Determining the process of rehabilitation and the outcomes of patients at a specialised

in-patient centre in the Western Cape

Conran Joseph

KEYWORDS

Stroke

Spinal cord injury

International Classification of Functioning, Disability and Health

Impairment

Activity limitation

Participation restriction

Disability

Rehabilitation

Outcome

Process of rehabilitation

Western Cape Rehabilitation Centre



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Abstract

The World Health Organisation estimates that the majority of the disabled population resides in the developing world, but most of the research on outcomes of patients originates from the developed world. In the light of the differences in healthcare structures and function, especially rehabilitation between settings and countries, it is imperative to have an understanding of the functioning of patients at discharge with the objective of measuring the level at which outcomes are met. The aim of this study was therefore to determine the process of rehabilitation and the outcome of patients following in-patient rehabilitation at a facility in the Western Cape. A quantitative research design was employed to address the objectives. Self-administered questionnaires were developed to collate information pertaining to the demographic-, socioeconomic- and medical profile of patients and data extraction sheets collected information relating to the process of rehabilitation and the impairment status of patients on admission. With regards to activity and participation, a longitudinal study design was used, which utilised standardised outcomes measures. The sample consisted of all patients with stroke and spinal cord injury admitted within a three-month period, and all ethical principles relating to research on human subjects, as stipulated in the Helsinki Declaration were adhered to during data collection, with ethical clearance obtained from relevant authorities. The SAS and the Microsoft Excel Package 2007 were used to analyse the quantitative data elements. Descriptive statistics using frequencies, percentages, ranges, means, and standard deviations and inferential statistics using chi-square, student T-tests and correlation tests, for determining the predictors of functional outcome, were calculated. There were 175 patients, whereof 82 were patients with stroke and 93 with spinal cord injury, with 143 (76 presenting with spinal cord injury and 67 with stroke) meeting the inclusion criteria on admission. The mean age of those with spinal cord injury and stroke was 34.14 and 52.95 years. Most of the patients with spinal cord injuries were single (73.68%), whereas the

majority (53.73%) of patients with strokes were married at the time of injury. All patients were managed by the doctor and the nurse, with most of the patients receiving physiotherapy, occupational therapy and social assistance from the social worker. With regards to recreational activities, 46.87% of patients with spinal cord injury and 39.39% of those with stroke attended the learn to swim programme, and 29.68% of patients with spinal cord injury attended the wheelchair basketball sessions. The mean length of hospital stay for patients with spinal cord injury and stroke was 73.11 and 51. 62 days, with most of the spinal cord injured patients (80.26%) and stroke patients (82.08%) discharged home without follow-up rehabilitation. The most prevalent impairments on admission of the spinal cord injury cohort were muscle weakness (75.0%), bladder incontinence (71.1%) and reduced sensation (69.7%), whereas patients with stroke presented mostly with muscle paralysis (80.6%), abnormal tone (76.1%) and aphasia (50.8%). Functional limitations experienced by the participants included, mobility, stair climbing and transfers. The participants experienced participation restrictions in the following domains, leisure activities and employment. A clinical significant improvement was noted in execution of functional task of patients with spinal cord injury (p < 0.0001) and stroke (p < 0.0001) between admission and discharge. A significant statistical change was also detected for the participation elements of both stroke and spinal cord injury cohorts. Functional ability on admission was found to be a predictor of functional outcome of the stroke diagnostic group at discharge, whereas the multiple predictor model of functional outcome of the spinal cord injured cohort at discharge was significant with remaining variables of functional outcome score on admission (p<0.0001) and bladder - and bowel impairment(s) (p=0.0247). The study findings suggest that despite the significant change in activity and participation, most of the patients were discharged home without further follow-up for rehabilitation, irrespective of the activity limitations and participation restrictions still experienced at the time of discharge. The latter finding

questions the duration of the length of hospital stay, which does not allow patients to be independent in all meaningful activities and participatory actions and roles by the end of inpatient rehabilitation. The study findings could assist authorities to adapt the existing rehabilitation programme and referral process.



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DECLARATION

I hereby declare that "**Determining the process of rehabilitation and the outcome of patients at a specialised in-patient rehabilitation facility in the Western Cape**" is my own work and that it has not been submitted, in part or in its entirety, for any degree or examination at any other university; and that all sources used or quoted have been indicated and acknowledged by means of complete reference.

Signature:

Conran Joseph

November 2011

Professor. Anthea Rhoda

DEDICATION

I dedicate this thesis to my family (dad, mom, brother and sister) who always believed in me, provided me with the love and constant support that was needed to complete my work, in which I have gained even more interest in.



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ACKNOWLEDGEMENTS

I would like to express my sincere gratitude and appreciation to the following people and institutions for their contributions:

Jesus Christ for granting me strength, understanding and courage in life, especially during my time of studies.

My supervisor, Professor Anthea Rhoda for her guidance, constructive feedback and support throughout this project. I am forever greatful!

South Africa Netherlands Research Programme on Alternatives in Development (SANPADreference group in the Western Cape, based at Stellenbosch University) for financial support and the fruitful meetings that without a doubt expanded and challenged my thinking on disability and rehabilitation.

To my extended family, Ousis, Aunt Judy, Uncle Shaun, Aunty Dollie, Melanie, Fredeline, Shane, Jennifer, Samantha and Donnite for your interest, prayers and support throughout the years.

To the Physiotherapy staff at the University of the Western Cape for the messages of encouragement and genuine interest. Thank you Professor J. Frantz for setting timelines and for your input whenever I was in doubt, and a special thanks to Marla Warner and Nicole Lendor for the administrative assistance. The staff at the Western Cape Rehabilitation Centre for their assistance, and the patients for their participation in this study. Without you this study would not have materialised.

Lastly, a special thanks to Professor Richard Madsen for the statistical analysis. Without your assistance I would not have been able to make sense of the data.



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ABBREVIATIONS

- ADL Activities of daily living
- BI Barthel Index
- LOHS Length of hospital stay
- SCI Spinal cord injury
- SCIM III Spinal Cord Independence Measure version III
- SD Standard deviation
- UNCRPD United Nations Convention on the Rights of Persons with Disabilities
- WCRC Western Cape Rehabilitation Centre
- WHO World Health Organisation



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CHAPTER ONE

INTRODUCTION

1.0 INTRODUCTION

This chapter commences with the backdrop to the study. It contextualises the prevalence of physical disabilities in a global-, national -and local context. Furthermore, a model of how disability is currently viewed is introduced within the International Classification of Functioning, Disability and Health. Rehabilitation as a strategy to manage the disabled population will be described with special reference to the constituents of the organisational structure and processes of care and how favourable outcomes can be achieved, using the Structure, Process and Outcome model. Furthermore, this chapter presents the problem statement, research questions, aims-, objectives- and significance of the study. The chapter concludes with definitions of the key terms used in the study, and the outline of the chapters that follow.

1.1 BACKGROUND TO THE STUDY

In 2004, the World Health Organisation (WHO) estimated that 10% of the world's population experienced various types and degrees of disabilities, of which a postulated 80% of people living with disabilities reside in developing countries (United Nations, 2006; Helander, 1999). A South African census conducted in 2001 reported that 5% of the total population had some form of disability, which is lower than the reported prevalence worldwide. This was the second national post apartheid census conducted in all nine provinces, of which the highest prevalence of disability was found to be in the Free State (6.8%), whereas the

Western Cape (4.5%) had the second lowest number of disabled persons when compared to other provinces.

In the light of the incongruity in prevalence data, the lack of sufficient and accurate data on disability has become a global concern. Moreover, reliable data are paramount since key stakeholders advocate accurate planning of the provision of services for disabled persons in the country as well as the creation of an enabling environment for the equalisation of opportunities based on the burden of disability (Statistics South Africa, 2001; WHO, 2001). Taking cognisance of the fact that disability is multidimensional, the provision of services, as stipulated by the United Nations, are directed towards limiting the consequences of sensory impairment (which include sight, hearing and communication), physical-, emotional-, and intellectual disability (United Nations, 2006). In South Africa, physical disabilities represent the second largest proportion of the disabled population, behind the leading cause of disability, which is visual impairments (Statistics South Africa, 2001).

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In South Africa and abroad, stroke is the leading cause of physical disability among middleaged adults. Despite the research attempts that were made to quantify the mortality, incidence, and prevalence locally, little understanding on the outcomes, especially in the long-term, exists (Connor & Bryer, 2006; The SASPI project, 2004). With regards to spinal cord injury, little attention had been granted to determine the burden, which is an umbrella term for mortality, prevalence, incidence and outcomes, of such patients in South Africa (QuadPara Association of South Africa, 2009).

Empirical evidence from rigorous epidemiological studies exists that underpin the emerging epidemic of chronic diseases of lifestyle including stroke, peripheral vascular disease and heart disease (Kengne & Anderson, 2006). Globally, stroke is the third highest cause of death (Bakas, Austin, Okonkwo, Lewis, & Chandwick, 2002), of which an estimated 5.7 million

deaths occurred in 2005 (Strong, Mathers, Epping-Jordan, & Beaglehole, 2006). Apart from the high mortality rate, the prevalence of stroke has been found to be higher in developed than in developing countries. In some developed countries the prevalence of stroke has been reported as high as 500-800 per 100,000 people (Fieschi, Falcou, & Sacchetti, 1998), whereas a much lower rate of 200-300 per 100,000 has been reported for Sub-Saharan Africa (Kengne & Anderson, 2006). Despite the lower reported prevalence of stroke in developing countries, the onset of stroke is at a much younger age (Connor & Bryer, 2006). This is reflected in prevalence studies conducted in the developing world suggesting that patients with stroke have a mean age of approximately 15 years younger than those affected by stroke in the developed world (Bonita *et al.*, 2004). According to Connor and Bryer (2006), South Africa is currently undergoing an epidemiological change similar to the health and health-related issues of developed countries. This postulated transition could be accompanied by an increase in the incidence and prevalence of chronic diseases of lifestyle, thus the monitoring of disease is imperative for sequential alignment of healthcare and resources (Connor & Bryer, 2006).

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Evidence is also available on the rising prevalence of spinal cord injuries (SCI), even though the reported incidence is rather low compared to chronic diseases of lifestyle. Based on international standards, this injury is considered a huge economic expense, resulting in severe disability, thus manifesting in a profound change in a person's life (Yarkony, Formal & Cawley, 1997). An SCI causes high personal and bio-psycho-social impacts, making the study of its epidemiology a high priority. However, limited evidence on the prevalence and incidence of spinal cord injury is available in the South African context, which eventually obscures the implementation of rehabilitation strategies imperative for optimising the recovery of these patients (Statistics South Africa, 2001; Hart & Williams, 1994). In contrast to predominantly health risk behaviours predisposing individuals to stroke, the causes of spinal injury include trauma, disease and congenital defects (Hulsebosch, 2002). One of the few epidemiological studies conducted by Hart and Williams (1994) among the spinal cord injury population in South Africa, found that gunshot violence was the commonest cause of injury, followed by injuries related to motor vehicle accidents (MVA), stab wounds and falls from heights. The results from the latter study show a disproportionately high incidence of violent injuries in South Africa compared to the rest of the world, which are postulated to be due to the socio-political changes by that time (Hart & Williams, 1994). It is conclusive that the younger age group is more affected than what is found in stroke (Hampton & Marshall, 2000). Despite the vast difference in the causes and nature of strokes and spinal cord injuries, both result in disability since onset, which could last a lifetime (Bakas *et al.*, 2002).

Literature highlights much debate on what constitutes disability. The absence of a globally excepted definition for disability was, and still is, evident in the disparity of the prevalence and incidence of health conditions when compared worldwide (Wyndaele & Wyndaele, 2006). However, with the introduction of the International Classification of Functioning, Disability and Health (ICF) framework in 2001 as the global standard, disability is defined as an umbrella term, encompassing impairment, activity limitations and participation restrictions (WHO, 2001).

Within this framework stroke affects over a thousand impairments, of which speech and thought processes were reported as the most common impairments among survivors at the time of the stroke, and approximately 40% experienced some impairment of movement in arm and leg (Tennant, 2000). On impairment level, patients with spinal cord injury almost always present with muscle weakness and reduced sensory ability (Biering-Sorensen & Sonksen, 2001). With reference to the domain of activity limitation, a study conducted in South Africa found that 60% of stroke survivors needed assistance with activities of daily living (The SASPI Project Team, 2004), whereas approximately one-third of all individuals

with paraplegia required assistance with daily activities such as dressing, transfers and mobility (Berkowitz, Harvey, Greene & Wilson, 1992). The participation restrictions that were experienced by patients with stroke and spinal cord injury included a decrease in physical mobility at home and in the community, an inability to return to perform previous occupation (Carpenter, Forwell, Jongbloed & Backman, 2007; Urimubenshi, 2009), and a decrease in social interaction (Dowswell *et al.*, 2000).

In order to optimise recovery within the domains of impairment, activity and participation, literature has found factors, such as age, severity and extent of the health condition, the onset to admission interval, the structure and process of rehabilitation to be predictors of outcome in stroke and spinal cord injury. However, high level evidence is still outstanding for certain factors (Staines, McIlroy & Brooks, 2009; Scivoletto, Morganti, Ditunno, Ditunno & Molinari, 2003).

Rehabilitation is the strategy to address the multifaceted nature of disability resulting from disease or health-related issues (Department of Health, 2000), which is guided by International standards set by the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities and the World Health Assembly (WHA) Resolution on "Disability, including prevention, management and rehabilitation" (WHO, 2004). These documents represent a strong moral and political commitment from governments to take action to attain equalization of opportunities for persons with disabilities. For example, in South African, the national Department of Health has embraced the need of stroke units, based on reports from the World Health Organisation describing the burden, and thus recommended that every province establish at least one stroke unit.

With the global acceptance of the ICF, which grounded its conceptual basis on the biopsycho-social model, rehabilitation has shifted from being stagnated in the medical model that fundamentally aims to 'correct' the problem within the individual, to focusing on outcomes that are important to the service provider and service user (WHO, 2002). The latter outcomes are, however, shaped and influenced by the social context of the patient, which is beyond repair from a medical perspective, but thus calls on the response of different sectors to bring about change in the social sphere.

Helander (1999) describes rehabilitation as "all measures aimed at reducing the impact of disability for an individual, enabling the patient to achieve maximal independence in home and community life, a better quality of life and self actualization". In order to achieve this holistic functioning of patients, rehabilitation has to be diverse in its approach and should offer a wide range of specific interventions to reduce the consequences of the heterogeneous nature of the patient characteristics altered by a health condition (Salter, Jutai, Teasell, Foley & Bitensky, 2005). Kaplan (2007) suggests that all rehabilitation outcomes are related to the complex interaction and nature of rehabilitation, whereas a non-exhaustive body of knowledge question the contribution of rehabilitation on outcomes (Cramer, 2008). The debate, on which rehabilitation practices account for the desirable outcome, stems from the lack of evidence on the structure and process of rehabilitation.

The complexity of rehabilitation could be understood within the Health Service Delivery framework of Structure, Process, and Outcome (SPO) (Donabedian, 1966). This SPO framework could provide valuable insight into the organisational structures and coordination of rehabilitation practices in establishing cost-effective and quality assured rehabilitation that meet the individual needs of the service user and the mission of the organisation (Kaplan, 2007; Hoenig, Horner, Duncan, Clipp, & Hamilton, 1999; Donabedian, 1966). Within this framework the components of rehabilitation are classified into three distinct groups namely

inputs (structure), processes and outcomes. Each component can further be divided into different dimensions.

The first component categorised the organisational practices for structure of rehabilitation into systemic organisation, staff expertise and technological sophistication. Strong level evidence from the literature reports that a specialised hospital setting is more beneficial than a generalist hospital (Cifu & Steward, 1999; Yeo *et al.*, 1998). In South Africa, the national Department of Health has approved the need for stroke units and recommended that every province establish at least one stroke unit. Despite the efficacy of stroke units compared to patients with stroke being managed in general wards, only two government funded stroke units are available, with both situated in the Western Cape (Fritz, 2000). In a guest editorial the author suggests, in the midst of the lack of agreement on what constitutes the "ideal" stroke unit, the key is a protocol and outcome driven multidisciplinary team made up of a range of professionals including: nurses, clinicians, physiotherapists, occupational and speech therapists, social workers and psychologists (Connor, 2005).

Within the SPO model the process of rehabilitation diverges into dimensions of guidelines and procedures, coordination of care, individualization, amount and timing, and specific interventions. Enough evidence supports the notion that a well-organised, multidisciplinary approach to rehabilitation results in better outcomes for patients (Cifu & Steward, 1999; Evans, Connis, Hendricks & Hasselkorn, 1995; DeVivo, Kartus, Stover, & Fine, 1990). Evidence also underscores that greater frequency of therapy improves functional outcomes across different clinical settings and case mixes (Teasall & Kalra, 2005). More specifically related to rehabilitation services, a study found that an increase in physiotherapy and occupational therapy services alone can result in a 14-day reduction in length of stay, while achieving similar outcomes (p<0.01) (Slade, Tennant & Chamberlain, 2002). The reduction in length of hospital stay could reduce the health cost associated with hospitalisation, which is an enormous expense for the patient, family and government (Kengne & Anderson, 2006; Hoenig et al., 1999), and could increase the admissions of more patients in a pressurised health care system.

The last component of the model is the outcomes of patient with the health condition, which is measureable within the ICF framework. The SPO model suggests that all outcomes, which in simple terms referring to the extent to which goals are achieved (Wilkin, Hallam, & Doggett, 1992), are relative to the interaction of the inputs and the processes, and outcome measures that were used during an episode of rehabilitation (Kaplan, 2007; Hoenig *et al.*, 2002). Hoenig *et al.* (2002) have done considerable work on patients with stroke, focusing on the interrelationship that exists between the structure, process and outcome of rehabilitation. The results of the prospective study showed that the structure of care did not have a statistical significant association with functional outcomes of stroke survivors, but the process of care did strongly associate (beta coefficient 0.18, P <0.01) with functional outcomes. It is important to note that the current study will only describe certain processes of rehabilitation and the outcome of the patients, without influencing the existing rehabilitation programmes, and no inferences or associations will be made between the process of rehabilitation and the outcomes of the patients.

The National Rehabilitation Policy is the guiding document for rehabilitation, advocating for the needs of all citizens. Moreover, rehabilitation is seen as one of the pillars of the healthcare system, thus highlighting the role of rehabilitation in providing comprehensive healthcare to citizens (Department of Health, 2006). Even more stringent requirements of rehabilitation have been made public with the Comprehensive Service Plan 2010 (CSP), which serves as the guiding document on core norms and standards for Primary Health Care and Rehabilitation in South Africa. The Department of Health in the Western Cape has envisaged to put high and low intensity rehabilitation services in place along the continuum of care, namely primary, secondary and tertiary level. The goal of rehabilitation within the context of South African healthcare is to enable individuals to return home to their communities with the highest possible level of functional independence and the best possible quality of life. However, the monitoring and evaluation of these services as recommended by the South African National Rehabilitation Policy (NRP), is lacking, especially in the specialised level of health care (Department of Health, 2000).

The Western Cape Rehabilitation Centre (WCRC) is one of the two institutions having designated specialised units for patients with stroke and spinal cord injury, and is without a doubt the "gold standard" of state-funded in-patient rehabilitation in the Western Cape. This rehabilitation centre provides interdisciplinary, outcome-orientated, individualised in-patient rehabilitation, which are key determinants of a specialised unit, for generally younger patients (<65 years old) with cerebrovascular accidents, traumatic brain injuries, spinal cord injuries, amputations and other diagnosed neurological health conditions. A study conducted five years ago investigated the outcome of patients with first ever stroke (Rouillard, 2007). Since the results of the latter study was only representative of the stroke population admitted to the WCRC, the current study broadened the scope and included patients with stroke and spinal cord injury, which exceeded 75% of all patients admitted during any period of time, and because specialised units for the aforementioned health conditions were available at the centre (Personal communication J. A. Hendry, November 16, 2010). The table below depicts the low prevalence of patient other than those with stroke and spinal cord injury for the year 2009.

Health Conditions	Number of	Percentage
	patients	
Stroke	429	38
Spinal cord injury	418	37
Amputation	105	8
Head injury	81	7
Peripheral neuropathy	58	4
Other or multiple conditions	69	6
Total UNIVERS	1160	100
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 Table 2.1 The prevalence of health conditions for 2009

The envisaged plan of this centre is to become the only high-intensity rehabilitation facility. For this to materialise rehabilitation services should be fashioned in such a way that personnel are in contact with their patients between four-six hours per day (Department of Health, 2006). Currently the therapist-to-patient ratio is too high in order to conform to these standards as stipulated in the Comprehensive Service Plan 2010 (Department of Health, 2006). However, these standards should be used as a reference framework against which research-informed changes are made to the current situation in rehabilitation. All these changes should be directed towards strengthening the health care system and improving the lives of those individuals living with disabilities (Department of Health, 2006). Therefore the advocacy for more rehabilitation personnel at the centre and the need for additional resources

could be substantiated by evidence on the outcomes of patients, which take into account the majority of the patients and the most commonly managed health conditions.

1.2 PROBLEM STATEMENT

Selected determinants of the process of rehabilitation have been found to directly influence the outcome of patients (Hoenig *et al.*, 1999).To this day only one research study has been carried out to determine the process of rehabilitation followed by patients with stroke at the WCRC, but no other studies investigated processes of rehabilitation followed by other prevalent conditions such as spinal cord injury, which is as common as the prevalence of stroke at the institution. The lack of information on the process of rehabilitation could hinder the development of guidelines that could be a barrier to the effective planning and prioritising of funding resources for the institution.

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Measuring outcomes are by no means a new concept in rehabilitation, but up until now the existing knowledge on outcome of patients, originates predominantly from studies in well resourced rehabilitation settings in developed countries (Turner-Stokes, Williams, Abrahams & Duckett, 2000). It is to the believe of the author that the majority of patients admitted to WCRC are discharged home following rehabilitation, but limited evidence of the functioning of patients within the domains of activity and participation at discharge is evident. The lack of baseline and follow-up data on the functioning of patients with stroke and spinal cord injury could delay the development of comprehensive rehabilitation programmes that could optimise functioning in all spheres of human endeavour. It further hinders the evaluation of the need for future formal rehabilitation after discharge from WCRC, and whether the activity

limitations and participation restrictions still experienced at discharge, are valuable predictors of limitations in these domains in the long run.

1.3 RESEARCH QUESTIONS

The specific research questions addressed in this study were:

1. What is the process of rehabilitation followed by patients with stroke and spinal cord injury at the Western Cape Rehabilitation Centre?

2. What is the nature and prevalence of documented impairments of patients with stroke and spinal cord injury on admission?

3. What are the outcomes within the domains of activity and participation of patients receiving specialised rehabilitation at the Western Cape Rehabilitation Centre?

1.4 AIM OF THE STUDY

1. To determine the process of rehabilitation followed by patients with stroke and spinal cord injury at the Western Cape Rehabilitation Centre.

2. To determine the nature and prevalence of documented impairments of patients with stroke and spinal cord injury on admission.

3. To determine the outcomes within the domains of activity and participation of patient with stroke and spinal cord injury admitted to the Western Cape Rehabilitation Centre for rehabilitation.

