whiteneck, 2008).

Three main ideas are encompassed in the definition of participation, namely, having activities to fill one's time, being independent in one's living situation and having relationships with other people (Dijkers, 1998). The measurement of community participation should therefore address these three categories of role functioning. Table 2.7 presents a comparison of the various measures of participation as summarised by The Participation Team (2005).

Table 2.6 The Participation Team's comparison of participation measures (Source: Participation Team, 2005)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
CHART (Craig Handicap Assessment and Reporting Technique)	Measure handicap in the community of persons with SCI (used with other populations, e.g. TBI, stroke, MS, amputations, burns)	Self or interview-administered	27 items Dimensions: physical independence, mobility, occupation, social participation, economic self-sufficiency	30	Yes Observer test-retest	Yes Content construct criterion	Gives similar weights in occupation subscale (i.e. hours worked on job and hours worked in household); does not attempt to measure disability (activity) and handicap (participation) together	Norms developed based on small sample and primarily working young adults from middle class background; ceiling effects with skewed distributions; therefore, recommend not using total score, but base analyses on sub-scores	Walker et al. (2003) Hall et al.. (1998) O'Neill et al. (1998) Whiteneck et al. (1992)

Table 2.6 The Participation Team's comparison of the participation measures (cont.)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
CIM (Community Participation Measure)	Measure community participation of persons with TBI (used with other populations)	Self or interview-administered (phone or face-to-face)	10 items (qualitative statements) measured on 5 point scale from always agree to always disagree e.g. "I can be independent in this community"	5	Yes Internal consistency	Yes Content construct criterion/discriminate	Domains empirically derived; uses client centred language; brief; used in practice with broad range of disabilities	Not widely used; further psychometric development and testing required	McColl et al. (1998) McColl et al. (1997)
CIQ (Community Integration Questionnaire)	Measure handicap as a function of community participation of persons with TBI (used with other	Self or interview-administered (phone or face-to-face)	15 items Dimensions: home participation, social participation, productivity	10	Yes Internal consistency test-retest	Yes Content construct construct	Widely used; brief; developed specifically for TBI population; based on ICIDH	Variation in inter-rater agreement; ceiling effects (home & social participation); using composite total	Dijkers (1997) Willer et al. (1993)



	populations)							score is questionable; gender effects; scoring system awards more points for certain activities for doing them alone than with others	
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Table 2.6 The Participation Team's comparison of the participation measures (cont.)

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
COPM (Canadian Occupational Performance Measure)	Measure changes in self-perception of occupational performance across a variety of disabilities and developmental stages	In-person interview (semi-structured)	2 (10 point scales) with 3 dimensions Dimensions: performance and satisfaction in occupational performance (self-care, productivity and leisure)	30-40	Yes Internal consistency test-retest	Yes Content criterion construct responsiveness	Considers importance and satisfaction with performance; measures client identified problems; problems are weighted by client in terms of importance; used with broad spectrum of disabilities and age ranges	May be challenging for persons with cognitive impairment to complete semi-structured interview; can extend beyond 40 minutes	McColl et al. (2000) Law et al. (1998)
IPAQ (Impact on Participation and Autonomy Questionnaire)	Measure autonomy and participation of people with chronic disorders	Self-administered	33 items Domains: autonomy indoors, family role, autonomy outdoors, social relations, and work and educational opportunities	30	Yes Internal-consistency test-retest	Yes Content construct convergent discriminate	Focuses on autonomy and participation rather than ability and capacity;	Responsiveness requires further study; does not address productivity other than paid work	Cardol et al. (2001) Cardol et al. (1999)

Table 2.6 (cont.) The Participation Team's comparison of the participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
LIFE-H (v 3.0) (Assessment of Life Habits)	Measure quality of social participation	Self-administered or external administrator	240 (long) and 69 (short) version items Dimensions: nutrition, fitness, personal care, communication, responsibility, interpersonal relationships, community, education, residence, mobility, employment, recreation	30-60 (short) and 20-120 (long)	Yes Internal consistency test-retest	Yes Content convergent	Measures level of difficulty, type of assistance, and satisfaction with life habit; documents the impact of assistive technology provision; short form available for more general screening; version available for children (5-13 years of age)	Responsiveness requires further study; lengthy to complete	Noreau et al. (2004) Noreau et al. (2002) Fougeyrollas et al. (1998)