1.5 OBJECTIVES OF THE STUDY

1. To obtain a description of patients with stroke and spinal cord injury admitted to the WCRC for rehabilitation based on:

- Demographic profile
- Socio-economic profile and
- Medical profile

2. To determine certain aspects of the rehabilitation process, including:

- Referral pathway (referral agency and discharge destination)
- Rehabilitation services received
- Length of hospital stay

3. To determine the nature and prevalence of the documented impairments of patients with stroke and spinal cord injury admitted to the WCRC.

4. To determine outcomes of patients' in the domains of activity and participation on admission and at discharge.

5. To predict selected factors that may influence activity limitation in patients with stroke and spinal cord injury at discharge.

1.6 DEFINITIONS OF KEY TERMS

Activity: the execution of task or action by an individual (WHO, 2001).

Activity limitation: difficulties an individual might have in executing activities (WHO, 2001).

Disability: an umbrella term for impairment, activity limitation and participation restriction. It denotes the complex interaction between an individual's health condition and contextual factors, which are environmental and personal factors (WHO, 2001).

Impairment: the loss and/or abnormality of mental, emotional, physiological or anatomical structure or function; this term includes all losses or abnormalities, not just those attributable to the initial patho-physiology, and it also includes pain as a limiting experience (WHO, 2001; Christiansen & Baum, 1997).

Participation: the extent of a person's involvement in life situations in relation to impairments, activities, health condition and contextual factors (WHO, 2001).

Participation restriction: problems an individual might experience in life situations (WHO, 2001).

Cerebro-vascular accident or Stroke: the WHO defines stroke as "rapidly developing signs of focal or global disturbance of cerebral or intracranial neuronal function with symptoms lasting for more than 24 hours or leading to the death of the patient with no apparent cause other than that of vascular origin (WHO, Monica Project, 1988)".

Multidisciplinary Rehabilitation: team consists of a diverse range of professionals usually including doctors, nurses, physiotherapists, occupational therapists, speech and language therapist, psychologists, dietician and social workers.

Process of rehabilitation: is defined as the content of care received, which includes team members involved in patient management, frequency and duration of rehabilitation, the

referral- follow up- and discharge process, as well as the interventions received (Hoenig et al., 1999). Within the context of this study, it refers to all rehabilitation services received, length of hospital stay and discharge destination.

Outcome measures: measuring instruments that systematically attempt to objectively as possible measure the level at which a person is functioning in a variety of domains, specifically impairments, activity, participation and overall quality of life (Lawton, 1971).

Spinal cord injury: is damage to the spinal cord that result in partial or complete loss of sensation and movement, including incontinence (Chinnock & Roberts, 2005).

1.7 OUTLINE OF THE CHAPTERS OF THE STUDY The thesis is organized into 6 chapters.

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Chapter One presents the background to the study by introducing pertinent concepts that encapsulate the broad aims of the study. In addition to providing the backdrop to the study, the motivation and importance of the study is presented, as well as the objectives and definitions of terms.

Chapter two summarises a narrative review of relevant literature to understand the need for the implementation of the study. It further describes the preferred approaches that was used to conceptualise and to a certain extend contextualise the results of the study.

Chapter three presents the methodology employed to answer the study objectives which cover the overarching broad aim of the study. Aspects discussed in this chapter include, but are not limited to, research design, study sample, development of questionnaires and data analysis.

Chapter four contains the results of the quantitative data that attempted to answer the objectives as stipulated under section 1.5. Results of both diagnostic groups were illustrated separately.

Chapter Five discusses the pertinent results of the study, with reference to published literature as well as highlighting the implication of these results both for the local and international audiences.

Chapter Six summarises the study and draws conclusions from the results. Recommendations for local and national stakeholders and for future research are made based on the study findings, as well as needs that emerged from the review of the literature. Limitations of the study are also presented.

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CHAPTER TWO

LITERATURE REVIEW

2.0 INTRODUCTION

In chapter 1, the background and the problem, purpose, objectives and scope of the study were described. As part of the background the epidemiology of stroke and spinal cord injury was loosely discussed, followed by an introduction of the international standard on what constitutes disability and rehabilitation, as well as the need for outcome research in South Africa. This literature review is presented according to these much debated topics that are derived from the research objectives:

- Incidence and prevalence of each diagnosed health condition
- Background to the conceptual framework (s) of the study
- Disability associated with each health condition following the onset, using the ICF.
- Factors influencing the functioning (activity) of patients with stroke and spinal cord injury
- A review of the standardised outcome measures used in this study
- The process of rehabilitation followed by patients with stroke and spinal cord injury.

An electronic and manual literature search was conducted to identify and collate available literature. Articles referenced in the literature review were identified using Pubmed/Medline, CINALH and Google scholar databases. Keywords used include disability, rehabilitation, outcome, impairments, activity, participation, stroke, incidence, prevalence, spinal cord injury, predictive factors/variables and outcome measures.

2.1 Incidence and prevalence of the diagnosed health conditions

The incidence of a disease is described as the number of new cases presented over a given period (Terent, 2003), whereas the prevalence of a disease refers to a proportion of the population affected by the specific disease at a given (prevalence point) - or certain period. (Orencia & Ballard, 1993).

2.1.1 Stroke

Annually, 15 million people globally suffer from a stroke. Proportionately, one-third reach optimal recovery, another-third die, and one-third are left with long-term disability (WHO, 2004a). A systematic review conducted by Feigin, Lawes, Bennet and Anderson (2003) attempted to analyse 15 population-based studies on stroke and statistically found that the incidence rate of stroke for those aged less than 45 years ranged from 0.1 to 0.3 per 1000 persons. In contrast to the significantly lower incidence rate of the less than 45 year olds, the 75-84 years old group had an incidence rate ranging from 12.0-20.0 per 1000 persons. From the study results it is conclusive that stroke occurs mostly in the elderly.

Limited literature is available on the incidence rate of stroke in developing countries. A possible explanation for this shortage could be the demography, lack of national health resources for conducting neuro-epidemiology and the absence of death certificates in rural areas (Connor & Bryer, 2006). Nicoletti *et al.* (2000) stated that very few door-to-door surveys had been conducted, which were thought to be highly reliable for the results that it yields.

Numerous studies reported that the stroke incidence is greater in males than in females. According to Wolfe (2000) men have a 25-35% increased chance of having a stroke compared to females. With regard to ethnic vulnerability to stroke, the incidence rate also appears to be higher in blacks than in whites. A literature review of ethnic variation in stroke epidemiology conducted by Stansbury, Jia, Williams, Vogel and Duncan (2005), found the incidence of first-ever strokes among blacks to be 288/100 000 compared with the rate of 179/100 000 for whites.

To date no reliable data are available on the incidence of stroke in South Africa. However a relatively recent attempt to estimate the stroke incidence through reviewing registers of certain urban hospitals in South Africa and Zimbabwe were made by Connor, Walker, Modi and Warlow (2007). The latter study found that the hospital-based incidence was lower than in the high-income countries, but significantly higher for younger age groups (Connor *et al.*, 2007). The major confounding factor to the lower reported incidence could be the failure to routinely hospitalise all patients with stroke in South Africa, irrespective of the severity and extent of the stroke. The aforementioned postulation tacitly agree that only the severe cases and those who can access health services easier, are most likely to be admitted.

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Given the variance in the incidence of stroke between countries that follow vastly different methodologies, Connor and Bryer (2006) emphasised the importance and the undisputable need for community-based stroke incidence studies in order determine the true extent of the burden of the disease. In the midst of limited literature, it is speculated that South Africa is currently undergoing epidemiological changes similar to the disease profiles of developed countries (Connor & Bryer, 2006), which could mean an increase in the prevalence of chronic diseases of lifestyle and an increase in the incidence of stroke (Poungvarin, 1998; Fritz, 2000). Thus, future studies investigating this transition are becoming a top priority, as future community-based epidemiological studies will contribute greatly to the prioritising and alignment of services centred towards the pandemics and uprising epidemics, which includes stroke (The SASPI Project Team, 2004; Hale & Eales, 2001). Concerning the prevalence of stroke, the high-income countries boast with a range from 461-733 per 100 000 for people aged 65 and more (Feigin *et al.*, 2003). Similar to the lower reported incidence of stroke in South Africa compared to results from developed countries, a study found the prevalence of stroke to range from 243-300 per 100 000 of the population. With regard to the gender prevalence rate of stroke in South Africa, a local study found a higher prevalence of stroke in females (348 per 100 000) than males (246 per 100 000) (The SASPI Project Team, 2004). This is in contrast to the results of a systematic review of 15 population-based studies, which found that the age-standardised prevalence rate for people aged 65 years or more ranging from 32.2 to 61.2 per 1000 population for females and between 58.8 to 92.6 per 1000 for males (Feigin *et al.*, 2003). Many studies investigated the factors influencing the disparity of stroke with reference to the gender-prevalence. However, preliminary results suggest that the disparity could be influenced by, but are not confined to, age, race, economic status and geographical-location differences (Stansbury *et al*, 2005).

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2.1.2 Spinal cord injury

The incidence of spinal cord injury (SCI) has been examined in various studies, but the findings vary considerably. To illustrate this variation, a worldwide literature review estimated the incidence rate of SCI ranging from 9-53 new injuries per 1000 000 persons per year (Wyndaele & Wyndaele, 2006), whereas the estimated annual incidence of SCI in the Unites States, taking into account those who die at the scene of an accident, is approximately 40 cases per 1000 000 population or approximately 12,000 new cases each year (National Spinal Cord Injury Statistical Center, 2005). In 1995, the incidence rate in the US was reported as 30-40 per 1000 000 per annum (Go, DeVivo & Richards, 1995), which was similar to the annual incidence of 40.2 per 1000 000 in Japan. In contrast to the higher

prevalence in the US and Japan, Schönherr, Groothof, Mulder and Eisma (1996) studied both traumatic and non-traumatic incidence of SCI in the Netherlands and estimated a crude incidence of 16 per 1000 000 persons per year.

In a budget report presentation by The QuadPara Association of South Africa (2009) the importance of the knowledge on the incidence and prevalence of patients with quadriplegia and paraplegia was reiterated. This knowledge was said to assist in the planning and coordination of health services and resources available to the different classifications of the spinal cord injured population.

Concerning the classification of spinal cord injuries, literature learned that two-thirds of patients with SCI's were paraplegic, whereas the remaining were quadriplegics. Contrary to the higher estimated prevalence of patients with paraplegia, a study conducted in Netherlands found that 57% of the population with SCI was quadriplegic (van Asbeck, Post & Pangalila, 2000), with close to similar findings from a demographic and hospital-based study, which found the prevalence rate to be 54% and 67.2% respectively, of patients with quadriplegia (Gupta, Taly, Srivastava & Murali, 2009; Jackson, Dijkers, Devivo & Poczatek, 2004).

A worldwide literature survey on the epidemiology of SCI reported the lack of published data on the prevalence of SCI. A recent literature review found that only two studies, one conducted in Finland and the other in Australia, reported the prevalence of SCI to range from 223-755 per 1000 000 inhabitants (Wyndaele & Wyndaele, 2006). However, the methodologies of the aforementioned two studies were vastly different; therefore these estimates should be taken with caution. It was concluded in the study that data on prevalence and incidence of SCI from Asia, Africa, and Latin America are still outstanding to permit global estimates. (Wyndaele & Wyndaele, 2006). Therefore improved registration of SCI is recommended, specifically in the developing world, but future studies should conform to uniform study designs in order to facilitate unambiguous comparison.

A literature review carried out by Blumer and Quine (1995) reported on the prevalence of SCI between 1975 and 1995, and found that the prevalence rate ranged from 110-1120 per 1000 000 inhabitants. The National Spinal Cord Injury Statistical Centre (NSCISC) estimated that the number of people in the United States, who are alive and have an SCI, to be approximately 250 000 persons in July 2005 (NSCISC, 2005).

Locally, limited reliable statistics are available on the prevalence of spinal cord injuries. This was part of the limitations of the census conducted in 2001, which classified people with disabilities into one mainstream category labelled "disability", therefore, no quantification of the prevalence of different disabilities were possible (Statistics South Africa, 2001). However, the Quadriplegic Association of South Africa (2009) estimated that the annual incidence in South African of those who sustain a spinal cord injury is approximately 500, whereas a single study conducted by Sereilis (2009) estimated that more than 50 000 people in South Africa are living with a spinal cord injury.

Inconclusive evidence exists on the prevalence and incidence of stroke and spinal cord injury. Various factors led to the disparity in estimated prevalence and incidence of these conditions when compared internationally. Apart from stroke, there is a lack of data on the epidemiology of spinal cord injury in South Africa. This finding underscores the need for conducting epidemiological studies, which is needed for the planning and implementation of healthcare and resources to meet the needs of the patients.

2.2 The International Classification of Functioning, Disability and Health

In rehabilitation literature, a uniform language for the classification of disability was often missing. The understanding of disability is complex and multi-dimensional, taking into account a number of different aspects that interrelate in a complex manner (WHO, 2001). These aspects include the health condition, the external physical, social and attitudinal environment, the person's quality of -and satisfaction with life, as well as the inherent personal factors (Schneidert, Hurst, Miller & Ustun, 2003). This complexity indicates that any single model of disability is inadequate to provide a sound theoretical model of understanding on the influence the health condition has on the individual, given the unique context in which the survivor conducts his or her life.

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In an attempt to conceptualise health and disability, the International Classification of Functioning, Disability and Health (ICF), formally known as the International Classification of Impairment, Disability and Handicap (ICIDH), was launched by the World Health Organisation (WHO, 2001). The ICF addressed many of the criticisms of the ICIDH, partly through representing its theoretical framework based on the bio-psycho-social perspective. This paradigm shift of understanding has been developed by stakeholders worldwide through consensus and was subsequently welcomed by the clinicians and researchers as a framework to better understand disability (Weigl *et al.*, 2006; WHO, 2001).

The framework consists of two domains. The first domain includes the direct or developing influence and consequences the specific health condition has on body structure and function (impairment), activity limitation and participation restriction. The World Health Organisation (2001) defines the categories of the first domain as follow:

- Impairment: "problem in body function or structure as a significant deviation or loss"
- Activity limitation: "difficulties an individual might have in executing activities"
- Participation restriction: "problems an individual may experience in life situations"

Since an individual's functioning and disability occur in a unique context, the second domain of the ICF further includes the contextual factors. The context is made up of both internal factors (age, gender, other co-morbidities, personality and coping style) and the external factors relative to the person including the physical, attitudinal and social environment (WHO, 2001). A comprehensive assessment of the aforementioned factors forms the basis for planning and executing a patient-oriented and effective intervention (Weigl *et al.*, 2006). The diagram below illustrates the interaction between the health condition and the two domains (WHO, 2001).

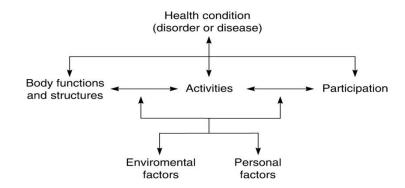


Fig 2.1 Interaction between the domains of the ICF

The ICF is useful in the understanding of disability of both individuals and populations. In the clinical setting the first domain of the ICF (consisting of impairment, activity and participation) is especially used for functional status assessment, goal setting, treatment planning and monitoring, as well as an outcome measurement for the individuals themselves. It further serves as a basis for standardised multidisciplinary documentation of functioning and disability of a patient based on history-taking, evaluation and synthesis of information to direct holistic planning of interventions (Weigl *et al.*, 2006; Stucki, 2005).

Apart from the clinical setting, the ICF can be utilised for research purposes. The ICF can serve as a benchmark for content- and underlying construct comparison of outcome measures and thereby facilitate the selection of the most appropriate measure to cover the desired dimensions of functioning (Scheepers, Ketelaar, Van De Port, Visser-Meily & Lindeman, 2007; Stucki, 2005). It further provides a basis for programme evaluation to ensure that service delivery is better matched to the patient's needs (WHO, 2001). Using this framework could assist researchers and clinicians to determine whether the impairments, activity limitations and participations were addressed by specific interventions or rehabilitation programmes; if not, this framework could serve as a platform that recommending the necessary changes that should be made in order to optimise recovery and improve functioning within each domain.

In conclusion, the widespread use of the ICF in practice and research leads to the assumption that the framework has been accepted globally. This conceptual model could ultimately be the common language that was needed in the past to facilitate the description of health and health-related issues and the measurements of the consequences of health conditions between individuals and populations worldwide.

2.3 Disability following the onset of the diagnosed health conditions

Disability following the health condition will be discussed within the three measurable domains of the ICF, namely: impairment, activity limitation and participation restriction.

2.3.1 Impairments related to the health conditions

2.3.1.1 Stroke

The consequences of stroke are vast and heterogeneous in nature, therefore none of the impairments or clinical manifestations are mutually exclusive (Lawrence *et al.*, 2001). A stroke is seen as a life-changing event, with highly disruptive emotional, physical and social consequences, which negatively impacts the quality of life of the survivors (Rudd, 2004).

A community-based study conducted by Lawrence *et al.* (2001) estimated the prevalence of acute neurological impairments and disability in a multi-ethnic population. The results of the study demonstrated that the most common impairments in the study sample (N=1259) were found to be in higher order of prevalence, upper-and lower limb weakness (77.4% & 72.4%), urinary incontinence (48.2%), dysphagia (44.7%), impaired consciousness (44.7%) and cognitive impairment (43.9%). Findings from numerous other studies corroborated on the fact that the most common impairment in stroke patients was motor deficit, with more upper limb than lower limb weakness (Steward, Cauraugh, & Summers, 2006; Warlow et al., 1996; Wade & Hewer, 1987). A literature review found similar results than the study carried out by Lawrence *et al.* (2001), with regards to the prevalence of urinary incontinence that ranged from 32% to 79% in hospital-based studies (Brittain, Keet & Castleden, 1998).

Impairments presented on a lesser scale in the large cohort (N=1259) of patients with stroke as carried out by Lawrence *et al.* (2001) were ataxia, gaze paresis, visual neglect, visual field defect, upper-and lower limb sensory deficit, sensory inattention, dysarthria, dysphasia and

urinary catheterisation (Lawrence *et al.*, 2001). In contrast to the lower prevalence of impaired sensation as reported by the latter study, a study carried out by Carey (1995) estimated that 60% of all stroke patients have impaired sensory ability. A retrospective evaluation of hospitalised stroke events deduced that 44.5% of 474 hospitalised patients with stroke presented with sensory impairment (Rathore, Hinn, Cooper, Tyroler & Rosamond, 2002).

Literature is available underpinning an even higher prevalence of sensory impairment. For instance, a prospective hospital-based study carried out on 128 patients suffering a stroke in Japan found that 88.3% of the study participants had impaired sensation in one or more sensory modalities (Isagoda & Nakamura, 1995). The discrepancy in reported prevalence of impaired sensation among the stroke population could have been facilitated by the problematic nature of assessment, knowing that only a few standardised measures have established validity and reliability (Wade, 1992).

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Prevalence of patients presenting with aphasia, both receptive (sensory) and expressive (motor) have been found less prominent than other impairments. A literature survey carried out by Dobkin (2005) found that 20% of patients with a stroke suffered some form and degree of aphasia. Another hospital-based study found that 24% of stroke incidence for that specific cohort presented with speech deficits (Rathore *et al.*, 2002).

The presence of cognitive impairment post stroke is common. A cross-sectional study was carried out to determine the prevalence of baseline cognitive impairment among 200 participants, of which 54.5% presented with various degrees of cognitive impairment. In the latter study multivariate analyses were conducted to establish predictors for cognitive impairments impairment. The results indicated that the significant predictors for cognitive impairments

were age (more than 81 years), education less than or equal to secondary level, severe neurological impairment and depression on admission (Saxena, 2006).

Impaired balance is found to be common in survivors of stroke and serves as a predictor for the execution of certain activities of daily living such as sitting, standing and walking. A prospective hospital-based cross sectional study conducted by Tyson, Hanley, Chillala, Selley and Tallis (2006) found that 83% of the subjects presented with impaired balance. The result further revealed that patients with severe balance problems suffered more severe strokes, impairments and disabilities (Tyson *et al.*, 2006)

The average number of impairments per stroke survivor varies, but their influence on outcomes are profound. Lawrence *et al.* (2001) found that more than half of the study sample (50.6%) presented with six to ten impairments. A limitation of the latter study was the neglect of determining the influence of the number of impairments per stroke survivor on the functional outcomes, which would inform the key stakeholders on rehabilitation approaches and processes that should be used to address the full spectrum of impairments, activity limitations and participation restrictions.

2.3.1.2 Spinal cord injury

The consequences of a spinal cord injury (SCI) are determined by the level and completeness of the lesion. What is known is that the higher the level of the lesion, the greater the loss of bodily function. Damage to the spinal cord leads to a disruption of ascending and/or descending nerve impulses and may lead to loss of voluntary control of movement, loss of sensation, and to severe impairment of bladder, bowel and sexual functions as well as visceral and autonomic functions (Bloemen-Vrencken, 2006; Biering-Sorensen & Sonksen, 2001).

A cross-sectional study conducted by Anderson (2004) determined the order of importance of certain body functions and activity limitations affected among a cohort of patients with complete or incomplete spinal cord injuries. The items of importance include the common primary impairments based on consumer feedback, empirical evidence, and categories predominantly used in the literature. The results show that the most severe impairment reported by the cohort was pain, followed by impaired sensation, walking movement, bladder and bowel function, trunk stability, sexual function and arm/hand function (Blight, 2002; Estores, 2003; Cohen & Marino, 2000; Widerström-Noga, Felipe-Cuervo, Broton, Duncan & Yezierski, 1999). Another important finding from the study by Anderson (2004) was the difference of the importance of certain physiological functions affecting the perceived quality of life between quadriplegic and paraplegic patients. Almost half (48.7%) of patients with quadriplegia ranked the importance of arm/hand motor function the highest, whereas patients with paraplegia (26.7%) ranked sexual function and bladder and bowel/autonomic dysreflexia (18%) the highest. Both groups ranked trunk stability third in order of perceived importance relative to the desired effects on quality of life (Anderson, 2004). This study serves as advocate for the alignment of rehabilitation towards addressing patients' problems on a level of impairment and thus fulfilling the rehabilitation philosophy of enhancing the quality of life of patients.

Estores (2003) reviewed six studies and found that pain was one of the most important concerns to the patients with a spinal cord injury. The impact of pain following spinal cord injury is demonstrated by a report of which 37% of SCI patients with high thoracic and cervical lesions and 23% of SCI patients with low thoracic and lumbosacral lesions would be willing to trade pain relief for loss of bladder, bowel, or sexual function (Nepomuceno, *et al.* 1979).

Many studies have reported on the prevalence of pain in patients with SCI, and unsurprisingly with little consistency. A summary from ten studies indicates that an average of 69% of patients experience pain, and that one-third of those in pain rate their pain as severe (Bonica, 1991). Another study of almost 1000 participants demonstrated a prevalence of chronic pain of 66% (Stormer et al., 1997) and a cross-sectional quantitative study, which utilised a postal survey, documented a prevalence of 66% (Siddall, Taylor, McClelland, Rutkowski & Cousins, 1999). In certain studies even higher prevalence rates were documented. One study reported the incidence of pain during in-patient rehabilitation following SCI as high as 90% (New, 1997). A community survey conducted among patients with SCI supported the findings of higher rates of pain prevalence (79%) than the previously reviewed articles on pain following spinal cord injury (Turner, Cardenas, Warms & McClellan, 2001). The increase in pain prevalence could be due to the fact that more patients with spinal cord injury in the community developed secondary complication such as contractures, spasticity/spasms and pressure sores, which is usually absent or well-controlled WESTERN CAPE for in an acute and rehabilitation setting.

Another primary impairment not uncommon to patients with spinal cord injury, specifically quadriplegics, is respiratory function. A cross-sectional study carried out by Anderson (2004) found that out of the sample of 347, 70 respondents were quadriplegic with lesions between C1-C4, which could have had impaired respiratory function. A limitation to the study carried out by Anderson (2004) was the use of electronic surveys which resulted in a low response rate and the possibility of selection bias in the respondents' characteristics.

Summary of impairments of the various diagnosed health condition

The most common impairments following stroke range from limb weakness, incontinence, cognitive impairment and sensory impairment. Spinal cord injuries result due to complete or

incomplete lesions to the spinal cord. The latter diagnosed health condition results in reduced muscle strength, sensory impairment, and the possibility of compromised respiratory function. Having highlighted the common impairments following each diagnosed health condition, the heterogeneity is clear. Since impairments are heterogeneous in nature, it is important to determine the nature and prevalence of impairments for the various diagnosed conditions with the prerogative of effectively planned appropriate resources, and the subsequent alignment of rehabilitation practices to match the needs of the patients (Kaplan, 2007).

2.3.2 Activity limitations commonly experienced post onset of the health condition

2.3.2.1 Stroke

Activity limitations are defined as any difficulty experienced by an individual in the execution of a specific action or task (WHO, 2001). Activity limitations within the ICF framework can be experienced in three broad domains of functioning, central to virtually every patient. The three domains include mobility, self-care and domestic life. Literature found that approximately 40-50% of patients with stroke are left with moderate functional disability, whereas 15-30% (American Heart Association, 2004) experience severe disability, thus leaving them dependent on others for activities of daily living (Rhoda, Mpofu & De Weerdt, 2011; Gresham *et al.*, 1975)

The most commonly used tasks or actions as included in the "gold standard" functional outcome measures are measures of independency in feeding, dressing, bathing, grooming, toileting, transfers and walking (WHO, 2001). Self-care activity limitations often reported by patients with stroke are eating, toileting and bathing (Urimubenshi & Rhoda, 2010).

Apart from self-care activities, a common concern by individuals after stroke is the possibility of regaining independent walking. This highly functional activity requires of patients to have the capacity to execute safe, efficient walking within a specific time-frame and strategies of how to overcome environmental constraints (Macko, Ivey & Forrester, 2005). A qualitative study conducted by Urimubenshi (2009) explored the activity limitations in a purposively selected sample with stroke, and found that walking was one of the critical limitations expressed by the group.

Mobility is not only exclusively referring to ambulation, but includes mobility of all body parts. Impaired fine hand use has been found common after acute stroke. The inability to use one's hand could result in limitation of activities of daily living, such as self care, gripping strength, writing, manipulation of objects, transfers and numerous other activities that require the use of the impaired hand (Sackley, *et al.*, 2006; Mayo *et al.*, 2000). A recent prospective study described and analysed the recovery of fine hand use and the association between find hand use and self-care. The result showed that 70% of all patients had limited hand use in the first week, 41% at three months follow-up and 45% at 18 months after stroke. The study found that with time after stroke, self-care became less associated with find hand use (Welmer, Holmqvist & Sommerfield, 2008).

Apart from self-care and mobility, stroke patients could experience limitations in domestic life. In a study carried out by Mayo, Wood-Dauphinee, Cote, Durcan and Carlton (2002) investigating the extent of activity and participation of individuals post-stroke, the result showed that 39% reported a limitation in functional activities, 54% reported limitations with domestic life activities such as housework and shopping. Another study found that domestic life activities limited in individuals with stroke were washing, cooking, shopping and cleaning (Pajalic, Karlsson & Westergren, 2006).

2.3.2.2 Spinal cord injury

The functional independence of persons with spinal cord injury is significantly lower than that of the rest of the population, and often relies on the assistance of others for straightforward tasks (Post, van Asbeck, van Dijk, & Schrijvers, 1995). SCI does not only affect the patient, but have profound implications on the functioning of the family, caregiver and broader community. Person with SCI can be completely independent or partially- or totally dependent on others for activities of daily living. The amount of assistance required is perpetuated by the level and completeness of the lesion. Thus, subjects with quadriplegia need more assistance than those with paraplegia (Middleton, Truman & Geraghty, 1998).

It is estimated that approximately one-third of all individuals with paraplegia require assistance with activities of daily living and/or community mobility (Berkowitz, Harvey, Greene & Wilson, 1992). The activity limitations often reported on in the literature among patients with spinal cord injuries are personal hygiene, dressing of the upper-and lower body, other aspects of personal care and feeding. One study reported that only 35.4% of the subjects were independently eating and drinking, 43.3% with personal care, but almost everyone was independent with wheelchair mobility (Post, Dallmeijer, Angenot, van Asbeck & van der Woude, 2005).

Patients with SCI's often reported regular bladder emptying, an activity that is limited or impaired due to the inability of safe and effective transferring and/or ambulating to the toilet or other appropriate devices (Sjolund, 2002). A cross-sectional study among patients with SCI (N=121) in Helsinki found that almost half (48%) of the sample needed assistance with bladder management (Dahlberg, Kotila, Kautiaien & Alaranta, 2003).

Mobility following SCI is virtually always affected because of the muscle paralysis. However, rehabilitation had always been centred towards equipping patients with the necessary skills that are important to facilitate safe transfers from bed to chair and vehicle, practicing wheelchair skills both in a manual chair and, in cases of more severe injuries, in an electric wheelchair (Sjolund, 2002). A literature review carried out by Estores (2003) found that among paraplegic patients ambulation was the most important activity limitation identified. A study by Post *et al.* (2005) reported that only 33% of patients with SCI were able to walk independently. Ambulant patients often need to walk on different surfaces and negotiate stairs at home or in a community environment.

A cross-sectional study conducted in Helsinki among 121 patients with SCI, reported that the item for which assistance was needed most was moving on stairs. A total of 65% of the study sample needed assistance on stairs. The same cohort further felt that bathing was the most difficult activity to perform, where close to one-third of the subjects needed assistance. Prevalence data on the functional independence of persons with SCI would be useful to authorities and assists with the planning and coordination of rehabilitation to match the day-to-day functional needs of the patient (Dahlberg *et al.*, 2003).

Summary of activity limitations following the diagnosed health condition

Activity limitations are common following the onset of stroke and spinal cord injury. This review highlights the limitations experienced within the dimensions of mobility, self-care and domestic life. Walking ability is compromised following the onset of the conditions. It is clear how the limitations in activities of daily living and specifically walking ability could lead to dependency on others for assistance and how it could influence participation in the broader community. The study on activity limitation is thus central to health professionals working in the rehabilitation arena.

2.3.3 Participation restrictions commonly experienced post onset of health condition

2.3.3.1 Stroke

Participation restrictions experienced within the stroke population are diverse in nature and context-specific. No two stroke sufferers experience participation restrictions to the same extent. It is well known to all individuals and key stakeholders that stroke is a life-changing event which could leave individuals incapacitated and unable to attend work. Returning to ones previous occupation had been found to be the most common restriction in participatory roles (Saka, McGuire & Wolfe, 2005). A study carried out by Vestling, Tufvesson and Iwarsson (2003) recruited 120 patients over a four-year period to determine the percentage of those who returned to work at six months post stroke. The results showed that only 41% returned to work, and the mean time to return to work was approximately one year for those who returned. In the same study predictive factors of returning to work were individuals who could walk independently, had a non-manual job, and had preserved cognitive abilities (Vestling *et al.*, 2003). In the light of planning and shaping rehabilitation services, it should be noted that the spectrum of participation restrictions after stroke almost always encompass the inability to work or to generate an income (Green & King, 2009; Dowswell *et al.*, 2000)

Apart from hindrances in the occupational life activities, patients with stroke experience decrease social interaction and restriction to participate in religious activities (Urimubenshi & Rhoda, 2010; Dowswell *et al.*, 2000). Limited literature of studies with a quantitative research design is available on participation restrictions following stroke, since the participatory domain is best described and conceptualised through lived-experience. A possible reason for this lack of quantitative literature could be the new concepts presented by the ICF, the heterogeneity of participation hindrances experienced by survivors of stroke, and the occupational gaps indentified in the stroke specific outcome measures, which could

confound the systematic and objective assessments among patients with stroke (Eriksson, Tham, & Borg, 2006).

In addition to decrease social integration, returning to work and religious activities, numerous studies concluded that participation hindrances in leisure activities had been experienced by patients with stroke. Some of the leisure activities people had previously enjoyed included dancing, knitting, travelling, and reading, going out for a stroll and watching sport on the television (Pound, Gompertz & Ebrahim, 1998). Patients with stroke often experience a sense of loss of their previously enjoyed hobbies and activities which had been a source of pleasure and achievement in the past (Ch'Ng, French & Mclean, 2008; Pound *et al*, 1998).



2.3.3.2 Spinal cord injury

With the start of the development process of core sets for patients with SCI, The International Classification of Functioning Disability and Health (ICF) identified a number of domains that exemplify the multifaceted nature of participation among patients with SCI. These domains of functioning include learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life (WHO, 2001).

Similar to stroke, patients with spinal cord injury are often faced by the reality of not returning to their productive state. Employment plays a significant role in defining people's lives, and has been extensively proven to be associated with higher quality of life (Duggan & Dijkers, 2002) and high life satisfaction among people with spinal cord injuries (Fuhrer, Rintala, Hart, Clearman & Young, 1992). A study conducted in 1996 reported that only 38% of Canadians with SCI's aged 15–64 were employed, compared to 70% of persons without

disabilities (Canadian Paraplegic Association, 1996). In the US, more than half (57.5%) of those persons with SCI admitted to a Central Model System reported to be employed at the time of their injury. At one year after injury, 11.6% of persons with SCI were employed, whereas two decades post injury, 35.4% were employed and a similar level of employment was observed three decades post injury (National Spinal Cord Injury Statistical Center, 2005). The only limitation of the US based statistics is the lack of explicit figures on the mortality of patients during the 30 years of record-keeping, which could have biased the relative employment figure post SCI.

Apart from restrictions experienced in employment activities, Noreau and Fougeyrollas (2002) identified more barriers to residence maintenance, participation in family roles and domestic tasks, and recreational (attending cultural events, sports, fitness, games) activities among patients with spinal cord injury (SCI).

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A community-based study (N=357) carried out by Carpenter, Forwell, Jongbloed and Backman (2007) determined the experiences of community participation of patients with spinal cord injury specifically in the dimensions of employment, social activities, computer use, transportation and community access, physical activity, accessing information and resources, home support services, relationship with others, access to professional services, and life satisfaction. The results revealed that more than two-thirds of the patients indicated that visiting and going out with family and friends were the most common activity, yet relationships are difficult to maintain, and reintegration into society is challenging because of the architectural, societal and the attitudinal environment that poses considerably barriers to the inclusion of patients with SCI's (Carpenter *et al.*, 2007; Noreau & Fougeyrollas, 2000).

The study carried out by Carpenter *et al.* (2007) reported that only 37% indicated that they attended social gatherings and event, and 36% engaged in physical activity.

In contrast to the relatively high percentages of participation in the aforementioned dimensions, only 6% mentioned their ability to do their own shopping. The study further explored individual participation hindrances faced by patients with SCI, and found that physical activity, fitness and sport, and attending more social events were the most commonly identified participation restrictions (Carpenter *et al.*, 2007).

Maintaining intimate and close relationships are often overlooked, but are challenging and compromised following a life-changing event such as SCI. Literature identified that both men and women reported a decreased desire and frequency of sexual activity following their injury (Alexander, Sipski & Findley, 1993).

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Summary of participation restrictions experienced following these health conditions

Participation restrictions are diverse even for patients with similar diagnosed health conditions. The context in which the activities are performed adds to the complexity of fully conceptualising the problem. What is known is that patients with varying types of neurological disorders experience problems with returning to-and maintaining work, continuing their hobbies and engaging in community life activities. It is important to be knowledgeable in the participation restrictions experienced by patients following stroke and spinal cord injury. This knowledge could assist with synergising available resources and manpower in order to combat hindrances faced within this sphere of human encounter.

2.4 Factors predicting the functional outcome following the health condition

2.4.1 Stroke

Knowledge of the factors affecting outcomes is important for the prediction of prognosis and length of hospital stay (Kwakkel, Wagenaar, Kollen & Lankhorst, 1996). The most common factor influencing stroke outcome is attributed to the initial severity, which is quantified clinically or functionally, and the size and location of the body structure at fault.

In addition to impairment variables influencing outcome, personal factors were also found to be strongly associated with outcome. Personal characteristics that were found to influence outcomes include age, gender, the presence of comorbidities, and activity patterns of the individual, particularly their active participation in formal rehabilitation (Staines, McIlroy & Brooks, 2009; Kwakkel, Wagenaar, Kollen & Lankhorst, 1996). A study carried out by Duncan *et al.* (2005) found that functional skills on admission and early initiation of rehabilitation services served as good predictors of outcomes on discharge. Intrinsic personal factors such as patients' level of motivation and adherence to programmes have also been found to be associated with favourable functional outcome (Maclean, Pound, Wolfe & Rudd, 2000).

Empirical evidence exists to support the notion that ethnic group and socio-economic status are valuable predictors of outcomes among survivors of stroke (Kwakkel *et al.*, 1996). Apart from heterogeneous intrinsic factors that could influence outcomes, extrinsic factors related to rehabilitation can also alter outcomes. According to the hierarchy of evidence, systematic reviews and randomised controlled trials demonstrate the highest level of scientific rigour and evidence. A systematic review conducted by Hoenig *et al.* (1999) successfully demonstrated that processes of rehabilitation can serve as a valuable predictor of outcomes. These factors are related to the intensity and frequency of rehabilitative care, the content of care, team

members involved in the active management of the patient's health condition, length of hospital stay, discharge follow-up and referral procedures, and the provision of caregiver training.

2.4.2 Spinal cord injury

Patient characteristics such as age, gender, severity, and aetiology of injury may provide an indication of prognosis for recovery (Scivoletto *et al.*, 2003). In a retrospective study 248 traumatic- and non-traumatic subjects with SCI, individuals older than 50 years of age were found to be more independent with activities of daily living and had a shorter length of hospital stay. However, the older age group (>50 years of age) had less favourable outcomes with walking, bladder and bowel independence, and a higher rate of secondary complications (Scivoletto *et al.*, 2003). These favourable outcomes among the older age group could be argued by the less traumatic nature of the injury, which could result in a lesser severity of spinal damage.

A large study, with a sample of 14,433 participants, found that women had significantly greater total motor scores improvement at 1-year compared with men. In contrast, men had higher Functional Independence Measure (FIM) motor scores at the end of rehabilitation, especially those with motor-complete injuries, except for those with C1-4 and C6 neurologic levels (Sipski et al., 2004).

The damage to the body structure (spinal cord) at fault could be a valuable predictor in the functional recovery of patients. A multicentre study showed that neurologic preservation and recovery correlate with increased ability in self-care and walking, with a prediction based on clinical examination on admission (Ditunno, Burns & Marino, 2005).

Complications following the injury have also found to affect functional outcomes. Patients with less oedema and without spinal cord haemorrhage on Magnetic Resonance Imaging (MRI) have significant improvement in self-care and mobility scores, although haemorrhage did not significantly affect locomotion and sphincter control scores (Flanders, Spettel, Friedman, Marino & Herbison, 1999). The findings from a study by Post *et al.* (2005) corroborate with that found in the latter described study, based on the premise that the level-and completeness of spinal injury, and the complications following the injury inversely predict LOHS.

In summary, the importance of understanding the factors predicting functional outcome in survivors of stroke and spinal cord injury could be used to alter the rehabilitation services, in order to respond to the health service delivery policy that advocates for establishing cost-effective, efficient and effective practices that promote optimal recovery.

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2.5 Outcome measures

In order to address the complexity of which underlying constructs to measure, standardised outcome measures were developed. (Salter, *et al.* 2005; Catz & Itzkovick, 2007). Outcome measures are particularly useful in the consistent and systematic evaluation of human functioning at any given time in the rehabilitation of patients (Kaplan, 2007). It should be noted that disease-specific and generic outcome measures have been developed at various levels of the ICF framework. The ICF places these measures into one of the three domains depending on what the measure intends to measure (Salter *et al.*, 2005). It is important to note that some measures fall into more than one category of the ICF (Scheepers *et al.*, 2007). This section reviewed standardised functional outcome measures used in other studies following a similar methodology among patients with stroke and spinal cord injury.

Criteria for deciding on the appropriate outcome measure

There are certain criteria that outcome measures should comply with before it can be classified as standardised measures, and before it can be effectively utilised by a broader community of clinicians and researchers. Before deciding on the outcome measure, one must be clear as to what construct of disability one wishes to study within the cohort, thereafter evaluating whether or not the items cover the desired underlying constructs. A study conducted by Scheepers *et al.* (2007) evaluated the content and relationship of widely used outcome measures to the categories of the ICF framework, and found that numerous items contained in the outcome measure overlapped different domains. This process of linking the items to the ICF framework further enhanced the validation process of the research undertaken.

After evaluating the outcome measure for content appropriateness, the psychometric properties should be studied. Salter *et al.* (2005) stated that appropriate outcome measures, especially in research and routine clinical use should be reliable, valid and sensitive to change. Apart from the psychometrically sound properties, these measures should offer a range of modes of administration, whilst presenting with good reliability, and should be completed in a short period of time.

Other factors were also considered on reviewing the appropriate functional outcome measure to be used in this study. These factors were the availability of the outcome measure in the appropriate language(s) spoken by South African citizens, rules for translation, purchasing cost of outcome measures or licensing and copyright. A literature review carried out by Joseph and Rhoda (2011) found that when utilizing certain measures, all data collected during that research project are subject to submission to the authors of the measure or the publishing agency. This could have major publishing implications, especially where projects have been funded by different organisations. Therefore, the authors recommended that all copyright clauses of outcome measures should be taken into account when deciding on the appropriate measure (Joseph & Rhoda, 2011).

The use of outcome measures in South Africa

In South Africa, many factors limit the use of outcome measures for both good practice in the clinical setting and for research purposes. A recent study among health professionals on the use of outcome measures in clinical practice found that most clinicians avoid the use of outcome measures because of their lack of awareness-, knowledge- and training on the use of existing standardised outcome measures, time constraints, lack of finances for purchasing license and the cost of translations, if needed (Inglis, Faure & Frieg, 2008).

A literature review conducted by Joseph and Rhoda (2011) found that most of the outcome measures utilised for patients with stroke in South Africa were reported by means of personal communications. The authors of the latter study concluded that results should be disseminated via publication, and thus increase the body of knowledge on outcomes of stroke and facilitate networking and collaboration between clinicians and researchers, which are the stakeholders pivotal to ensuring the flow of knowledge from research to action (Joseph & Rhoda, 2011).

Having taken cognisance of the aforementioned criteria and arguments, the selection of outcome measures was based on rating the functional ability of patients, sound psychometric properties, the availability of translated versions, mean of administration via verbal interview by the researcher or an assistant without tertiary education and the utilisation of the measure without purchasing a license or any agreement contracts. The tables below summarise the outcome measures according to the aforementioned criteria.



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Outcome measures	Aim- and scoring system of the measure	Limitations	Reliability and validity	Responsiveness to change	Reported use of outcome tool in S.A	Means of Administration	Translations available	Permission or cost attached to the use of the outcome measure
Barthel Index	This tool measures the level independence with functional activities: It includes basic mobility, self- care activities and functions of bladder and bowel continence. The score range from 0-100. A score lower than 50 indicates maximal dependence and above 75 minimal dependence (Mahoney & Barthel, 1965).	Limited range of disability within which it is able to detect change as evidenced by significant ceiling effects (7%)	Test –retest reliability coefficients r=0.98 The inter-rater reliability of the BI using weighted kappa ranged from 0.53 (adequate) to 0.94 (excellent) (Hsueh, Lee & Hsieh, 2001). Excellent construct and criterion validity compared to SF- 36 (Wilkinson, Wolfe, Warburton, Rudd, Howard, Ross-Russell, <i>et</i> <i>al.</i> , 1997).	This scale has been found to be insensitive to small changes in functional status and has a ceiling effect, therefore should be taken with caution when administered to patients suffering from mild strokes (Duncan <i>et al.</i> , 1997).	Yes (Rhoda <i>et al.</i> , 2011)	Direct observation takes about 20 minutes or self- report, which could take 2- 5minutes. Can also be completed by proxy. Administration of the BI does not require training and has been shown to be equally reliable when administered by skilled and unskilled individuals (Wade & Collin, 1988).	Afrikaans Isi-Xhosa English Dutch German Turkish French Persian Chinese	No permission is required

Table 2.1 Most commonly used functional outcome measures (activity limitation)

Outcome measures	Aim- and scoring system of the measure	Limitations	Reliability and validity	Responsiveness to change	Reported use of outcome tool in S.A	Means of Administration	Translations available	Permission or cost attached to the use of the outcome measure
Functional independence measure (FIM)	This measure aims to determine motor- and cognitive function. Furthermore, it was developed to address issues of sensitivity and responsiveness which were found problematic in the Barthel Index.	Certain items showed low responsiveness, especially the cognitive category. Poor- moderate ceiling effects were reported.	Inter-observer reliability of 0.95 and test – retest reliability of 0.95 Concurrent validity: showed strong association with BI (r=0.74 admission) (r=0.92 discharge) (Hobart & Thompson, 2001). Content and face validity determined by a Delphi panel (experts in the field of outcome rehabilitation).	The motor items of the FIM demonstrate high responsiveness to change, similarly to the Barthel Index. Certain items reported low responsiveness to change (Hobart & Thompson, 2001).	No-published articles or books were retrieved from data-bases. However, one study was reported via personal communicatio n (JA Hendry, WCRC).	Administration by direct observation, by someone who has received certified training. Administration time= 30-45 minutes.	German Italian Swedish Spanish Finnish Portuguese Afrikaans Turkish French	Licensing is mandatory for the use of the FIM. Significant purchasing costs.

Outcome measures	Aim- and scoring system of the measure	Limitations	Reliability and validity	Responsiveness to change	Reported use of outcome tool in S.A	Means of Administration	Translations available	Permission or cost attached to the use of the outcome measure
Spinal Cord Independence Measure (SCIM III)	This is the only comprehensive rating scale that measures functional ability in all primary daily activities relevant for patients with spinal cord lesions. The measure is divided into four areas namely, self- care, respiration and sphincter management, mobility in room and toilet and mobility in- and outdoors. The total score range from 0- 100.	This tool classifies all spinal cord lesions and level of lesions on the same rating scale, despite the unique pathological distinctions between the lesions and levels. E.g. a patient with a C4 complete injury will never be able to walk compared to a patient with a L4 injury, which would be able to walk unaided. This could be a confounding factor.	Total agreement between raters range from 74.5 to 96.2. Intraclass correlation coefficient values range from 0.94-0.97. The findings from the SCIM III support the validity of the tool despite intercultural differences (Catz & Itzkovich, 2007).	Studies found that the SCIM III was significantly more sensitive than the FIM that is classified as the gold standard for responsiveness (Wirth, van Hedel, Kometer, Dietz & Curt, 2008; Itzkovich <i>et al.</i> , 2003)		This measure can be administered via direct observation by the team member experienced in the management of the domain covered by the subscale (Catz & Itzkovich, 2007. It can also be completed by a single team member or by interview (Itzkovich <i>et al.</i> , 2003).	English	No licensing needed. The outcome measure can be recruited from any available source.