Table 2.7 (cont.) The Participation Team's comparison of the different participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
LHS (London Handicap Scale)	Measure degree of handicap of persons with disability	Self or interview-administered	6 items Dimensions: mobility, orientation, occupation, physical independence, social participation, economic self-sufficiency	10-15	Yes Test-retest internal consistency	Yes Content construct/convergent responsiveness	Takes into account aids and environmental modification available; based on ICDH dimension of handicap; brief; easily understood; simplified scoring system revised in 2000	Includes concept of orientation and physical independence which have been criticised for not being dimensions of handicap or participation	Jenkinson et al. (2000) Harwood et al. (1994)
RNL (Reparticipation to Normal Living Index)	Measure resumption of normal patterns of living after disability or disease (e.g. stroke, SCI)	Self or interview-administered	11 items with 10cm visual analogue scale response format Dimensions: disability, role performance, interpersonal relationships	5-10	Yes Internal consistency observer	Yes Content criterion construct	Easy to score and interpret; brief; used in numerous research studies and practice domains; empirically derived	Visual analogue scale may pose difficulties for persons with cognitive deficits; combines domains of disability (activity) and handicap (participation)	Wood-Dauphinee et al. (1988)

Table 2.6 (cont.) The Participation Team's comparison of the participation measures

Title	Purpose	Administration Mode	Number of items	Time (min)	Reliability studies?	Validity studies?	Strengths	Limitations	References
SPRS (Sydney Psychological Participation Scale)	Measure specific types of psychosocial disabilities and handicaps that occur after TBI	Interview (structured and/or semi structured) or independent rating by clinician who is familiar with client	12 statements (with 4 items in each of the 3 dimensions) Dimensions: occupational activities, interpersonal relationships, independent living skills	15	Yes Inter-rater internal consistency	Yes Content construct / convergent responsiveness	Developed based on ICIDH; compares person against their own pre-morbid level of functioning; sensitive enough to detect change over time	Some items do not apply to all individuals (e.g. people not currently in a relationship); difficulties with 7 point rating scale (distinguishing between levels); relatively new assessment; not used widely in research to date	Tate et al. (1999)

Of the instruments described in Table 2.7 above, the Reintegration to Normal Living Index (RNLI) was selected as the instrument of choice to measure community participation in this study. The RNLI (Appendix I) developed by Wood-Dauphinee et al. (1988) is an 11-item instrument that evaluates how people living with chronic and disabling conditions (like SCI) perceive their involvement in community participation activities such as self-care, recreational and social activities.

The reasons for selecting the RNLI were the following:

- The RNLI is short (11 items), easy to understand and quick to complete (May & Warren, 2002). A copy of the RNLI is freely available on the internet and it does not require any licensing or special training to administer or score.
- The RNLI reflects the concept of person-perceived participation by assessing an individual's satisfaction with performance in life activities including mobility, self-care, daily activity, recreational activity, and family roles (May & Warren, 2002).
- The RNLI has been widely studied in different countries among different patient population groups (Bourdeau, Desrosiers & Gosselin, 2008; Carter, Buckley & Ferraro et al., 2000; Daneski, Coshall, Tillingand & Wolfe, 2003; Pang, Eng & Miller, 2007) and is recommended as a participation measure (Participation Team, 2005; Willkie, Peat, Thomas & Croft, 2004).
- The RNLI has been validated as a measure of participation. A recent study by Stark, Edwards, Hollingsworth and Gray (2005) to establish the validity and reliability of the RNLI in a population of community-dwelling adults with mobility limitations (including PLWSCI) found the RNLI to have a Cronbach alpha value of 0.91, which is excellent reliability (Arias & de Vos, 1996; George & Mallery, 2003; Nunnally, 1978). In their review of conceptual and methodological issues related to the construct of participation as defined by the ICF, the Participation Team (2005) identified the RNLI as the participation measure of choice for client centred rehabilitation. Similarly, a review of 27 participation instruments by Willkie, Peat, Thomas and Croft (2004) found the RNLI to be the most relevant

measuring instrument of participation restrictions with the largest proportion of participation items when compared with other instruments.