Summary on functional outcome measures

Literature identified the Barthel Index and Functional Independence Measure as the gold standard measures for stroke (Chamlian & Melo, 2008; Houlden, Edwards, McNeil & Greenwood, 2006; Turner-Stokes, 2000). Both of these tools present with good psychometric properties. However, the BI was chosen because of its desired mode of administration via interview administer, the availability of translated version and the fact that no licensing is required, unlike the FIM, which can only be administered via direct observation and which could be too time consuming for this study. Moreover, the utilisation of the FIM involves purchasing of a valid license and that of a training manual. The only diagnosis-specific outcome measure available for patients with spinal cord injury is the SCIM III (Catz & Itzkovich, 2007), which was decided on as the measure for data collection. Despite the unavailability of a translated version, the measure presents with substantial reliability, validity and responsiveness, can be used freely used without purchasing a license, and can be administered via interview (Wirth et al., 2008).

2.6 The outcome based approach

The outcome-based approach, or elsewhere referred to as the goal setting approach is globally accepted as a fundamental and effective part of the rehabilitation process (Duff, Evans & Kennedy, 2004). This approach has six distinct outcome levels of functioning along recovery from the health condition. These outcome levels are loosely defined as groupings or categories of patient problems and conditions, which are understood to represent levels of progress along a continuum in the process of rehabilitation (Landrum, Schmidt & Mclean, 1995). This approach to patient management is paramount to the following: it can be utilised by health professionals to guide treatment, to motivate patients and to measure patients' progress during rehabilitation, but

the establishment of goals needs to be collaborative (between the health professional(s) and the patient), relevant and meaningful to the patient (McClain, 2005). In addition the goals specified by the stakeholders should preferably be specific, measurable and time bound to guide progress (Hurn, Kneebone & Cropley, 2006).

A retrospective study done by Liu, McNeil and Greenwood (2004) highlighted the need for the usage of the outcome-based approach (goal-achievement) as an adjunct to the use of standardised outcome measure, with the sole purposes of guiding treatment and improving the constructs of functioning that are meaningful to the patients. The latter study used the Modified Barthel Index and the Functional Independence Measure as the outcome measures on admission and at discharge to determine the variance between the measures and the goals achieved, as set out by the patients on admission. The results demonstrated that patients improved significantly on all disability scales employed and that the attainment rate of long-term goals were 75% per patient. It was further noted that non-achievement was most frequently due to cognitive problems (38%), followed by behavioural difficulties and physical limitations. Thus, goal achievement correlated poorly with the outcomes of the standardised measures (Liu *et al.*, 2004). This study greatly contributed to the understanding that the process of rehabilitation should be altered in order to respond to the goals set out by the patient on admission.

The Western Cape Rehabilitation Centre has adopted the outcome-based approach. At this institution goals are set between the interdisciplinary team and the patient on admission, with weekly meetings to discuss the progress. This weekly updates ensure that patients do achieve short-term goals within a reasonable time, and further allow the interdisciplinary team to revise the treatment regime, and if goals are not met, to investigate factors that impede progress (Personal communication. J.A Hendry, 2011). On admission, the patient's current outcome level is determined and a projected discharge outcome level is set. Table 2.2 outlines the requirements of each outcome level.

Table 2.2 Outcome Levels According to Landrum, Schmidt and Mclean (1995).

OUTCOME LEVEL DESCRIPTION OF OUTCOME LEVELS

Level 0- Physiological	Usually occurs early after onset in an acute setting. Assessment,
instability	diagnosis and management of medical conditions are ongoing.
	Includes unmanaged medical problems presenting at a later stage
	e.g. pressure sores/ inadequate bladder management.
Level 1- Physiological	Medical problems addressed and appropriately managed.
stability	Condition is stable- no longer requires acute care setting.
Level 2- Physiological	Management plans in place to ensure ongoing maintenance of skin
maintenance	integrity, nutrition, range of movement and bowel and bladder
	care. Basic functional goals at this stage may include bed mobility,
	self-care and communication.
Level 3- Residential re-	Safe function at home. Includes: self-care, mobility around home,
integration	effective communication, simple housekeeping, household
	planning and home management.
Level 4- Community	Subject functions appropriately in the community. Includes: self
re-integration	management, self-directed care of health, ability to function
	socially, community mobility, recreational activities, community
	activities, complex home management, financial management and
	safety in the community.
Level 5- Return to	Productive activities within the patients' level of ability. Includes
productive activity	paid work, unpaid work, volunteer work, and education/ training.

2.7 Rehabilitation as a strategy

According to Helander (1999), the term rehabilitation refers to "all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self actualization". A more recent definition refers to rehabilitation as a strategy of retraining patients to improve their capacity, which will finally enable them to perform the tasks that are important and to become participating members of their household and community (Staines, McIlroy, & Brooks, 2009).

The high level of complexity associated with rehabilitation is evident in its role to address the outcomes that are important to the service provider and the patient. Strasser and Falconer (1997) proposed a conceptual hierarchy for measurement of rehabilitation outcomes, using the ICF to link the interventions to the domains of the theoretical framework. In order to respond to the vast consequences of any neurological condition, as guided by the ICF, rehabilitation needs to be diverse in its procedures and interventions, as well as the service providers that are needed to optimise recovery. Rehabilitation further needs to be diverse and dynamic in the ways that it is provided (Helander, 1999).

For the purpose of this study the process of rehabilitation and its altering effect on outcomes will be discussed as part of the Structure, Process and Outcome (SPO) model, with special reference to rehabilitative services received, length of hospital stay and discharge destinations.

2.7.1 Reported rehabilitative services received

2.7.1.1 Stroke

Rehabilitation literature often refers to the coordination and provision of services as either interdisciplinary or multidisciplinary. The fundamental difference between the two approaches is

that with the interdisciplinary approach, services are provided by diverse professionals who constitute a team that communicates on a regular basis and uses its varying skill and expertise to work towards the common goals, whereas with the multidisciplinary approach, the team consists of similar professionals as an interdisciplinary team, but with less communication and common goal achievement between the different team members (Cifu & Steward, 1999). The team may consists of a physician, nurse, physical therapist, occupational therapist, kinesio-therapist, speech and language therapist/pathologist, psychologist, recreational therapist, patient, and family/caregivers (Duncan *et al.*, 2005). A large body of evidence is available indicating that a well-organised, multidisciplinary approach to sub-acute rehabilitation after stroke results in better outcomes for patients (Cifu & Steward, 1999; Evans et al., 1995). A prospective study carried out by Evans, Harraf, Donaldson and Kalra (2002) further suggests that specialised care was found more beneficial to patients' outcomes than general care.

Systematic research further explains that organised multidisciplinary care and rehabilitation reduce patient mortality and improve independency, as well as reducing the length of hospital stay, which would cut back on health costs (Langhorne & Duncan, 2001; Stroke Unit Trialists Collaboration, 2000). In all rehabilitation centres physiotherapists and occupational therapists form a pivotal part of a formidable multi- or interdisciplinary team. This is evident in the results of a randomised- controlled trial which demonstrated that physiotherapy and occupational therapy services alone resulted in better functional outcomes as measured by the Barthel Index, and a two week reduction in hospitalization (Slade *et al.*, 2002). However, what is less clear in available literature is whether certain strategies or approaches to rehabilitation are more effective than others (Van Peppen *et al.*, 2004; Cifu & Steward, 1999). One study found no difference in functional outcomes between two units, with the one provided rehabilitation addressing impairments and the other centred towards disability (Patel, Potter, Perez & Kalra, 1998).

2.7.1.2 Spinal cord injury

A large body of literature is available that proves the superiority of highly specialised care over generalist care for patients with spinal cord injury. It has been found that highly specialised care for these patients has dramatically improved the life expectancy the last five decades. For example, in Scandinavia the life expectancy during the late 1950's was 1.5-2.0 years, whereas persons with paraplegia now have almost the same life expectancy as the general population, while those with tetraplegia seem to live 10-20 years less than the general population (Yeo *et al.*, 1998).

Similar to stroke, early rehabilitation in an organised multidisciplinary SCI care system has been shown to be beneficial, with lower mortality, decreased pressure sores, slightly greater chance of neurologic recovery, and shorter lengths of hospital stay with lower hospital charges (Devivo *et al.*, 1990). The following care disciplines have been found pivotal in the management of persons with SCI: rehabilitation physicians, occupational therapists, physiotherapists, nurses, social workers, psychologists and sport teachers (Bloemen-Vrencken, 2006).

2.7.2 Reported length of hospital stay of each health condition

2.7.2.1 Stroke

Institutional policies on the length of hospital stay for patients with stroke vary considerably across studies. To depict this discrepancy, one study reported the mean length of stay in rehabilitation centres as 97.1 days (Yavuzer, Kucukdeveci, Arasil & Elhan, 2001), whereas a study conducted by Jette *et al.* (2005) in the United States, found that the mean length of stay in rehabilitation hospitals was 18.7 days. Consistent results illustrating a reduced LOHS were found by a systematic review carried out by Kengne and Anderson (2006), which found the LOHS to be three weeks. The early discharging patterns from rehabilitation hospitals could be

due to support of patients in their home environment (Jette *et al.*, 2005) in the form of homebased care and rehabilitation.

Apart from the policies and guidelines, literature indicates that certain processes of rehabilitation and certain patient characteristics could serve as predictors of LOHS. A randomised single-blind controlled trial found that an intensity of 67% more physiotherapy and occupational therapy for the experimental group, translated in a 14-day reduction in length of stay (p<0.01) (Slade *et al.*, 2002). A meta-analysis conducted by Kwakkel, Wagenaar, Koelman, Lankhorst and Koetsier (1997) further supports the notion that greater frequency of therapy improves functional outcomes and reduces length of hospital stay.

It is important to have insight into the factors shortening the length of hospital stay in order to reduce cost of hospitalisation, but in contrast, it is equally important to be knowledgeable in the factors impeding discharge to identify focus areas of cost-control strategies. A recent observational cohort study with a sample of 200 patients found that medical complications and functional dependence on admission lengthen hospital stay (Saxena, Koh, Ng, Fong & Yong, 2007). Similarly, a study conducted in 1977 showed that severity of weakness and functional disability on admission increased length of hospital stay. The latter study included three groups with varying degrees of limb weakness and the results demonstrated the average length of hospital stay as 47-, 41-, and 32 days respectively. The study further found that long onset-admission interval, the presence of severe perceptual or cognitive dysfunction and homonymous hemianopsia increase the length of hospital stay (Feigenson, McDowell, Meese, McCarthy & Greenberg, 1977).

The study on the length of hospital stay is associated with financial implications and bed occupancy. A study conducted by Feachem *et al.* (2002) found that hospital-bed occupancy is the most expensive component of any health care system. This finding necessitates the need to

identify the organisational practices and processes of care needed to optimise recovery and reduce length of hospital stay.

2.7.2.2 Spinal cord injury

In the Netherlands, the LOHS depends on the patient's physical state and the opportunities for admission to a rehabilitation centre. A recent study showed that the LOHS in the acute phase, in the Netherlands, varies considerably and is on average 50 days (Post *et al.*, 2005). In the US, the median days hospitalized in the acute care unit for those who enter a Model System immediately following injury have declined from 24 days between 1973 and 1979 to 12 days since 2005. Contrary to the relatively reduced LOHS of patients with spinal cord injury in the acute setting, patients tend to stay longer in rehabilitation centres, usually until a plateau phase is reached or until full reintegration into their home and community life is achieved.

The length of stay in clinical rehabilitation varies globally. In a recent prospective study carried **WESTERN CAPE** out by Post *et al.* (2005), which included eight rehabilitation centres across the Netherlands, found that the mean LOS was 240 days. The extended hospital stay in the aforementioned studies could be criticised from an economical and functional approach. Despite escalating health cost related to hospitalisation, it is unclear whether rehabilitation is context-driven in the light of patients receiving rehabilitation for up to nine months without providing the patients the opportunity to experience the barriers to integration.

In contrast to the extended LOHS, downward trends are noted in US for LOHS in rehabilitation units (from 98 to 38 days). The mean days of hospitalisation (during acute care and rehabilitation) were also found to be greater for persons with neurologically complete injuries (National Spinal Cord Injury Statistical Center, 2005).

The discrepancy in length of hospital stay between developed and developing countries have been found to be significant. The available studies reported the mean LOHS in in-patient rehabilitation may vary from 60 days in the United States (Eastwood, Hagglund, Ragnarsson, Gordon & Marino, 1999) up to 267 days in Japan (Sumida *et al.*, 2001). It is unknown whether this disparity in LOS is due to the differences in caseload, system differences, or differences in effectiveness and efficiency of medical rehabilitation. Within the local context the LOS for the different health conditions at the Western Cape Rehabilitation Centre ranges from 30-180 (Department of Health, 2006). What is unknown is the mean LOHS of each health condition, which is an important indicator of health cost.

2.7.3 Discharge destination following rehabilitation of various health conditions

2.7.3.1 Stroke

The goal of rehabilitation is to restore normal function and integrate persons with a health condition back into their social sphere, previous residence and workplace (Duncan *et al.*, 2005). The discharge destination following rehabilitation could serve as a programme evaluation with regards to the pertinent factors that need to be addressed during rehabilitation and to ensure the safe and effective functioning of patients in their home environment (Somerford, Lee & Yau, 2004). Patients are usually discharged to their community-based dwellings, other hospital-, hostel- or nursing home care (Tooth, Mckenna, Goh & Varghese, 2005).

A controlled comparison between two stroke units, following different rehabilitation approaches (theoretically driven versus pragmatic driven), showed that 70% of patients were discharged home, whereas the remaining 30% were discharged to step-down institutions (Patel *et al.*, 1998). A deduction can be made that irrespective of the approach to rehabilitation the discharge rate to

primary residence remained the same. Another study found similar results for discharging of patients with stroke back into their community dwelling and nursing homes (Tooth *et al.*, 2005).

The ability to ambulate and intact bowel-and bladder function remain pertinent factors in the discharge planning of patients following stroke. Non-ambulatory patients with the capacity to walk with aids are usually hospitalised longer than average in order to promote safe and efficient walking before they are discharged home (Feigenson *et al.*, 1977). A large-scale retrospective study found that females (12.8%) were more likely to be discharged to a nursing home than males (7.8%), and that males (69.8%) were more likely than females (62.4%) to be discharged home (Somerford *et al.*, 2004). In the same study, the oldest patients were more likely to be discharged home. Apart from these factors discussed above, it is important to understand the factors that could prolong hospital stay in order to develop strategies and appropriate rehabilitation to manage the length of hospital stay and the cost of hospitalisation (Somerford *et al.*, 2004).

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2.7.3.2 Spinal cord injury

The discharge destination following rehabilitation varies depending on the functional –and social factors of the patient. Most of the patients are discharged home, but could be discharged to a supported living facility or a nursing home (Bloemen-Vrencken, 2006). Overall, 87.7% of all persons with SCI who are discharged alive are sent to a private, non-institutional residence (in most cases their homes before injury). Only 5.9% are discharged to nursing homes. The remaining patients are discharged to hospitals, group living situations or other destinations (National Spinal Cord Injury Statistical Center, 2005). However, it is important to identify the 'other destinations' and compare the cost of care, as this could have financial implications for the patient and health care system.

In summary, an inter- or multidisciplinary approach to patient management has been found to be prevailing above other approaches, and that specialised care is more beneficial than generalist care. The length of hospital stay of both patients with stroke and spinal cord injury varies considerably, but in the light of limited results from the developing world, international comparison was limited to a few studies only. However, the factor of international standards on the functioning of patients at discharge was also neglected in the comparison as the studies failed to indicate the benchmark functioning of patients at discharge. Literature indicated that most patients with stroke and spinal cord injury were discharged home following in-patients rehabilitation, with only a few patients discharged to an alternative setting. However, the studies neglected to indicate the cut-off functional level or abilities of patients still eligible for rehabilitation post discharge. The criteria are however needed to provide a plausible motivation for continuing rehabilitation along the continuum of care of patients in need.

2.8 Summary of the literature review

In short, neurological health conditions are becoming increasingly prevalent in South Africa due to the emergence of chronic diseases of lifestyle, HIV/Aids epidemic, motor vehicle accidents and violence. However, the incidence and prevalence of these health conditions are poorly monitored. These health conditions could be life-changing and cause varying degrees and extents of disability. Rehabilitation as part of a health service delivery model emphasises the need for quantifying the consequences of the conditions, and where it is less clear, explore the effects, in order to align rehabilitation processes and identify desirable organisational practices to better match the needs of the survivors of such health conditions. Empirical evidence exists on the financial burden length of hospital stay has on the patient, their family and the government. Therefore, the study of factors affecting prognosis in patients is valuable, and could inform institutional Head of Departments to adapt rehabilitation processes to reduce length of hospital stay with no compromise in the outcomes of the patient.

CHAPTER THREE

METHODOLOGY

3.0 INTRODUCTION

This chapter contextualises the study setting and the research design adopted for data collection. In addition, it provides a clear overview of the selection of the study population and the sampling strategy. All data collection instruments (self-administered questionnaires, standardised outcome measures and data extraction sheets) are presented in terms of the study objective(s) addressed and its psychometric properties. A step-by-step description of the data collection procedure is given with results of the pilot- and reliability study. Lastly, the methods for data analysis and the ethical statement are presented.



3.1 RESEARCH SETTING

The study was conducted at the Western Cape Rehabilitation Centre (WCRC), which is situated in Mitchell's Plain, South Africa.

The WCRC is a 156 - bed in-patient facility. The facility provides rehabilitation services to patients with various medical and surgical conditions, which include cerebral vascular accident, spinal cord injuries, amputations, head injuries and peripheral neuropathies. Rehabilitation programmes are offered on both an in- and out- patients basis at the facility, and may include home- or work-site assessments as part of the outcome-based approach adopted at the institution. Apart from the rehabilitation programmes, the facility offers specialised out-patient clinics including scoliosis-, specialised wheelchair seating, shoulder-, hand- and urology clinics.

Referrals are received from primary, secondary and tertiary health care levels, as well as selfreferrals from the entire Western Cape and neighbouring provinces. Patients are accepted for admission according to their expected capacity to benefit from the interdisciplinary approach, and those who fulfil to the requirements of outcome level 2. The interdisciplinary team who follows an outcome-based approach to patient management consists of doctors, nurses, physiotherapists, occupational therapists, speech-and language therapists, dieticians, social worker and psychologist (Personal communication, J. A Hendry, November 16, 2010).

Apart from these professional services, recreational activities and supporting services are also provided as part of the comprehensive rehabilitation programme. This approach allows for patients to set rehabilitation goals that are central to them, based on their functional activity and participation in various social roles prior to the diagnosed health condition, in collaboration with the interdisciplinary team. Once admitted to the centre, patients will be required to actively participate in the patient-centred rehabilitation programmes on a daily basis. (Provincial Government of the Western Cape, 2005). The average length of hospital stay ranges from 30-180 days based on the patient's health condition, their active participation in rehabilitation and the achievement of the projected outcome level, which is decided upon admission (Personal communication, J. A Hendry, November 16, 2010).

3.2 RESEARCH DESIGN

A descriptive, observational, longitudinal design was used to answer the study objectives. The descriptive study method was the most suitable study design to determine the number of patients with different diagnosed health conditions admitted to the facility within the three-month period, whereas the longitudinal design measured and described outcomes between two intervals (Smith & Smith, 2003). The two points of data collection for this study were on admission and at

discharge. Apart from determining whether or not patients improved since admission to discharge, the longitudinal design allowed for the study of factors influencing functioning (dependent variable) at the end point of data collection. The adoption of this design to the current study allowed the measurement of outcomes of the same cohort between the points of data collection, and predictors of functional outcomes were determined at discharge, only in instances where the sample size of each diagnosed group was sufficient.

In addition to the study being longitudinal in nature, it was also observational. This type of design allowed the researcher to describe, analyse and interpret the situation as it appears, without attempting to influence the situation in any particular way (Smith & Smith, 2003). This study allowed the researcher to describe and analyse the process of rehabilitation and the outcomes of patients at discharge, following an existing rehabilitation programme by members of the interdisciplinary team at the WCRC.

In an attempt to answer the second and third objective, which was to determine the process of rehabilitation followed by patients and the nature and prevalence of impairments presented by patients on admission respectively, a retrospective (historic) cohort research design was used. A retrospective cohort design is a form of archival research, which makes use of medical records of groups of individuals who are alike in many ways, but differ by a certain characteristic.

3.3 STUDY POPULATION

The study population consisted of all persons with the pre-determined two most prevalent diagnosed health conditions managed at the WCRC. According to the data of 2009 on the diagnosed health conditions managed at the centre, over a one year period (2009), the two most prevalent conditions constitute 75% of the total admissions, whereas the additional three

conditions (amputation, head injury and peripheral neuropathy) only contributed 19% to the total number of patients admitted to the centre.

3.4 SAMPLING

3.4.1 Type of sampling

A convenient sampling method was adopted for the selection of patients, in which every consecutive participant meeting the inclusion criteria was invited to participate in the study. This non-probability sampling technique is particularly useful in cases where the whole population for the given period of time is studies and for ensuring the largest possible sample sizes, without random exclusions. Since this study essentially aimed at providing a snapshot of the process of rehabilitation and the outcomes of patients receiving rehabilitation at the WCRC, this sampling method sufficed, given the level of evidence (III) and time-constraints.

3.4.2 Sample size

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The sample size was time-based, therefore dependent on every consecutive patient meeting the inclusion criteria, for a three month period. The intake of newly admitted patients was from 01 November 2010 to 31 January 2011. Based on anecdotal information, the current length of hospital stay at the WCRC ranges from 30-90 days, depending on the severity of the health condition on admission. Taking the projected range of the length of hospital stay into account, three months were added (from the end of January 2011) to accommodate for the collection of data of patients admitted at the end of intake of newly admitted patients (31 January 2011). Thus, all data collection was completed by the 31 April 2011.

Preceding the planning of the study the researcher reviewed retrospective statistics for a threemonth- and one year period on the various diagnosed conditions of patients admitted to the centre, and the proportions thereof. Throughout the review process the stroke and spinal cord injury categories collectively constituted more than 75% of the total number of patients. Therefore the focus of the study was centred towards reaching the desired sample size of the two prevalent diagnosed health conditions.

The three- month time-frame allowed for the desired sample size for the stroke and spinal cord diagnostic group to be reached in order to answer objective five, which was to determine six predetermined factors (excluding age and gender) influencing functional independence of patients with stroke and spinal cord injury on discharge. The literature recommends that for every one dependent variable at least ten independent variables are needed, therefore, the three month period allowed for a minimum of 60 participants to be included for each diagnostic group, which was needed to study the factors predicting functional outcome (Munro, 2001).

The motivation of limiting the inclusion of patients to stroke and spinal cord was prompted because these health conditions constitute three-quarters of the total admissions annually, and that the intake of the remaining conditions (traumatic brain injury, peripheral neuropathy and amputation) are slow, which would not have been feasible in terms of resources, manpower for data collection, and time commitments to complete the study. The exclusion of the aforementioned health conditions were also based on the evidence of inferential statistical analysis which suggests that small sample sizes, constituting of non-parametric data, could result in unreliable findings (Personal communication, R. Madsen, April 20, 2010; Domholdt, 2000)

Inclusion criteria:

- All patients presenting with a stroke or spinal cord injury.
- All eligible participants aged 18 years and above
- All patients that consent in writing to participate
- Patients proficient in English, Afrikaans or Xhosa

Exclusion criteria

- Patients who could not follow a three-step command due to receptive aphasia
- All patients presenting with diagnosed health conditions other than stroke and spinal cord injury
- All patients under the age of 18
- Patients that refrain from consenting to participate in the study
- Patients presenting with a mental disability as a co-morbidity

3.5 DATA COLLECTION INSTRUMENTS

This section describes all the data gathering instruments, self-administered questionnaires and standardised outcome measures that were used to collect baseline and discharge data from patients and their medical files.

3.5.1 Data gathering instruments

Following a literature search, no standardised data gathering instruments could be identified to quantitatively record the medical, demographic and socio-economic profile of patients and the process of rehabilitation that were followed by each patient. In response, the three interview-administered questionnaires were developed and piloted. Below are short descriptions of each questionnaire and the process of establishing validity and reliability.

3.5.1.1 Data extraction sheet

A data extraction sheet was developed to retrieve the information from the medical folders of the patients. The items included were based on the underlying constructs of the process of rehabilitation (Kaplan, 2007; Hoenig *et al.*, 1999) as indicated by the literature and key

informants in the field of rehabilitation. The final data extraction sheet comprised of two main sections.

Section one: Recorded the medical profile (diagnosed health condition and referral source) and the demographic profile, which included the patient's age, gender and place of residence (postal address). Information obtained in this section of the questionnaire collected data to address objective one.

Section two: Recorded information related to the process of rehabilitation, which addressed the second objective. The following information was captured: length of hospital stay, which was calculated by the sum of days between the admission- and discharge date, all rehabilitative services received, and the discharge destination. The rehabilitation outcome levels on admission and discharge was also recorded.

To ensure face- and content validity of the data extraction sheet, it was subjected to peer review, by key informants knowledgeable in the field of rehabilitation. Domholdt (2000) suggested that peer review by experts is sufficient for face-and content validity, thus the informants were the study supervisor, the deputy director of the WCRC and the study co-ordinator of the project, which aims at evaluating rehabilitation services in the Western Cape.

Some changes were recommended by the reviewers. One of the recommendations was to change "home address" to "postal address". The reviewers argued that with the postal address the researcher can identify the sub-district that the participant resides in, and therefore quantify prevalence of the conditions per sub-district. Another comment by one of the key reviewers was the suggestion that rehabilitation is a 24-hour concept, and that all additional services received at the WCRC are rehabilitative in principle, and thus contributing to the functional outcomes of the patient. Thus under the section "all services received during the length of hospital stay" the following were included: health and wellness centre that is managed by the biokineticists, learn

to swim, ballroom dancing, wheelchair basketball, fun walks and outings. Lastly, it was recommended that "group home" and "old age home" should be added to the list of discharge destinations as some of the patients were discharged to these settings.

3.5.1.2 Impairment extraction sheet

After an extensive literature search on available outcome measures for identifying the nature of bodily impairments for the stroke and spinal cord injury diagnostic groups, no diagnosis-specific measures that cover the full spectrum of impairments resulting for the health condition were retrieved. Following a focus group discussion of therapists, researchers and academics working on the rehabilitation project in the Western Cape (this group of people will be referred to as the "reference group"), a diagnosis-specific impairment measure for each health condition was developed. For the development process, all primary impairments related to the condition were essential to cover the spectrum of impairments following the onset of the health condition. The impairments were identified via the aforementioned reference group consisting of therapists, researchers and academics, the ICF framework on body structures and functions (WHO, 2001), journal articles (Anderson, 2004; Estores, 2003; Lawrence *et al.*, 2001), books and the internet.

After the initial design the data extraction sheet was distributed to the same experts in the field of rehabilitation as described under section 3.5.1.1 with the aim of ensuring the face- and content validity. The following changes have been recommended by the critical reviewers and the researcher after conducting the pilot study, which was done prior to data collection. Under the impairment labelled "balance", the 3-point scale (undocumented, impaired and not impaired) should be added to accommodate for the lack of precise description in instances where balance was documented. A similar change was made for "cognitive function" as it was observed from

the medical records that there was a lack of specific information pertaining to the underlying constructs of cognitive impairment.

In addition to the validity, the inter-rater reliability of the impairment extraction sheet was determined using Intraclass Correlation Coefficients (ICC). The instrument consists of 12 items relating to impairment dysfunction in stroke and seven items for SCI (Appendix K). For the purpose of this reliability trial the medical records of eight patients, either diagnosed with stroke or spinal cord injury, were examined by two independent raters. The data were captured and analysed using SPSS version 18. The ICC of all the items (stroke and SCI) averaged together for both raters ranged between 0.471-1, which indicates moderate to perfect agreement (Fleiss, 1981).



3.5.1.3 Questionnaire completed on admission

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This questionnaire was developed to gather information related to the socio-demographic characteristics and previous rehabilitation received of persons with disabilities at the Western Cape Rehabilitation Centre on admission. The questionnaire is divided into five main sections. A brief overview of each section is provided below.

Section one: This section collated information pertaining to the personal demographic factors (gender, ethnic group, marital status) and medical information including, but not confined to, diagnosis of health condition, cause/nature of disability, the presence of co-morbidities and previous rehabilitation received.

Section two: This section described the socio-economic status of the participants. The information required was related to the household income, the participants' monthly income, number of members in the household, source of income and highest educational level.

Section three: This section described information related to the participants' primary residence and the availability of basic needs that include running water, electricity, telephone and ablution facilities.

Section four: This section described information related to availability of transport to the rehabilitation centre and to ascertain the transport needs of participants accessing the rehabilitation centre.

Section five: The last section described whether the patient was involved in previous research and whether they have received feedback on the outcome of the research.

The questionnaire was developed by the reference group (which investigate rehabilitation services in the Western Cape) and adopted for the current study. After the initial full draft was developed the questionnaire was subjected to peer-review. The questionnaire was also piloted to ascertain whether the participants understood the questions and whether the necessary information was gathered. Some changes were recommended by the review panel (see pilot study). The final draft was further subjected to review by the study supervisor, the deputy director of the WCRC and the study coordinator of the Western Cape project on rehabilitation services, thus, the face and content validity of the questionnaire were established.

3.5.1.4 Questionnaire completed at discharge

This questionnaire was designed by the researchers to gather information related to accessibility of the rehabilitation centre, the rehabilitation process and the engagement of the participants in various social roles during weekend-leave. Each of three sections collected data regarding different aspects. Section 1: This section described information related to the participants' awareness about their rights to rehabilitation and their participation in social roles and community life activities during weekend-leave, but over the length of hospital stay.

Section 2: This section described information about the necessary assistive devices received and the participants' level of satisfaction with these appliances.

Section 3: This section described the services and interventions patients received during rehabilitation, and based on their perception, the services they still require.

Upon drafting the questionnaire, it was subjected to rigorous peer review and piloted as part of the validation process (see pilot study for changes). The final draft was further subjected to review by the study supervisor, the deputy director of the WCRC and the study coordinator of the Western Cape rehabilitation project; thus, the face and content validity of the questionnaire were established.

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3.5.2 Standardised outcome measures

The section on functional outcome measures were described and discussed in detail in the literature review. The Barthel index was used to assess activities of daily living in the stroke diagnostic group, whereas the Spinal Cord Independence Measure III tested the functional abilities of those with spinal cord injury. Both functional outcome measures have been validated and found reliable.

3.5.2.1 Zambian survey on living conditions

Since limited participation measures are available, especially generic outcome measures, this questionnaire was adapted for the purpose of this study. This questionnaire was adapted from the

Zambian survey on living conditions, which was utilised to study the influence of physical disabilities on activity and participation of patients in Zambia (Loeb, Eide & Mont, 2008).

The Zambian questionnaire on living conditions consists of 9 sections that measure constructs of impairment, activity limitation and participation restriction within the ICF framework. The nine constructs relate to functioning of the senses, communication, mobility, caring for self, household life, interpersonal behaviour, important areas of life and community, social and civic life. For the purpose of the study this outcome measure was adapted. The items relating to impairment were removed as the gathering of this information will become redundant as impairment of body structure and function was extracted from the medical folders using the data gathering instrument. Some of the questions omitted from the final adapted version were related to impairments, such visual and auditory function and higher brain function. For example, "can you see or hear" and "can you feel any sensation".

Each item is described in terms of the relative ease or difficulty that the participant experiences with the execution of the task or action. The scale is scored on a four-point scale. A score of 0 indicates no problem, and a score of 4 indicates the inability to perform the respective activity. It is well known that physical disabilities can cause the inability of a participant to perform a specific task, thus, the score 9, which within the parameters of the scale refers to not specified, can be scored if the patient had refrained from engaging in the specific task or action since the onset of the health condition. Furthermore, some of the items are diverse and not mutually exclusive among patients with similar of different diagnosed health conditions, thus patients are not required to perform a specific task or action in his or her day-to- day life. For instance, some patients have never driven a car in their lifetime, therefore the score 8 refers to not applicable, thus explicitly inferring that the patient does not need to perform the task or action.

As this questionnaire was adapted it was once again reviewed by the reference group for content and face validity. In addition a test retest reliability study was conducted. For the reliability test the researcher recruited ten chronic stroke patients who were part of a stroke group. Informed consent was obtained from the participants before the reliability study commenced. The participants were interviewed at one point and two week later using the questionnaire. The data were captured and analysed using SPSS version 18. The information for activity was captured separately from those for participation. The Intraclass Correlation Coefficient (ICC) scores for the participation domains ranged from .431 to 1. While the ICC scores for the activity items ranged from .410 to 1. The majority of the items however demonstrated good to excellent ICC scores with only the item referring to "lifting" having poor scores in both activity and participation sections. The item referring to lifting was kept in the questionnaire, irrespective of the low ICC score, as with the removal of this item the overall internal consistency would have been reduced (Domholdt, 2000). The reference group further decided that the removal of the item (lifting) would negatively affect the content validity of the questionnaires, as it was felt that lifting is an essential construct of functioning of both patients with stroke and spinal cord injuries.

3.5.3 Translation process

The languages spoken by people in Cape Town are English, Afrikaans and IsiXhosa. The Spinal Cord Independence Measure and the adapted Zambian survey on living conditions were only available in English. Therefore, the aforementioned questionnaires were translated into Afrikaans and IsiXhosa.

All the questionnaires were forward translated from English to Afrikaans and English to IsiXhosa respectively by one translator, thereafter the translated questionnaires were backward translation into the original language (English) by a another translator. Both translators were independent to the research project and not familiar with the medical or rehabilitation field. The questionnaires (both standardised and adapted) were scrutinised by the researcher and study supervisor for correctness and whether the content of each item remained the same irrespective of the translation. It is often found when an outcome measure is translated into a different language, the translated language may express and interpret the items differently than the original version (Chang-Hoon, Dong-Jae, Se-Kang, Dong-Jun, Hwan-Mo & Heui-Jeon, 2006; Mkoka, Vaughan, Wylie, Yelland & Jelsma, 2003). Therefore, based on consensus among the researcher and both translators the following changes were made to the questionnaires.

The IsiXhosa translation of the Spinal Cord Independence Measure (SCIM) presented with the following changes. The word "oksijini" meaning oxygen from the natural environment/atmosphere was changed to "umoya omncedisaya" which refers to artificial oxygen produced by a mechanical ventilator. This change was imperative as this would have influenced the results of respiratory function among spinal cord injuries as the aforementioned words have contrasting meanings. The word "oksijini" has an active component to breathing, whereas the desired word "umoya omncedisaya" has a passive or assisted component to respiration. The IsiXhosa word describing mobility was changed from "iintshukumo", meaning shaking, to "ukuhla usenyuka", which refers to walking as a higher functional task. Thus, the word was originally used to describe a patient's ability to walk as a means of mobilisation. Lastly, the word "udinga" was changed to "ufuna". "Udinga" is the Zulu word for someone who needs help; therefore it was replaced with the IsiXhosa word "ufuna".

No changes were made to the Afrikaans version of the SCIM III and the Afrikaans and IsiXhosa versions of the Salsa Scale and the adapted Zambian questionnaire on living conditions.

3.5.4 Pilot study

A pilot study was conducted at the Western Cape Rehabilitation Centre to determine the feasibility and practicality of the instruments to be used for data collection. Teijlingen and Hundley (2001) reiterate the advantages of a pilot study. Some of these advantages are that it might give advance warnings about where the main research project could fail, where research protocols may not be followed, or whether proposed methods or instruments are inappropriate or too complicated (Teijlingen & Hundley, 2001). The aim of the pilot study was to determine whether the questionnaires were understood by the participants and to assess the consistency of the terminology used. Ten participants with stroke and spinal cord injury were interviewed.

The following changes were made to the demographic questionnaire and the inclusion criteria of participants into the study. A change was made to the admission questionnaire (question 18) that related to the patient's residence. Initially the question was "what type of house do you live in" and "are you the owner or do you rent the house". The researcher found that some of the participants did not own or rent the house, but cohabiting with someone. Therefore, the option of cohabiting was included for final data collection. The other change was made to question 27 of the same admission questionnaire. Patients did not understand the term responsiveness of transport, but rather responded on the appropriateness and adequacy of transport. Therefore, the item that referred to the responsiveness of transport was omitted from the questionnaire.

Throughout conducting the interviews with the patients suffering from stroke, the researcher noticed that one of the participant's instinctively answered yes to all questions. It was later apparent that the patient suffered from severe receptive aphasia. After discussion the researcher and study supervisor decided to exclude patients with severe receptive aphasia from the study population as this could introduce potential bias into the study (Srivastava, Taly, Gupta & Murali, 2010; Hilary, Owen & Farrelly, 2007).

Subsequently the three step command test, which is a valid and reliable tool to exclude patients with receptive aphasia, was used as the screening tool to evaluate the ability of patients with stroke to comprehend and process spoken and/or written information prior to the inclusion in the sample for the actual study. The three steps were as follow: The first instruction was "point to the keys", followed by "hand me the cup", and lastly "turn the page". The commands were repeated twice, those who were unable to perform the test accurately were excluded from the study. A number of studies reported the use of the three-step-command test as a screening tool for excluding patients suffering from receptive aphasia due to stroke and traumatic brain injuries. (Srivastava et al., 2010; Hilary, Owen & Farrelly, 2007). The importance of excluding patients who could not pass the three step command test due to aphasia was to ensure accuracy.



3.6 PROCEDURE FOR DATA COLLECTION

A research assistant was employed to assist the researcher with data collection for both the pilotand the actual study. Training of the research assistant was done prior to the pilot, thus the pilot study was also further used for training and the verification of data elements. The research assistant was given a list of synonyms and abbreviations related to data elements, as recommended by Banks (1998). During the pilot study the research assistant conducted the interviews with five patients. All the necessary data collection instruments were completed; thereafter the collected data were examined by the researcher for completeness. The research assistant was advised in the beginning that her work will be examined for accuracy (Worster & Haines, 2004).With regards to commencement of data collection, permission to conduct the study was obtained from the Deputy Director at the WCRC and relevant committees mentioned in paragraph 3.8.

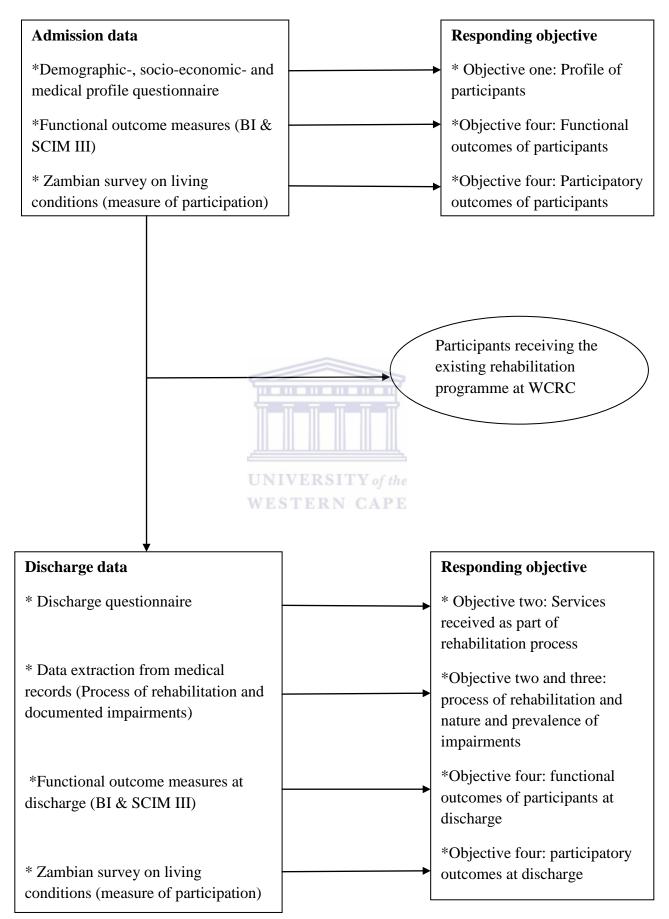
Stages of data collection

The researcher visited the WCRC every Monday and Thursday to identify the new admissions within the last two working days. The admission records with the information were provided by the relevant administrative staff in the respective ward. Patients meeting the inclusion criteria were approached in their respective wards to request participation in the study. Those who agreed were thoroughly explained of the purpose and their rights with regards to withdrawal from the study. Data were collected at the two intervals (on admission and on discharge) within a window period of two days after admission and two days prior to discharge. The patients that were assigned to the researcher and research assistant respectively were assessed by the same person on admission and at discharge. The diagram below illustrates the data collected of both diagnosed health conditions on admission and at discharge.



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Figure 3.1 Data collected on admission and discharge



Means of administration

All data collection instruments, except the medical record review, were administered via interview to accommodate for patients finding difficulty reading or writing, since patients with a neurological conditions often present with impaired cognitive-and hand function (Lawrence *et al.*, 2001). The interviews were conducted in certain cases at the bedside of the participants and other times in a private room. The interviews took approximately 30-45 minutes at both intervals of data collection.

3.7 DATA ANALYSIS

All data elements were coded and captured twice in Windows Excel 2007, and imported to SAS for analysis of the data for main study, whereas data elements for the reliability study (impairment data extraction sheet and Zambian survey on living conditions) were analyses in SPSS version 18. Based on the descriptive nature of the study, data analysis for the first three objectives comprised only of descriptive statistics. Results were presented as frequencies, means, standard deviations and percentages.

The Shapiro Wilk W test was used to determine the normality off data elements. With reference to the measurement of outcome on admission and discharge, the outcome variable which was the difference in score was found to be normally distributed for both diagnostic groups. Thus the paired t-test was used to determine the significant difference in functional outcome of patients between admission and discharge, with the use of the independent t-test for the calculated mean differences between sub-classifications of the spinal cord injured population. Data related to the functional ability of patients with spinal cord injury were collected according to completeness of injury and each level of lesion. However, due to the small sample sizes (<10) for each level, inferential statistics were not advised, due to the inaccurate results in the case of small samples. A 5% significant level was used, which translates to an alpha level of 0.5 (Domholdt, 2000). In

response to objective four, the paired t- test was used to determine both the functional (activity) and participation outcome of patients between the two points of data collection.

In response to the last objective both linear and multi logistic regression models were considered to determine the relationships between independent variables and the dependent variable (functional outcome score as measured by the Barthel Index and Spinal Cord Independence Measure III). Based on the study of mean outcome scores for different categories data were found to be abnormality distribution, thus prompted the use of non-parametric statistics. For dichotomous predictors (e.g. gender) a Wilcoxon Rank sum test was used to compare outcome scores of each outcome measure for both diagnostic groups, and the Spearman's rank order correlation co-efficient was used for continuous independent variables such as length of hospital stay, age, functional outcome score on admission (0-100).

A multiple regression model was fitted for four individual independent variables which were found to be strongly associated with the functional outcome score of patients with spinal cord injury as measured by the SCIM III. The five independent variables were considered together and the final model was established through the backward elimination process.

3.8 ETHICAL CONSIDERATIONS

3.8.1 Confidentiality

Participants were assigned a unique reference number as they were included in the study. This number was used as reference from that point forward in all documentation, including questionnaires and data table, thus adhering to anonymity as indicated in the Helsinki Declaration, which is a guiding document of ethical practices on human subjects (World Medical Organisation, 1996). Participants were informed of anonymity prior to their consent to participate. Participants were informed that findings of the research project may be published,

but that confidentiality anonymity would be maintained. They were assured that the collected and collated information from this study would be used for the sole purposes of this research project, and would not be disclosed to any unauthorised parties for statistical use or manipulation. All data collected were stored in a locked filing cabinet, where they could not be accessed by unauthorised persons.

3.8.2 Informed consent

Informed consent was considered to have been gained once a participant had understood and signed a copy of the document entitled "Information sheet and informed consent document" (Appendix C/D/E and F/G/H respectively). Prospective participants were informed of the study purpose and objectives, as well as the requirements of participation during the study period. Participants were asked to carefully read the consent form, which were translated into the languages spoken by the people within the catchment area of the institution. If the participant was unable to read, the form was then read to him/her by the researcher or research assistant. A translator fluent in English and isiXhosa had been appointed for the purpose of participants who were unable to speak or comprehend English or Afrikaans. The participants, the researcher and a witness signed the document to verify that the information had been correctly and completely conveyed. The participants were given the opportunity to ask questions relating to the study and their involvement. The researcher further clarified their understanding by asking them to recap the main purposes conveyed to them and to summarise the expectation of their involvement in the study. The participants were told if any psychological or emotional trauma result due to questioning, the researcher/assistant will inform the responsible therapist to possibly refer the patient to an appropriate health professional at the centre.

3.8.3 Approval

Permission to conduct the research was obtained from the University of the Western Cape's Faculty of Community and Health Sciences Higher Degrees Committee, Senate Research Grant and Study Leave Committee, the Western Cape Department of Health and the deputy director of the Western Cape Rehabilitation Centre, prior to commencement of data collection (Project registration number: 10/3/24).

3.8.4 Dissemination of results

The results of the study will be made available to all relevant parties upon successful completion. A PowerPoint presentation will be presented by the principal researcher to the staff members of the centre and a written bound copy of the final thesis will be given to the WCRC to be kept in the library.

3.9 Summary of the chapter

In this chapter, the Western Cape Rehabilitation Centre as the research setting was described. The researcher outlined the research design, study population and provided a motivation for the selected sample sizes of the two health conditions included. The methodology was specifically designed to answer the overarching aim and objectives, thus data collection instruments were described with reference to its aim and psychometric properties. This chapter concluded with the statistical analysis and the ethical considerations that were adhered to throughout the study period.