2.6.4 Instruments for measuring personal factors

Personal factors refer to the bio-psychosocial aspects of the individual, which are not part of their injury (Bornman, 2004). These are typically assessed using a checklist, and include age, gender, marital status and socio-economic status (Westaway, 2007). The socio-demographic part of the previously mentioned SDIP (2.6.1) was selected for measuring personal factors in this study.

2.6.5 Instruments for measuring environmental factors

Very few instruments have been designed for measuring the impact of environmental factors on people with disabilities (including PLWSCI). The Craig Hospital Inventory of Environmental Factors is practically the first instrument specifically designed for this purpose; therefore there was no real choice of instruments in this regard. The CHIEF is “*a broad-based measure of the environment that quantifies the degree to which elements of the physical, social, and political environments act as barriers or facilitators to full participation for people with disabilities*” (Whiteneck, 2001, 14). For the above reason, the CHIEF short form (Appendix K: CHIEF-SF) was selected to evaluate the impact of perceived environmental barriers to community participation as reported by individuals with SCI. The CHIEF has also been used in South Africa (Vosloo, 2009), but the psychometric properties of the instrument were not reported.

The CHIEF is a 25-item instrument designed to measure accessibility, accommodation, resource availability, social support and equality. The CHIEF items ask participants questions about frequency and magnitude of environmental barriers experienced over the past year. For example, CHIEF item 2 reads: “In the past 12 months, how often has the natural environment – temperature, terrain, and climate – made it difficult to do what you want or need to do?” Each question is graded

according to the frequency of the problem, the magnitude of the problem and then added to measure the overall impact of the perceived barrier/facilitator, as described in section 3.2.5.5.1(c) on the scoring of the CHIEF instrument.

The CHIEF total score has high test-retest reliability (Intraclass correlation coefficients [ICC] = 0.93) and high internal consistency (Cronbach alpha = 0.93) (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue, & Gerhart, 2004).

The short version of the CHIEF, CHIEF-SF, was selected for use in this study. The CHIEF-SF utilises only 12 items of the original CHIEF without compromising the validity and reliability of the instrument. Psychometric properties of the CHIEF-SF were evaluated using a sample of convenience of 409 individuals with disability, including 124 participants with SCI (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue & Gerhart, 2004). The CHIEF-SF has a high correlation of subscale and total scores, suggesting good construct validity. The internal consistency of the CHIEF-SF was found to be acceptable with a Cronbach alpha of 0.75 (Whiteneck et al., 2004).

It takes about 10 minutes to administer the CHIEF as a self-report measure, and up to 15 minutes if administered by an interviewer. The CHIEF-SF takes about seven to eight minutes to administer.

2.7 SUMMARY OF THE LITERATURE REVIEW

This chapter has provided a review of the literature with regard to the research relevant to this study. Owing to limited research on the subject in South Africa, most of the literature reviewed focussed on international studies. The chapter discussed the background of the ICF as the model underpinning the conceptual framework of this study. Factors influencing participation and the various instruments for measuring community participation and related factors following SCI were also discussed within the conceptual framework.

The reviewed literature indicated that the participation of PLWSCI in various societal roles is a global challenge, and that there is a dearth of contextually relevant and local literature on the topic. Most studies reviewed were conducted in developed countries, and their findings may not necessarily apply to developing contexts like South Africa. There is thus a knowledge gap to be addressed in this study.

Based on the literature review, the following instruments were selected for use in the methodology:

- The Socio-Demographic and Injury Profile was selected to describe the SCI and personal profile of the participants.
- The Reintegration to Normal Living Index (RNLI) was selected as a measure of the participants' level of satisfaction with their community participation.
- The Spinal Cord Independence Measure (SCIM) was selected as a measure of participants' functional abilities in terms of activities of daily living, respiration and bladder management and mobility.
- The Craig Hospital Inventory of Environmental Factors – short form (CHIEF-SF) was selected as a measure of the participants' perceived barriers to community participation.

The next chapter discusses the methodology of this study, as informed by this literature review.