CHAPTER FOUR

RESULTS

4.0 INTRODUCTION

The results of the study were presented in sections which related to the study objectives. The first section described the demographic profile, socio-economic status, and medical status of the study population including co-morbidities. The next section described the process of rehabilitation of patients with stroke and spinal cord injury at the WCRC. Process issues which were determined for the aforementioned health conditions included the length of hospital stay, services received by the participants, and the referral pathway, which includes the referral agency and discharge destination. Thereafter, the nature and prevalence of the documented primary impairments related to stroke and spinal cord injury were presented. The penultimate section presented the participants' outcomes, with reference to the activity limitations and participation restrictions on admission and at discharge. The chapter concluded with the factors which predict functional outcome at discharge of both patients with stroke and spinal cord injury.

4.1 Participant recruitment

4.1.1 Recruitment of the study sample

A total of 233 patients were admitted to the WCRC between November 1, 2010 and January 31, 2011. Patients with stroke and spinal cord injury constituted 175 (75%) of the total admissions. Of those, ten patients were under the age of 18 years old, four declined consent, eight subjects presented with missing data and the remaining ten presented with co-morbidities and receptive aphasia, which was part of the exclusion criteria. Thus, the sample meeting the inclusion criteria,

given that they consent to participation in the study was 143 patients with either a spinal cord injury (76) or a stroke (67). The sample size at discharge was 130, which indicated a dropout rate of 9%.

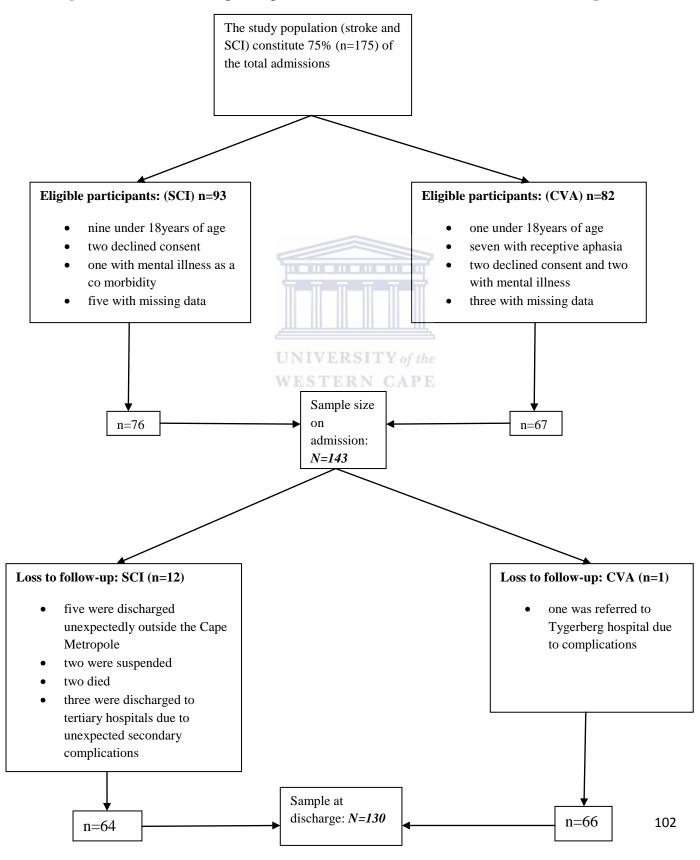


Figure 4.1 Outline of the participants' recruitment from admission to final sample

4.2 Description of the participants

The results that will follow are specific to spinal cord injury (n=76) and stroke (n=67)

4.2.1 Demographic profile of the participants on admission

The following items will be presented in this section of demographic characteristics: gender, age, marital status and geographical location.

Table 4.1 Demographic information of	f patients with spina	l cord injury and stroke

Demographic variables	Spinal Cord Injury (n;%)	Stroke (n;%)
Gender		
• Male	56 (39.16)	35 (24.48)
• Female	20 (13.98)	32 (22.38)
Age		
• 18-25	20 (26.3)	1 (1.5)
• 26-33	18 (23.7)	3 (4.5)
• 34-49	32 (42.1)	21 (31.3)
• 50-59	4 (5.3)	23 (34.3)
• 60-64	0 (0.0) SITY of the	8 (11.9)
• 65-75 W	1 (1.3) RN CAPE	9 (13.4)
• 76 and >	1 (1.3)	2 (3.0)
Marital status		
Single	56 (73.68)	15 (22.39)
Married	14 (18.42)	36 (53.73)
Cohabiting	0 (0.00)	1 (1.49)
Separated	0 (0.00)	2(2.98)
• Divorced	4 (5.26)	6(8.96)
Widowed	2 (2.64)	7(10.45)
Residence (District)		
Cape Metropole	58 (76.32)	53 (79.10)
Cape Winelands	6 (7.89)	6 (8.96)
 Westcoast Wineland 	6 (7.89)	3 (4.48)
Cape Overberg	2 (2.63)	2 (2.99)
 Klein Karoo 	2 (2.63)	3 (4.48)
 Neighbouring Province 	2 (2.63)	0 (0.00)

A total of 91 were male and 52 were female, with a mean age of 42.95 for the total sample. The gender distribution was different for the two conditions with more males (74%) having a spinal cord injury while the distribution for gender in patients with stroke was almost equal. There was a statistical significant difference in gender distribution for the spinal cord injury diagnostic group (Chi-Square test; p <0.01), which indicated significantly more males than females. The mean age (standard deviation) of patients with spinal cord injury and stroke were 34.14 (12.42) and 52.95 (12.19) respectively. The Shapiro-Wilk W Test (W=0.98, p>0.05) revealed that age was normally distributed for both conditions. The male: female ratio for patients with stroke and spinal cord injury was 1.2:1.1 and 2.8:1 respectively. More than one-third (42%) of the participants with spinal cord injuries were between the ages of 34-49 and 34.32% of the patients with stroke were between the age group 50-59. Ninety seven percent of patients with spinal cord injuries and 71.64% of those with stroke were at an age where they could still be employed (<60 years). Most of the patients with spinal cord injury were single (73.68%) at the time of injury, whereas most of the patients with stroke (53.73%) were married when they suffered a stroke. Of those who were single about 10% of the patients with stroke were divorced at the time of their injury, whereas fewer patients with spinal cord injury were left behind by their partners due to death. It was notable that most of the patients with spinal cord injury (76.32%) and stroke (79.10%) resided within the Cape Metro district, which is the immediate catchment area of the centre.

4.3.1 Socio-economic Status of the participants

The socio-economic status of the participants was assessed on admission since the WCRC is an in-patient facility. The following items will be presented in this section: level of education, household income and source of income on admission and employment status. Furthermore the different types of work of those still employed on admission and the results on living environment and access to basic needs are discussed.

Variable		Number (%)
Level of education		
No formal education		6 (4.19)
Primary		30 (20.97)
Secondary		96 (67.13)
Tertiary		11 (7.69)
Monthly household income in	South African Rand	
No Income		55 (38.46)
1 - 1000		11 (7.69)
1001 - 2000		56 (39.16)
2001 - 5000		10 (6.99)
5001 - 10000		6 (4.19)
10001 - 15000		3 (2.09)
> 15000	UNIVERSITY of the	2 (1.39)
Source of income	WESTERN CAPE	
No income		55 (38.46)
Disability grant/ All pay		41 (28.67)
Pension-private		13 (9.09)
Childcare grant		2 (1.39)
Carer dependency grant		1 (0.70)
Formal Employment: Permaner	nt/contract	20 (13.98)
Informal Employment: Casual/	contract/seasonal	6 (4.19)
Other forms of income		5 (2.72)
Occupational status of those e	mployed	
Professional or managerial		3 (2.09)
Skilled or semi-skilled		15 (10.49)
Unskilled		13 (9.09)

Table 4.2 Socio-economic status of the participants on admission (n=143)

The majority (67.13%) of the participants had received formal schooling up until secondary level, which represents grades 8-12, whereas the minority of 4.19% had no formal education, while 20.97% of the participants had a low level of education, which is a category of any grade between one and seven (Stats SA, 2006). The results revealed that 46.15% of the participants would be classified in the lower income bracket as they have a monthly family income of \leq R 1000 (Stats SA, 2006). This result is to be expected as the majority were unemployed at the point of data collection. More than one-third (39.16%) of the participants received an income ranging R1001-R2000. High number of participants (38.46%) had no fixed formal income and was unemployed at the time of hospitalisation. Of those who were unemployed, 28.69% were receiving an old age and 9.09% received private pension. Of the 31 participants who were employed prior to the onset of the health condition, the largest percentage (48.39%) of those in paid employed was in the skilled or semi-skilled category.

4.3.2 Type of work

This table below depicts the different types of work done of those in paid employment prior to hospitalisation and the percentage in relation to the final sample (N=143).

Category	Number of	Type of work
	Participants (%)	
Professional/Managerial	3 (2.09%)	manager, teacher, nursing sister
Skilled/semi-skilled (Includes technicians, clerical, crafts, trader, service and sales	15 (10.49%)	welder, electrician, printing technician, audit clerk, secretarial, carpenter, chef, sales person, driver, interpreter
workers) Unskilled	13 (9.09%)	labourer, cleaner, general assistant, domestic worker, paid caregiver, bakery assistant
	31 (21.67%)	

Table 4.3 Frequency by type of work for participants in paid employment (n=31)

4.3.3 Housing and access to basic services

Prior to hospitalisation, 97 participants lived in formal housing and 28 participants lived in informal housing. The majority of the participants lived in self-standing or semi-detached houses. Of those who resided in informal housing, five participants rented a room in the backyard, whereas 23 patients lived in informal dwellings in informal settlements. Five of the participants lived in an old age home. An alarming 17 (11.88%) participants lived in "other" forms of residence, ranging from no housing, lodging in shelters for short periods of time and rehabilitation facilities. With regards to basic needs, the majority of the participants had access to electricity (94.57%), running water indoors (80.43%) and a telephone (75.54%). Most of the participants also had indoor toilet facilities (58.70%).

4.4 Medical profile of the participants on admission

This section will illustrate and describe the medical profile of the sample on admission, and the following will be included: the classification of the stroke and spinal cord injury and the comorbidities of patients.

4.4.1 Classification of diagnosed health conditions

Table 4.4 illustrates the classification of both spinal cord injury and stroke diagnostic groups

Diagnosed health condition	Total (n/N)	(%)	
Classification			
Spinal cord injury	76	53.14	
Paraplegia	58/76	76.31	
Tetraplegia	18/76	23.69	
Stroke	67	46.86	
Left brain lesion	34/67	50.75	
Right brain lesion	30/67	44.77	
Undiagnosed	3/67	4.48	
Total	143	100	

Table 4.4 Classification of the diagnosed health conditions (n=143)

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Most of the patients in the spinal cord injury cohort were classified as paraplegic (76.31%), whereas within the stroke cohort, the laterality of the brain lesion was almost similar for either side, but with slightly more left side lesions (50.75%).

4.4.2 The prevalence of co-morbidities for the study sample

Table 4.5 illustrates the prevalence of co- existing illnesses/diseases among the study sample.

The responses for co-morbidities were gathered from the patient on admission via interview.

	Frequenc	y (%)
	SCI (n= 76)	Stroke (n= 67)
Co-morbidity		
Hypertension	1 (1.31)	39 (58.21)
Diabetes Mellitus	1 (1.31)	21 (31.34)
Hyperlipidemia	0.00 (0.00)	8 (11.94)
Heart disease	0.00 (0.00)	4 (5.97)
Renal failure	2 (2.63)	2 (2.96)
Liver failure	0. (0.00)	1 (1.49)
Cancer	3 (3.95)	1 (1.49)
HIV/ Aids	18 (23.68)	10 (14.93)

 Table 4.5 The prevalence of co morbidities among stroke and spinal cord injury (n=143)

The most common co-illnesses for stroke were hypertension and diabetes mellitus with a prevalence of 58.21% and 31.34% respectively. In contrast to the high prevalence of hypertension and diabetes mellitus among stroke, the most common co-illness worth mentioning among patients with spinal cord injuries was HIV/Aids, which affected almost one-quarter (23.68%) of the cohort. The majority (68.42%) of the patient with spinal cord injury and only 22.38% of the patients with stroke reported no co-illnesses on admission.

4.5 PROCESS OF REHABILITATION

This section of the results presents the rehabilitation services received, length of hospitalisation and the referral process. Information pertaining to services delivered was obtained by interviewing the patients during the completion of the discharge questionnaire following rehabilitation at the WCRC. With regards to information related to the length of hospital stay and the referral process, a data extraction sheet was used to gather the needed information from the patients' medical records.

4.5.1 Services Received

It is noteworthy to mention that the sample sizes for spinal cord injuries and stroke were 64 and 66 respectively, due to dropouts. Therefore, all data collected at discharge will reflect the respective sample sizes of the two diagnostic groups. On discharge the participants provided information regarding the services received during their length of hospital stay. Table 4.6 illustrates all serviced received by patients during in-patient rehabilitation at the WCRC.

Table 4.6 Services received by the participants with spinal cord injury (n= 64) and stroke (**n= 66**)

Frequency and percentage				
	SCI (n= 64)	%	CVA (n= 66)	%
Services Received				
Counsellor	1	(1.56)	5	(7.57)
Psychologist	6	(9.37)	7	(10.60)
Prosthetist/Orthotist	0	0 (0.00)	0	(0.00)
Doctor	63	(98.43)	65	(98.48)
Pharmacist	0	(0.00)	1	(1.51)
Physiotherapy	64	(100.00)	65	(98.48)
Occupational therapy	62	(96.87)	63	(95.45)
Speech therapy	4	(6.25)	36	(54.54)
Radiologist	13	(20.31)	1	(1.51)
Home-based care	1	(0.63)	0	(0.00)
Nursing care	64	(100.00)	66	(100.00)
Social Worker	UN60VERSIT	(93.75)	64	(96.96)
Dietician	WHO TERN	(15.62)	11	(16.66)
Health and Wellness Centre	5	(7.81)	1	(1.51)
Learn to swim	30	(46.87)	26	(39.39)
Ballroom dancing	10	(15.62)	5	(7.57)
Wheelchair basketball	19	(29.68)	1	(1.51)
Fun walks/recreational outings	16	(25.00)	9	(13.63)
Peer supporter	11	(17.18)	8	(12.12)

Key: SCI = spinal cord injury; CVA = cerebrovascular accident

The most common health professionals seen by participants include the doctor, nurse, physiotherapist and occupational therapist. The speech therapist was more common among patients with CVA. With regards to recreational activities, almost half (46.87%) of patients with spinal cord injuries participated in the "learn to swim" programme, and just less than one-third (29.68%) attended the wheelchair-basketball therapeutic sessions, which are offered to patients at the centre. Furthermore, it is important to mention that the minority (less than 20%) of the

patients from both diagnostic groups was referred to the health and wellness centre facility and the peer supporter. Generally, the additional recreational activities were more utilised by those with spinal cord injury than the stroke sample.

4.5.2 Mean length of hospital stay

The patient records were perused to determine the length of hospital stay in days, calculated since the day of admission to the day of discharge. Patients requesting to go home over the weekend is not officially discharged from the centre, therefore discharge at the WCRC was only authorised at the end of rehabilitation. Table 4.7 illustrates the mean length of hospital stay per diagnostic group.

Diagnostic group	MLOS	STD	Min	Max
	UNIVE	RSITY of the		
Stroke (n=66)	51.62 VESTE	RN 17.47	9.00	114.00
• Left brain lesion	49.79	19.85	9.00	107.00
• Right brain lesion	52.98	16.54	13.00	114.00
Spinal cord injury (n=64)	73.11	43.74	3.00	184.00
• Paraplegics	68.32	40.10	7.00	124.00
• Tetraplegics	85.65	50.35	3.00	184.00

Table 4.7 Mean length of hospital stay per diagnostic group (n=130)

*MLOS= Mean Length of Hospital Stay; STD = standard Deviation; Min = minimum; Max = maximum

The mean length of hospital stay for the spinal cord group was 73.11 days with a standard deviation of 43.74, which was significantly longer, as measured by chi-square test (p=0.003), than that of the stroke diagnostic group. The maximum length of hospital stay of patients with spinal cord injury was six-months, whereas the maximum length of stay for stroke was almost

four months. With reference to the sub-classification of spinal cord injury, the mean length of hospital stay was longer for those with tetraplegia than those with paraplegia.

4.5.3 Referral process

This section of the results discusses the referral process, taking into account the referral agency/institution to the centre and the discharge destination post rehabilitation at the WCRC.

4.5.3.1 Referral to the centre

Frequency and percentage				
	SCI (n= 7	6) %	CVA (n=	= 67) %
Level of health care				
Primary	3	(3.95)	7	(10.44)
Secondary	11 UNI WES	(14.47)	28	(41.80)
Tertiary	53	(69.74)	23	(34.32)
Specialised centre	8	(10.52)	5	(7.46)
Private hospital	1	(1.31)	4	(5.97)

 Table 4.8 Frequency of patients referred from different levels of health care (n=143)

The above-illustrated results suggest that most of the referrals of spinal cord injury patients were received from tertiary hospitals, followed by secondary hospitals and private hospitals. In contrast to most of the referrals of spinal cord injury coming from tertiary hospitals, the results showed that most of the referrals of patients with stroke were received from secondary hospitals followed by referrals from tertiary hospitals.

4.5.3.2 Discharge destination

This section describes and illustrates the discharge destinations of patients following rehabilitation.

	SCI n (%)	CVA n (%)
Discharge destination		
Home ¹	61 (80.26)	55 (82.08)
Health care facility	4 (5.26)	4 (5.97)
WCRC-OPD	9 (11.84)	5 (7.46)
Other	2 (2.61)	3 (4.47)
Total	76 (100)	67 (100)

Table 4.9 Frequency	of discharge	destinations of	² nortiginants r	or diagnostia grou	n(n-1/3)
Table 4.9 r requency	of discharge	e desunations of	participants p	per diagnostic grou	p (n=143)

* Key: WCRC-OPD- Western Cape Rehabilitation Centre- Out-Patient Department

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The majority of the patients with spinal cord injuries (80.26%) and stroke (82.08%) were discharged home following hospitalisation at the WCRC. Moreover, 11.23% of the total sample was referred to a secondary or tertiary hospital, whereas 19.30% continued, no longer in-patient but out-patient rehabilitation at the WCRC Out-Patient Department.

¹ Table 4.13 illustrates the discharge destinations following in-patient rehabilitation at the WCRC. Patients that were discharged home were not referred for further rehabilitation (on an in-or out-patient basis), whereas those who were discharged to WCRC-OPD will still continue with rehabilitation post discharge, but also discharged home.

4.5.4 Outcome levels achieved on admission and discharge

The WCRC uses the outcome levels as bases for admitted patients and as an indicator for discharge planning, including discharge destination. The figures below illustrate the outcome levels of patients with stroke and spinal cord injury on admission and those that were achieved at discharge.

4.5.4.1 Outcome levels of the stroke population

The figure below illustrates the outcome levels on admission and discharge of the spinal cord injured population.

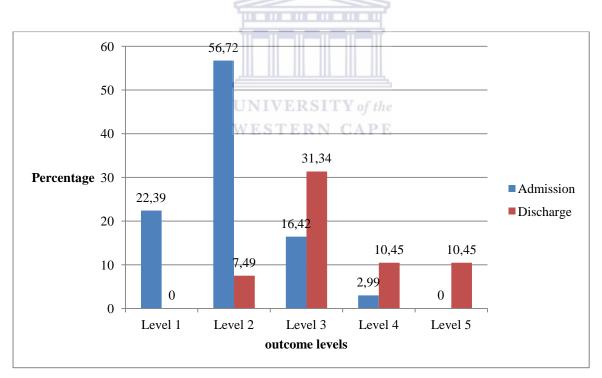


Figure 4.2 Outcome levels of the stroke population on admission and discharge

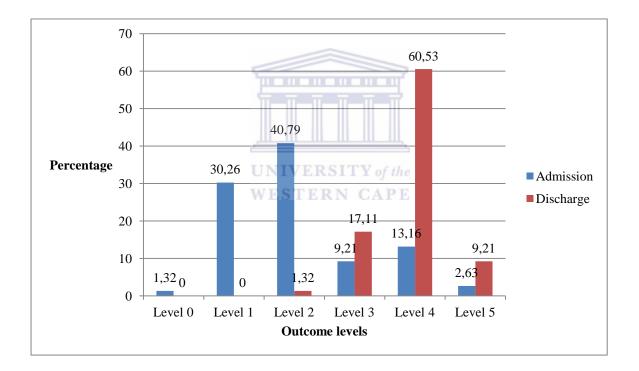
The majority of patients with stroke (56.72%) were admitted with a level of health corresponding with outcome level two. Concerning outcome levels obtained at discharge, all patients with stroke moved from outcome level one to a higher level at discharge. Furthermore, the highest percentage of patients with stroke (50.75%) achieved an outcome level four at

discharge. Only 10.45% of the patients with stroke achieved an outcome level five, which represents the highest level of functioning on the hierarchy of the outcome based approach.

4.5.4.2 Outcome levels of the spinal cord injured population

The figure below illustrates the outcome levels on admission and discharge of the spinal cord injured population.

Figure 4.3 Outcome levels of the spinal cord injured population on admission and discharge



The largest number of patients with spinal cord injury (40.79%) was admitted with a level of health corresponding with outcome level two, with the second largest percentage of admitted with an outcome level one, which represents a lower level of health status. With regard to the outcome levels obtained at discharge, firstly, it is noticeable that all patients with spinal cord injury moved from outcome level one to a higher level at discharge. Secondly, the highest percentage of patients' spinal cord injury (60.53%) achieved an outcome level four at discharge.

4.6 OUTCOME OF REHABILITATION

This section of the results will illustrate and describe the outcomes of patients with reference to the domains of the ICF, which are the impairments, activity limitations and participations restrictions. For the first domain, the prevalence of primary impairments of each diagnostic group on admission will be tabulated. The pre- and post rehabilitation outcomes determined were the participants' activity limitations and participation restrictions on admission and at discharge. This section will present the mean outcome score and mean individual item score as measured by the standardised outcome measure of each diagnostic group on admission and at discharge. Furthermore, an indication of the statistical significance between the mean scores at the different points of data collection will also be tabulated.

4.6.1 Primary impairments on admission

These results summarise the frequency of each primary impairment on admission as gathered by the data extraction sheet. Since data for this section of work were collected via the medical record of the patients, the undocumented responses per primary impairment were also calculated as a percentage of the total sample.

	factor for contrast		
	Impaired (%)	Not documented (%)	
Primary impairments			
Dysphagia	9 (13.43)	24 (35.82)	
Aphasia (receptive and/or expressive)	34 (50.75)	14 (20.90)	
Dysarthria	22 (32.84)	39 (58.21)	
Cognitive function	17 (25.37)	13 (19.40)	
Proprioception	7 (10.45)	54 (80.60)	
Sensation	28 (41.79)	8 (11.94)	
Bowel incontinence UNI WES	$\begin{array}{c} \mathbf{VERSITY} \text{ of the} \\ \mathbf{T} 4 (5.97) \\ \mathbf{APE} \end{array}$	20 (29.85)	
Bladder incontinence	8 (11.94)	16 (23.88)	
Muscle weakness	54 (80.60)	6 (8.96)	
Active selective movement (upper limb)	13 (19.40)	49 (73.13)	
Active selective movement (lower limb)	4 (5.97)	60 (89.55)	
Abnormal muscle tone	51 (76.13)	7 (10.45)	
Balance	17 (25.37)	45 (67.16)	

Table 4.10Frequency of impairment of the stroke diagnostic group (n= 67)

Frequency and percentage

The most prevalent impairments in this cohort of patients with stroke were muscle weakness/hemiparesis, abnormal tone and aphasia with 80.60%, 76.13% and 50.75% of patients affected respectively. It is further evident that only 5.97% presented with bowel incontinence and 11.94% with bladder incontinence. Interestingly, among the least prevalent impairments, which were proprioception (10.45%) and active selective movement function (5.97%), most of the assessments were undocumented.

	Frequency and percentage			
	Impaired (%)	Not documented (%)		
Primary impairments				
Sensation	U 53 (69.74) ITY of the WESTERN CAPE	19 (25.00)		
Muscle weakness	57 (75.00)	8 (10.53)		
Bowel incontinence	41 (53.95)	17 (22.37)		
Bladder incontinence	54 (71.05)	7 (9.21)		
Balance	13 (17.11)	53 (69.74)		
Respiration	4 (5.26)	25 (32.89)		
ROM	8 (10.53)	50 (65.79)		

Table 4.11Frequency of impairment of the spinal cord injury diagnostic group (n= 76)

*SCI= spinal cord injury, ROM= range of motion

The most prevalent impairments in this cohort of spinal cord injuries were muscular weakness, bladder incontinence and impaired sensation, which affected 75.00%, 71.05% and 69.74% of

patients respectively. In contrast to the higher prevalence rate of the aforementioned impairments, the patients were least affected by respiratory dysfunction (5.26%) and reduced range of motion (10.53%). It is noteworthy to mention that the lower prevalence rates of certain impairments were accompanied by higher percentages of "undocumented" responses. This was evident for the impairments related to "balance dysfunction (69.74%)" and "range of motion (65.79)".

4.6.2 ACTIVITY LIMITATIONS OF THE PARTICIPANTS

The Barthel Index (BI) was used to assess the activity limitations of the participants with stroke, whereas the Spinal Cord Independence Measure (SCIM) version III was used for patients with spinal cord injury.



4.6.2.1 Mean, standard deviation and significance level at different time points

Table 4.12 presents the mean and standard deviation of the Barthel Index Scores for the different time periods.

Variable	Admission	Discharge	Significance-value
	n = 67	n = 66	
Barthel Index	Mean (SD)	Mean (SD)	p < 0.0001
	58.85 (24.70)	81.59 (14.91)	

 Table 4.12 Barthel Index mean scores, standard deviation and significance level

A significant difference was found between the mean admission and discharge Barthel Index scores (p<0.0001) as determined by the paired t-test (t=8.18).

4.6.2.2 Barthel Index scores according to level of stroke severity

The participants' ability to perform functional activities of daily living was measured using the Barthel Index. The scores for the Barthel Index range from 0-100, where higher score indicates a higher level of functioning. The participants were grouped according to level of severity on the basis of the Barthel Scores. This information is presented in Table 4.13

Table 4.13 The functional	ability of patients'	with stroke acc	ording to the B	Barthel Index
Score				

Category	Admission	Discharge	
	n = 67 (%)	n = 66 (%)	
Dependent	35 (50.00)	5 (7.58)	
(0 -55)			
Moderate Assistance	21 (30.00)	27 (40.91)	
(60 -80)	UNIVERSITY of the WESTERN CAPE		
Minimal Assistance	11 (15.71)	22 (33.33)	
(85 -95)			
Independent	3 (4.29)	12 (18.18)	
(100)			

The above results indicate that at the discharge assessment period only 18.18% of the participants were fully independent with the majority (81.82%) still needing assistance with at least one activity of daily living at discharge.

4.6.2.3 The independent execution of functional tasks on the Barthel Index

One of the benefits of utilising the Barthel Index is its ability to determine the frequency of independent execution of each item on the questionnaire. The derived results could externalise the percentage of patients moving from performing functional task with maximal or some assistance to the independent execution of those tasks, which are thought to have clinical significance. The figure below illustrates the frequency of independent execution of daily tasks as captured by the Barthel Index

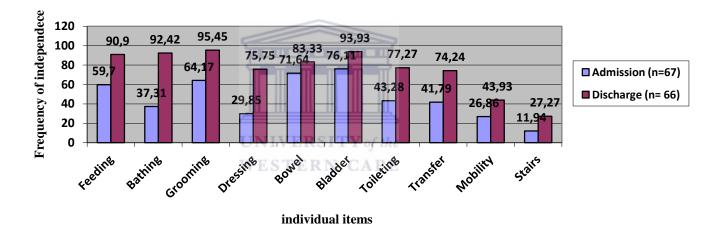


Figure 4.4 The independent execution of functional tasks on Barthel Index on admission and at discharge

The results depicted in the figure above suggest that for percentage of patients for each item increased in terms of the independent execution of each task or action, even though the ratio of independence when comparing the percentages of change of each item at the different intervals is variable. The independence of performing tasks on admission was greatest for bladder continence, bowel continence and grooming with 76.11%, 71.64% and 64.17% respectively. It is further noticeable that on discharge the independence of tasks were the highest for items relating to grooming, bladder continence and bathing with 95.45%, 93.93% and 92.42% of patients performing the respective tasks independently. Furthermore, it is noteworthy to mention that irrespective of the increase in percentage of independent execution of the items relating to mobility and stair climbing between the two intervals, the percentages of independence remained

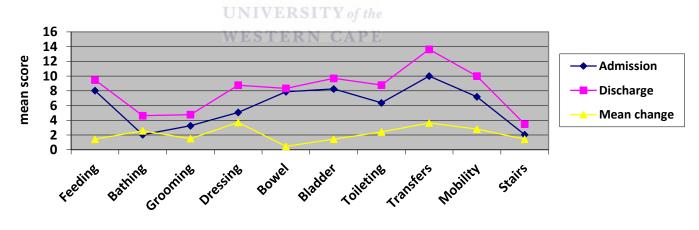
the lowest. The greatest increases in the independent execution of tasks between admission and discharge were found for bathing, dressing and toileting with 55.11%, 45.90% and 33.99% of additional patients who were not independent with the execution of the respective tasks on admission.

4.6.2.4 The mean procedure of individual items of the Barthel Index

Each item on the Barthel Index represents a different functional construct and is weighed differently based on the complexity of the functional task. The score for each item on the Barthel Index ranges from 0-5, 0-10, or 0-15. The line chart will illustrate the mean procedure of each item of data collected on admission and at discharge, and the mean change for each item.



Figure 4.5 The mean procedure of individual items of the Barthel Index



individual items

The results illustrated in this line chart suggest that the mean scores of each item at discharge were larger than the mean scores obtained on items on admission. The pre and post comparison of the mean of each item indicated a p- value <0.0001 for feeding, bathing, grooming, dressing, bladder, toileting, transfers and mobility; and a p=0.025 for stair climbing. The only insignificant

change in mean scores between admission and discharge was for bowel incontinence, with a p-value = 0.471. The greatest mean score change was for dressing and transfers.

4.6.3 Activity limitations as measured by the Spinal Cord Independence Measure III

The participants' activity limitations were measured using the Spinal Cord Independence Measure (SCIM) III. The scores for the SCIM III range from 0-100, where a higher score indicates a higher level of functioning and independence. The weighing of each item on the questionnaire is variable, but the allocated score represents the complexity of each task.

4.6.3.1 Mean, standard deviation and significance level at different time points

Table 4.14 presents the mean and standard deviation of the Spinal Cord Independence Measure III scores of the total spinal cord injury population for the different time periods as well as the significance level between mean scores on admission and discharge. Table 4.15 illustrated the mean (SD) and difference between mean scores on admission and discharge with the alpha level set at 0.05%

Table 4.14 Spinal Cord Independence Measure III mean scores, standard deviation and significance level

Variable	Admission	Discharge	Significance-value
	n = 76	n = 64	
SCIM III score	Mean (SD)	Mean (SD)	
	48.03 (24.31)	67.07 (23.04)	p < 0.0001

The sum score on the Spinal Cord Independence Measure III at discharge was significantly larger than that on admission as determined by the paired t-test (t=7.07; p<0.0001).

 Table 4.15 Spinal Cord Independence Measure III mean scores, standard deviation and

 mean difference of the sub-classification of SCI

	Admission Mean (SD)	Discharge Mean (SD)	Significance-value
<i>Variable</i> SCIM III score of <i>paraplegics</i> ²	53.67 (22.15)	73.23 (18.24)	p=0.006
SCIM III score of <i>tetraplegics</i> ³	41.53 (30.57)	52.92 (33.30)	p=0.033

With the alpha level set at 0.05, both sub-classifications of the spinal cord injured population demonstrated a significant change in mean overall scores as measured by the Spinal Cord Independence Measure III between admission and discharge. The significance between the means scores of those with paraplegia and tetraplegia was also analysed using independent student t-test, which indicated that the mean score of the paraplegic population, on both admission and discharge, was significantly higher than the tetraplegic group with p=0.023 and p=0.007 respectively.

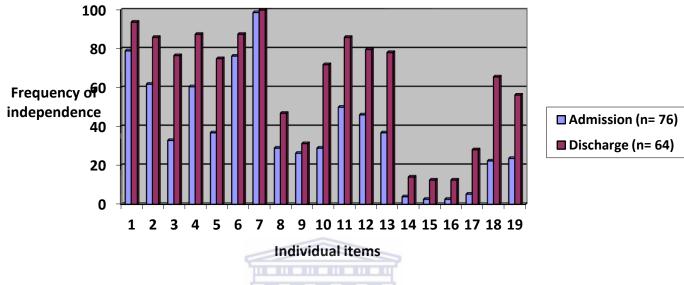
4.6.3.2 The independent execution of functional tasks on the SCIM III

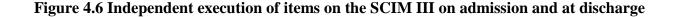
The SCIM III can be utilised to determine the frequency of independent execution of each item on the questionnaire. The results to follow will illustrate the percentage of patients moving from

² The sample (n) of those with paraplegia was n=58 and n=52 on admission and discharge respectively.

³ The sample (n) of those with tetraplegia was n=18 and n=15 on admission and discharge respectively.

performing functional task with maximal or some assistance to the independent execution of those tasks.





* Key: 1- Feeding; 2- Bathing upper body; 3- Bathing lower body; 4- Dressing upper body; 5- Dressing lower body; 6- Grooming; 7- Respiration; 8- Bladder management; 9- Bowel management; 10- Use of toilet; 11- Mobility in bed and action to prevent pressure sores; 12- Transfer from bed to wheelchair; 13- Transfer from wheelchair-toilet and tub; 14-Mobility indoors; 15- Mobility for moderate distances; 16- Mobility outdoors; 17- Stair management; 18- Transfer from wheelchair to car; 19- Transfer from ground to wheelchair

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The results from this figure suggest that there was an increase in the subjects performing tasks independently for each item when comparing the data on admission with that obtained at discharge. The degree of independent execution of tasks on admission was greatest for respiration, feeding and grooming with 98.68%, 78.94% and 76.31% of patients functional with the respectively tasks. It was further noticeable that on discharge the independence of tasks was the highest for the same items as on admission, with everybody (100%) independent with maintaining their own airway/respiratory system, 93.75% fully functional with feeding him or herself, and 87.50% of patients needing no assistance with grooming and dressing the upper body. The greatest increases in the independent execution of tasks between admission and discharge were found for bathing of the lower limbs, transfer from the wheelchair to the car, and

toileting with 43.67%, 43.26% and 42.93% of additional patients who were not independent with

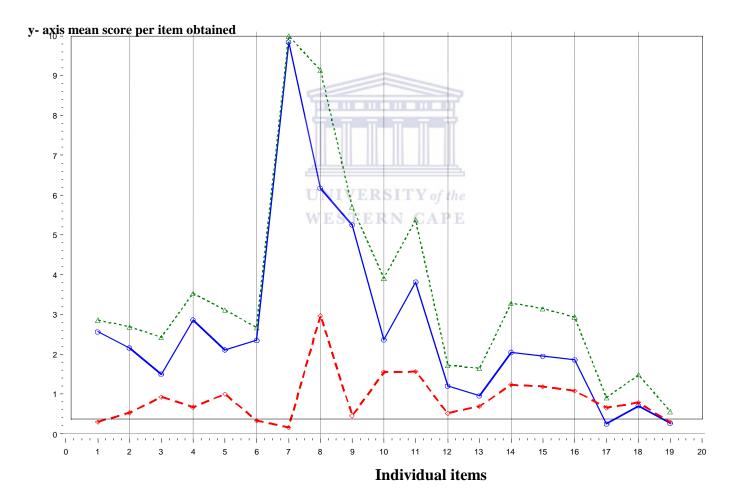
the execution of the respective tasks on admission.

4.6.3.3 The mean procedure of individual items of the Spinal Cord Independence Measure III

The line chart illustrates the mean procedure of each item of data collected on admission and at

discharge, and the mean change for each item.

Figure 4.7 Mean procedure of individual items on the SCIM III for the spinal cord injured patients Blue=Pre, Green=Post, Red=Post-Pre Difference



* Key: 1- Feeding; 2- Bathing upper body; 3- Bathing lower body; 4- Dressing upper body; 5- Dressing lower body; 6-Grooming; 7- Respiration; 8- Bladder management; 9- Bowel management; 10- Use of toilet; 11- Mobility in bed and action to prevent pressure sores; 12- Transfer from bed to wheelchair; 13- Transfer from wheelchair-toilet and tub; 14- Mobility indoors; 15- Mobility for moderate distances; 16- Mobility outdoors; 17- Stair management; 18- Transfer from wheelchair to car; 19- Transfer from ground to wheelchair

Similar to the mean procedure of the stroke diagnostic group, the results illustrated in this line chart suggest that the mean scores of each item at discharge were larger than the mean scores obtained on items on admission. The pre- and post comparison of the mean of each item indicated a significant p < 0.05 for feeding, bathing upper and lower body, dressing upper and lower body, grooming, bladder management, use of toilet, prevention of pressure sore, bed to wheelchair transfers, wheelchair-toilet-tub transfer, mobility indoors, mobility for moderate distances, mobility outdoors, stair management, wheelchair to car transfer and ground to wheelchair transfer. The only insignificant change in mean scores between admission and discharge was for respiration and bowel management, with a p=0.321 and p=354 respectively.

4.6.4 Measuring participation restriction among patients with stroke and spinal cord injuries

Many authors suggest that the domains of activity and participation are blurred, therefore items relating to activity and participation were presented. The Zambian survey on living conditions had been used to measure the degree of restriction in certain tasks/ action and life situations. The scoring system range from 0-4, with each individual number representing the degree of difficulty that the patient performing the tasks/ actions and taking on the various social roles. It should be noted that lower scores represents lower levels of difficulty.

A total score for all the items were calculated based on the number of responses (that ranged from 0-4) received for each item. The number of responses (n) was kept similar for the mean calculation difference on admission and at discharge of each item. Therefore, a mean change could be calculated and is thus only reflective of the sample with responses ranging from 0-4.

4.6.4.1 Participation restrictions experienced by patients with stroke

The mean procedure of each item on admission and at discharge is illustrated. In addition, the post-pre mean difference is also presented in the same graph, with a cut-off line inserted at a mean change score of -1 (which indicates an improvement of at least one unit on the scoring scale of the survey), which is clinically meaningful. It is important to note that not the entire cohort of stroke and spinal cord injury engaged in every participatory tasks included in the questionnaire, neither did all the patient attempt the specific participatory tasks since the onset of the health condition, thus in those instances the response labelled "8" and "9" (See appendix S) were not included in the analysis of those specific items. Therefore, these results should be taken with caution as the sample size (n) was variable for most of the items for both diagnostic groups.



UNIVERSITY of the WESTERN CAPE Table 4.8 Mean procedure of items on participation scale for stroke



Neg Post-Pre indicates improvement Blue=Pre, Green=Post, Red=Post-Pre Difference

Items as described on Zambian survey

* Key: 1- understanding others; 2- producing messages; 3- communicating directly with others; 4- communicating using devices; 5- staying in one body position; 6- changing a body position; 7- transferring oneself; 8 - lifting/carrying/moving/handling objects; 9- fine hand use; 10- hand & arm use; 11- Walking; 12- moving around; 13- using transport as a passenger; 14- driving a vehicle; 15- washing oneself; 16- care of body parts, teeth etc; 17- toileting; 18- dressing and undressing; 19- eating and drinking; 20- shopping; 21- preparing meals; 22- doing housework; 23- taking care of personal objects; 24- taking care of others; 25- making friends and maintaining friendships; 26- interacting with persons in authority; 27- interacting with strangers; 28- creating and maintaining family relationships; 29- making and maintaining intimate relationships; 30- going to school and studying; 31- getting and keeping a job; 32- handling income and payments; 33- involvement in clubs/organisations; 34- recreation/leisure; 35- religious/spiritual activities; 36- political life and citizenship

The results on the participatory tasks/ actions suggest that the mean scores of each item was greater (it is important to note that lower scores on the scoring system represents improvement and lower levels of difficulty when performing the tasks) at discharge than on admission, except for items 2, 21, and 22, which represents the tasks of producing messages (communication), preparing meals and doing housework respectively. The aforementioned items showed no improvement when comparing means score. It is important to mention that the sample sizes for WESTERN CAPE item 21 and 22 were 11 and six respectively. Items that did demonstrate clinically meaningful change, with at least a mean change of 1 on the scoring system, were the tasks of transferring oneself (n=53; mean change -1.30), walking (n=41; mean change-1.00), moving around as in crawling, running, jumping (n=6; mean change-1.33), washing oneself (n=57; mean change-1.14), toileting (n=61; mean change-1.00), dressing and undressing (n=56; mean change-1.26), recreation/leisure activities (n=28; mean change-1.10) and religious and spiritual activities (n=40; mean change-1.00). All the aforementioned items demonstrated at least sample sizes of more than 60% of the total sample for stroke, except for the item referring to moving around and recreation/leisure. The only other item with a mean change of two units was related to involvement in clubs and organisation, but the sample size was relatively small (n=4).

With regards to activities and or social roles, the items related to hand and arm use (n=26), walking (n=41), moving around (n=6), involvement in clubs and organisations (n=4), and participation in leisure and recreational activities (n=28) are still performed with mild to moderate difficulty by those with stroke engaging in the respective activities (This could be found at the cut-off point inserted at mean score 1). Overall, the mean score difference of the participation questionnaire for the stroke sample was 13.09 with a p<0.0001, as determined by the student t-test.

4.6.4.1 Participation restrictions experienced by patients with spinal cord injury

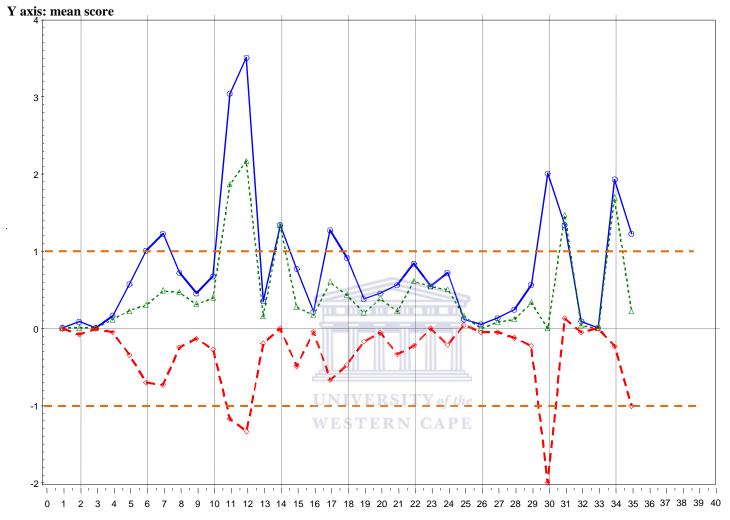
Figure 4.9 illustrates the level of restrictions experienced by patients with spinal cord injury on admission and at discharge as well as the improvement in the degree of difficulty between the

points of data collection



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Table 4.9 Mean procedure of items on participation scale for SCI



Blue=Pre, Green=Post, Red=Post-Pre Difference

Items as described on participation survey

* Key: 1- understanding others; 2- producing messages; 3- communicating directly with others; 4communicating using devices; 5- staying in one body position; 6- changing a body position; 7- transferring oneself; 8- lifting/carrying/moving/handling objects; 9- fine hand use; 10- hand & arm use; 11- Walking; 12moving around; 13- using transport as a passenger; 14- driving a vehicle; 15- washing oneself; 16- care of body parts, teeth etc; 17- toileting; 18- dressing and undressing; 19- eating and drinking; 20- shopping; 21- preparing meals; 22- doing housework; 23- taking care of personal objects; 24- taking care of others; 25- making friends and maintaining friendships; 26- interacting with persons in authority; 27- interacting with strangers; 28creating and maintaining family relationships; 29- making and maintaining intimate relationships; 30- going to school and studying; 31- getting and keeping a job; 32- handling income and payments; 33- involvement in clubs/organisations; 34- recreation/leisure; 35- religious/spiritual activities; 36- political life and citizenship

The above figure shows that the mean scores at discharge are greater than the mean scores of items on admission except for item 14 (n=3), 23 (n=13), 25 (n=63) and 31 (n=15), which refers to activities related to driving a vehicle, taking care of personal objects, making friends and maintaining friendships and getting and keeping a job respectively. It is evident that the sample sizes for each of the aforementioned items were small, except for the task related to making friends and maintaining friendship. The items that showed most clinically related change (mean change of at least one unit) were related to tasks of walking (n=29; mean change-1.17), moving around as in crawling and jumping (n=12; mean change-1.33), the ability of going to school and studying (n=2; mean change-2.00) and the engagement in religious and spiritual activities (n=32; mean change-1.00).

Concerning activities-and or social roles as depicted on the survey, the items related to walking (n=29), moving around (n=12), driving a vehicle (n=3), getting and keeping a job (n=15), and participation in leisure and recreational activities (n=26) were still performed with mild to moderate difficulty by those with spinal cord injury engaging in the respective activities at discharge. With the variable sample sizes that were kept constant for each item

between the two intervals of data collection, the total mean score difference for the spinal cord injury diagnostic group was 7.23 with a p<0.0007.

4.7 FACTORS INFLUENCING FUNCTIONAL ACTIVTY SCORES ON DISCHARGE

This section of the results addressed objective five. The Barthel Index score was used as the main outcome for the stroke diagnostic group, whereas the Spinal Cord Independence Measure III score was used as the main outcome dependent variable for the spinal cord injured population.

4.7.1 Independent variables for stroke outcomes

Table 4.16 presents the independent variables which were either binary or continuous that was considered.

Table 4.16 Bivariate testing of variables that could influence activity as measured by the Barthel Index at discharge (n=66)

Variable	Nature of variable	Measurement	Test	Spearman's correlation value	Significance
Gender	Categorical	Male; Female	Wilcoxon Rank	N/A	p=0.21
Age	Continuous	Years	Spearman's rho	r=(-)0.17	p=0.16
LOHS	Continuous	Days	Spearman's rho	r=0.43	p=0.07
BI (Admission)	Continuous	0-100	Spearman's rho	r=0.49	p=0.0001
Cognitive function	Categorical	Yes; No	Wilcoxon Rank	N/A	p=0.21
Abnormal tone	Categorical	1-4 categories	Kruskal-Wallis	N/A	p=0.75
Education	Categorical	Low; High	Wilcoxon Rank	N/A	p=0.57

* Key: LOHS-length of hospital stay; BI-Barthel Index on admission; N/A- Not applicable

The results from the linear regression suggest that only functional ability on admission, as measured by the Barthel Index, was found to have a statistical significant association with the outcome score at discharge. Other factors that were tested but were found not to be significantly associated with the Barthel Index score on admission included gender, age, length of hospital stay, cognitive impairment, abnormal tone and lower level of education.

Since the outcome score on admission is a numeric variable, the Spearman's correlation coefficient was calculated to identify the relationship between the outcome score on admission and discharge. Even though the correlation is significantly different from 0 (Spearman's r=0.49; p<0.0001), it was not large numerically.



4.7.2 Factors predictive of outcome for patients with spinal cord injuries

The Spinal Cord Independence measure III was used to measure functional abilities in the cohort of patients with spinal cord injuries. This measure was considered as a continuous dependent variable with the score ranging between 0-100. The list of independent variables (which was both continuous and categorical) that was considered for the bivariate analysis is summarised below.

Table 4.17 Bivariate testing of variables that could influence activity as measured by

	the Spinal Cord Inde	pendence Measure I	II at discharge (n=64)
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Variable	Nature of variable	Measurement	Test	Spearman's correlation value	Significance
Gender	Categorical	Male; Female	Wilcoxon Rank	N/A	p=0.97
Age	Continuous	Years	Spearman's rho	r=(-)0.30	p=0.0176
LOHS	Continuous	Days	Spearman's rho	r=(-)0.28	p=0.0346
SCIMIII	Continuous	0-100	Spearman's rho	r=0.66	p=0.0001
(Admission) B & B impairment	Categorical	Yes; No	Wilcoxon Rank	N/A	p=0.0005
Learn to swim	Categorical	Yes; No	Wilcoxon Rank	N/A	p=0.013
Muscle weakness	Categorical	Yes; No	Wilcoxon Rank	N/A	p=0.62
Education	Categorical	Low; High	Wilcoxon Rank	N/A	p=0.10

* Key: LOHS-length of hospital stay; SCIM III-Spinal Cord Independence Measure version III on admission; B&B impairment-Bladder and Bowel Impairment; N/A- Not applicable

The results indicate that higher activity scores on admission, younger age, shorter length of hospital stay were found to be the continuous variables that predict better functional abilities, as measured by the SCIM III, at discharge. The inverse relationship between age and length of hospital stay on the functional outcome score at discharge is evident in the Spearman's correlations of -0.30 and -0.28 respectively. It is important to note that the negative sign on the correlation means that as age and length of hospital stay increase, the outcome score tends to decrease. The only categorical variables that was found to be a predictor of functional ability was the absence of bladder -and bowel impairment on admission and participation in the learn-to swim programme offered at the centre, as this was confirmed by a p<0.0005 and p=0.013 respectively. The relationship was strong between the activity levels on admission as

measured by the SCIM III compared to the activity level at discharge. This relationship was confirmed by Spearman's r=0.66 and a p<0.0001.

4.7.3 Multiple predictor model considered for spinal cord injury

Since there were two variables that showed a relatively strong relationship to outcome level scores (as measured by the SCIM III) and three other variables showing a weaker relationship, but yet significant, these variables were considered together in a multiple regression model.

Table 4.18 Summary of remaining variables in the Multiple predictor model

Variable	Parameter Estimate	Standard Error	F Value	Pr > F
Intercept	51.15839	8.17371	39.17	<.0001
Outcome score admission Impaired bladder and bowel	0.57208 -13.99178	0.09795 6.04505	34.11	<.0001 0.0247

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During the backward elimination process age and length of hospital stay were insignificant predictors when considered with outcome score on admission and bladder-and bowel impairment. The estimated regression equation for the above mentioned predictive variables is Y=51.16+0.57X - 13.99BB. This model suggests that the estimated effect of patients with spinal cord injury presenting with bladder and bowel impairment on the discharge score is a decrease of about 14 points (on the SCIM III) compared to the subjects with intact bladder -and bowel function. Moreover, with a 95% confidence interval the coefficient lies within a wide range (-1.86, -26.13). Hence the effect of bladder -and bowel impairment could be as small as a loss of about 2 points or as great as a loss of about 26 points.

With regards to the parameter estimate of the outcome score on admission, the analysis indicates that for every one point (as achieved on the SCIM III) on admission, the predicted

value of the outcome score at discharge (as measured by the SCIM III) will have an additional 0.57 points.

4.8 Summary of the results chapter

There was a 9% drop out rate in the present study. Significantly more males presented with spinal cord injuries compared to females, with almost the same number of males affected with stroke than females. The mean ages for the cohort of patients with spinal cord injuries and stroke were 34.14 and 52.95 years of age respectively. The majority (50%) of the participants with stroke on admission were classified as functionally dependent on the BI severity scores, with muscle weakness found to be the most prevalent impairments. The most common impairments amongst the spinal cord injury diagnostic group were muscle weakness and reduced sensory awareness. Most patients were managed by the doctor and nurse, physiotherapist, occupational therapist and social worker. Patients with both stroke and spinal cord injury utilised to a lesser extent from the recreational activities offered at the centre, but more patients with spinal cord injury were exposed to these services. A significant improvement was noted in functional ability of patients with spinal cord injury and stroke, as measured by the Spinal Cord Independence Measure III and Barthel Index between intake and discharge. Significant improvement was also found for participatory tasks and actions for both diagnostic groups, as measured by the Zambian survey on living conditions. The activity score on admission, as defined by the BI, was found to be the only predictor of functional outcome scores of patients with stroke at discharge. Concerning patients with spinal cord injury, activity score on admission, shorter length of hospital stay, younger age and bladderand bowel continence were found to be predictors for favourable functional outcomes as defined by the SCIM III. The multiple predictor model showed that activity score on admission and length of hospital stayed important predictors even when considered together using one model.

CHAPTER FIVE

DISCUSSION

5.0 INTRODUCTION

This chapter discusses the results of the study as it addresses the research questions and the objectives. The aim of the study was to determine the process of rehabilitation and the outcomes of patients admitted to a specialised in-patient rehabilitation facility in the Western Cape. The concepts related to the process of rehabilitation that were addressed include the rehabilitation services received by the participants, as well as the length of hospital stay and the referral process. Furthermore, the outcomes of participants with stroke and spinal cord injury were also discussed. The outcomes were conceptualized using the International Classification of Functioning, Disability and Health, which views disability as an umbrella term for impairments, activity limitations and participation restrictions. Therefore, the outcomes of the participant at these levels, as well as the predictive factors of functional outcome (on the level of activity) are discussed. Each section of the chapter is sub-divided into the discussion of the results of patients with stroke and spinal cord injury. Throughout the chapter relevant literature from both international and local perspectives are highlighted to compare similarities and differences based on the data presented.

5.1 Demographic profile of the participants

5.1.1 Stroke

The mean age of those with stroke was found to be 52.95 years for the current study. The findings of the present study are in agreement with a similar study conducted at the same

institution five years ago, which found the mean age of patients with first ever strokes to be 51.3 years (Rouillard, 2007). Furthermore, the younger age of stroke onset is reiterated by other African studies conducted by Urimubenshi and Rhoda (2010), and Zenebe, Alemayehu, and Asmera (2005), which found the mean age in district hospitals in Rwanda and in Ethiopia to be 56.3 and 53.2 years respectively. Contrary to the findings of studies conducted in developing countries, participants in the sample were younger than those found in developed countries (Graham, Kruger, Teasell, Foley, & Salter, 2008). In a study done by Graham et al. (2008) the mean age of participants with stroke in developed countries was 75 years. It is noteworthy to mention that prevalence studies conducted in the developing world suggest that patients with stroke have a mean age of approximately 15 years younger than those affected by stroke in the developed world (Bonita *et al.*, 2004; Walker *et al.*, 2000). This difference in age of the onset of stroke in developing countries was found to be related to the escalating prevalence of risk factors such as hypertension, tobacco use, unhealthy diet, physical inactivity and obesity (WHO, 2004).

In the current study more than 90% of the patients were younger than 65 years of age. The aforementioned figure is of importance to the country as citizens are still employable up to the age of 65 (Statistics South Africa, 2006). Of stroke survivors it is noted that the younger patients have a longer time to live with physical impairment that may incapacitate productive activity and present with more psychosocial complications, compared to the older stroke survivors (Jacobs, Boden-Albala, Lin, & Sacco, 2002). Having said that, the younger age of disease onset has become an enormous economic burden to the country, as more people are unemployed at the age where they are still employable, thus the financial support should be provided for more patients. Apart from financial support that should be granted, article 27 of the United Nations on the Convention on the Rights of Persons (UNCRPD) with Disabilities (2006), which was ratified by the South African Government, advocates for the equalisation

of work and employment opportunities through mobilising relevant resources. The mandate of UNCRPD prompts the need to evaluate the percentage of patients who return to work and identify the factors that influence return to work.

In the current study the distribution by gender showed that slightly more males (52.23%) with stroke were admitted to the WCRC than females (47.77%). These findings are in contrast to the local studies done by Rouillard (2007) and Rhoda (2003) which found that females were more affected by stroke than males. However, some international studies record a slightly higher incidence of stroke in males than in females (Kuptniratsaikul, Kovindha, Dajpratham & Piravej, 2009; Zenebe *et al.*, 2005; Walker *et al.*, 2000). An Ethiopian based study reported that out of 128 admitted patients with stroke, 60% were men and the remaining 40% were women (Zenebe *et al.*, 2005). Literature highlights that males with stroke are in general more motivated and achieved higher levels of functioning due to their active participation in the rehabilitation programme, whereas women seem to be more affected by a stroke, achieved lower scores in tests for motor, cognitive and ADL functions, both in the acute phase and one year after the stroke (Wyller, Sødring, Sveen, Ljungren & Bautz-Holten, 1997). Admitting more males to the WCRC could thus have been consciously or unconsciously embedded within the admission criteria, or simply the demographic transition of stroke causation could have accounted for this marginal gender disparity.

5.1.2 Spinal cord injury

The mean age of patients sustaining their injury in this study is reported to be 34.14 years of age. Results on the mean age of patients affected with SCI of a worldwide literature survey corroborate with the current study (Wyndaele & Wyndaele, 2006), whereas a recent community-based study conducted in South Africa found those affected by SCI to be slightly

younger than reported, with a mean age of 29.19 years (Mothabeng, 2011). This difference in spinal cord injury onset between the current study and the research carried out by Mothabeng (2011) could simply be due to demography and exposure to risk factors (trauma and violence) between the two settings. Another study found that the age range of patients sustaining a SCI was between 25 and 34 years (McColl, Walker, Stirling, Wilkins & Corey, 1997). Although the general perception is that SCI affects the younger age group, a study conducted by Burt (2004) indicated that spinal cord injury occurred in a bimodal distribution, thus affecting both the young adult between the ages of 18-24 and the elderly (mostly above 65 years of age) particularly due to falls on level surfaces (van den Berg, Castellote, Mahillo-Fernandez & de Pedro-Cuesta, 2010).

In the current study only 7.9% of the patients with spinal cord injury were recorded as an age above 50 years, however the younger onset of injury could be justified by the high prevalence of gunshot violence, motor vehicle accidents and stab wounds resulting in spinal cord injury in South Africa (Hart & Williams, 1994). The traumatic nature of spinal cord injury causation can explain the difference in age onset compared to stroke, which is usually associated with engagement in health risk behaviours such as smoking, alcohol abuse, physical inactivity and an unhealthy diet, and co-morbidities (Salter, Teasell, Bhogal, & Speechley, 2007).

Conclusive evidence exists on the gender prevalence of SCI, which suggests that more men than women are affected. The gender distribution (men: women) of SCI in the current study is 2.8:1. Recent national and international studies found the gender distribution to be 3.4:1, where it used to be 4.8:1 (Mothabeng, 2011; Wyndaele & Wyndaele, 2006). Compared to the reviewed literature males with spinal cord injury are slightly under-represented in the current study, but undoubtedly still more men are at risk for SCI. Based on the current study and evidence from literature we can conclude that most patients with SCI are young employable men, in the beginning of their thirties. This has profound socio-economic consequences as most men will be working to support their families. Acquiring a SCI does not only prompt the need for health care but also for social security system, including financial support. Since men are at the mean productive age, it influences the economic and social structure of the society they live in (Wyndaele & Wyndaele, 2006).

With regard to marital status, the majority of patients with spinal cord injury were single (73.68%), whereas a lower number is found elsewhere in South Africa (Mothabeng, 2011). Only 18.42% of those with spinal cord injury were married, which is lower than what is recorded in South Africa and in the US (Mothabeng, 2011; NSCISC, 2009). Despite the high frequency of unmarried status among patients with spinal cord injury, the majority (53.73%) of those with stroke were married, which corroborates with the findings from another study conducted at the WCRC (Hassan, 2009). The difference in marital status between the two diagnostic groups could be the onset of a spinal cord injury at an earlier age where survivors may not be married yet, compare to the onset of those with stroke.

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5.2 Socio-economic profile of participants with stroke and spinal cord injury

Of those who received a fixed income, the majority of the participants in this study (both stroke and spinal cord injury) only had a secondary level of education and a household income >/or = to R1001 to R2000 per month. The study conducted at the WCRC in 2007 found that the majority of the mean household income was <R1000 (Rouillard, 2007). A possible explanation for the change in household income bracket between the current and the reviewed study is that the disability grant incrementally increased from <R1000 to the current R1080. This is further justified by the result showing that 28.67% of the patients are currently receiving a disability grant, which inevitably categorised them into the household income bracket >R1001-R2000.

In the current study only 21.67% of patients with stroke and spinal cord injury were employed before the onset of the health condition. Of those employed, the majority was in skilled or semi-skilled positions, which required physical labour. The study at the WCRC five years ago found that more than 50% of the sample was employed prior to the stroke event (Rouillard, 2007), whereas another study among patients with stroke in an out-patient facility in South Africa found that 31% of the sample with stroke was employed prior to the stroke (Rhoda, 2010). What is, however, important to note between the study carried out by Rouillard (2007) and the current study is that even though the current study included patients with spinal cord injury, given that the age of onset was younger compared to patients with stroke, less patients were employed prior to the onset of the health condition. Thus, the high unemployment rate in the light of the younger age group of patients with spinal cord injury could be attributed to the lack of job opportunities nationally (Statistics South Africa, 2011) and variables such the demography, socio-economic status and personal factors.

Moreover, given the rather low levels of employment in the previous studies compared to the statistics of the Department of Labour (Statistics South Africa, 2011), it is unambiguous to postulate that the participants could have been experiencing social challenges even prior to their stroke or spinal cord injury. Now that these patients are facing physical limitations, the social challenges could have more profound implications for return to work for those left with residual disabilities. Thus, an important area of interest is the evaluation of productive living and the implications that a further reduction in employment status has on family life, the increased burden on the economic system and the participatory restrictions experienced by the patients post stroke or spinal cord injury.

The area of research that has gained momentum the last few decades is the study of factors predictive of outcome. The current study found no correlation between demographic and socio-economic factors among patients with stroke, but has found a significant relationship between age and functional outcome at discharge of the spinal cord injury diagnostic group. Numerous studies have investigated the correlation of demographic and socio-economic factors on outcomes, but inconclusive evidence is still prevailing as the context and demographic bias are such strong confounders to the predictive model (Kaplan, 2007). However, some studies have found that higher educational levels were associated with improved motor and functional recovery during in-patient rehabilitation (Putman *et al.*, 2007). It has also been found that women have a lower quality of life and lower physical functioning scores post stroke (Reeves *et al.*, 2008). The importance of identifying predictive factors on outcome is embedded in the rehabilitation strategy on establishing effective and efficient rehabilitation practices in order to guide treatment and change practices accordingly (Kaplan, 2007). More in-depth discussion on predictive factors on outcome will follow later

in the chapter.



5.3 Process of rehabilitation followed by participants with stroke and spinal cord injury

This section discusses the process of rehabilitation with reference to the referral agency, the length of hospital stay, rehabilitation services received and discharge destination. The UNCRPD (2006), which is one of the guiding documents of the rehabilitation strategy in South Africa, promotes the optimisation of function of patients in all spheres of human endeavour by reducing the impact of disability. The first chapter of this thesis introduced the Structure, Process and Outcome model that suggests that all outcomes are relative to the interaction of the structural organisation of the facility and the process of rehabilitation (Kaplan, 2007). What is still obscured are the individual constituents, of both structure and process, which culminate into the desirable practices and outcomes (Hoenig *et al.*, 1999).

5.3.1 Referral agency

In the current study participants with stroke were referred from different levels of state health care, with the largest number being referred from secondary level hospitals. The previous study conducted at the WCRC found similar results with regards to the largest percentage of patients that are referred from secondary level hospitals (Rouillard, 2007). This could be explained as part of the admission criteria of the WCRC, which explicitly states that patients should be at a functioning of physiological stability, meaning that all major bodily functions are normalised and maintained without artificial aids (Personal communication, J. A. Hendry, October 10, 2010). Thus, patients might reach the state of physiological function sooner in secondary hospitals, due to the less severe nature of the injury, than in tertiary hospitals that usually admit the serious cases.

The advances in medical care over the last three decades resulted in the survival of persons with spinal cord injury (Lifshuts & Colohan, 2004). In contrast to most of the referrals of patients with stroke coming from secondary level health care facilities, almost three-quarters of the referrals of patients with spinal cord injury are from tertiary level hospitals. This difference in referral agency stems from the need of patients with spinal cord injury of traumatic aetiology. Massive central nervous system trauma deaths result from failed oxygenation of the vital organs, massive central nervous system injury, or both, and could lead to inadequate ventilation and/or disruption of brainstem regulatory centres (Dries, 2011). This life-threatening event often requires patients to be admitted to an Intensive Care Unit, which usually have the necessary services available to mechanically ventilate and closely monitor patients. In the South African health care context all state-funded Intensive Care Units to be found in secondary level hospitals (Department of Health, 2006). Therefore the high number of referrals from tertiary hospitals further justifies the serious traumatic nature

of the spinal cord injury and the seriousness of National Government to enhance the lifeexpectancy of South African citizens, especially those of vulnerable groups (Matsoaledi, 2011).

5.3.2 Length of hospital stay

The length of hospital stay is an important indicator of the efficacy of rehabilitation and the economic impact of hospitalisation on state resources (Post *et al.*, 2005). The mean LOHS of the participants with stroke was 51.62 days. The results from another study conducted at the WCRC showed fairly consistent agreement with regards to the mean length of hospital stay which was reported to be 59.1 days compared to the current study (Rouillard, 2007). However, literature recorded length of hospital stay to be either longer or shorter than what was found in the current study. To illustrate this inconsistency in length of hospital stay, one study found the LOHS to be 97.1 days (Yavuzer *et al.*, 2001), whereas studies conducted in the US and in Thailand found a mean length of stay of 18.7 days (Jette *et al.*, 2005) and 27 days respectively (Kuptniratsaikul *et al.*, 2009). The downward trend in length of hospital stay globally could have been accompanied with an increase in readmissions to rehabilitation facilities and discharge to other health care facilities instead of discharge to community (Eastwood, Hagglund, Ragnarsson, Gordon, & Marino, 1999).

The arbitrary nature of institutional policies or other contextual factors could account for the variance in length of hospital stay globally. For example, the WCRC only allows patients to be discharged once they reach their expected or projected outcome level as identified on admission or at the first interdisciplinary meeting, or whenever serious complications arise and the need of referral to other health care services is prompted (Personal communication, J. A Hendry, October 10, 2010). It was found that almost half of the patients were discharged

upon reaching outcome level four, which based on tacit agreement refers to the full integration of patients into community life (Landrum, Schmidt and Mclean, 1995). This goal setting approach could result in the difference in length of hospital stay between patients, but reflects the patient-oriented approach in action. Despite these postulations, literature suggests that the LOHS has become too short, thus questioning the level at which outcomes are met. It is also evident in cases where the length of hospital stay is very short that early discharging patterns could be due to supported rehabilitation in the patient's home environment (Jette *et al.*, 2005; Mayo *et al.*, 2000).

The current study found the mean length of hospital stay (LOHS) for the patients with spinal cord injury to be 73.11 days (STD 43.74), which was longer than that of the cohort with stroke. Most available literature recorded length of hospital stays greater than what was found in the current study. To illustrate the lack of uniformity of the length of hospital stay of patients with spinal cord injury at the WCRC, one study conducted in the Netherlands reported the LOHS to be 240 days (Post *et al.*, 2005), whereas a study conducted in Japan found the mean length of stay to be up to 267 days (Sumida *et al.*, 2001), and finally in Israel with a mean of 239 days for traumatic and 106 days for non-traumatic injuries (Ronen *et al.*, 2004). Contrary to the perceived extended LOHS as highlighted by the latter studies, literature demonstrating a shorter duration of hospital stay is also available. There is level 3 evidence that suggests rehabilitation LOS has become progressively shorter during the period of 1973 to 2006, predominantly in the US (Wolfe, Hsieh & Mehta, 2010). These downward trends are noted for LOS in rehabilitation units, which are evident by the figures that suggest a drop from 98 days to 38 days (NSCISC, 2005).

The LOHS of those with spinal cord injury in the current study seems to be realistic and goaloriented. Having said that, the outcome levels achieved at discharge indicate that 69.74% of patients with spinal cord injury were discharged with a level of functioning corresponding with community integration and productive activity, which is the ultimate goal of rehabilitation. However, the question is whether an extended LOHS would result in more patients achieving community integration (level 4) and productive activity (level 5).

Since no international standard is available on the LOHS of patients with spinal cord injuries, it is recommended that it should be guided by the achievement of activity tasks and participatory roles (Janssen-Potten, 2001). With most of the patients with spinal cord injury discharged home (82.08%) following rehabilitation at the WCRC, it is recommended that the rehabilitation programme of each patient should be tailored towards the activities and participatory actions and roles relevant and meaningful to the patients. Of those with spinal cord injury, only 86.88% were discharged home with a level of functioning corresponding to home (level 3)-and community integration (level 4) and productive activity (level 5). The current study also found that patients incapable or dependent on others for certain essential activities at discharge, which is evident in high percentages of tasks related to mobility (85.94%), stair management (71.88%), and specific transfers (wheelchair to car) (34.38%), and floor to wheelchair (43.75%), could result in long-term disability, a reduced quality of life and possible rehospitalisation. In the light of patients still experiencing functional limitations and restrictions, the Comprehensive Service Plan 2010, which is a guiding document for health care and rehabilitation in South Africa, suggests the provision of care along the continuum of the disease progress, perhaps rehabilitation should be provided on an out-patient basis, post in-patient rehabilitation.

5.3.3 Rehabilitation services received

Since the outcome-based approach is embedded within the strategy of the WCRC, the interdisciplinary team plays a pivotal role in conjunction with the patient, at achieving the desirable outcomes. The WCRC offers a wide range of services but not many of the patients reported receiving these services. With regards to the non-therapeutic services the majority of the participants were managed by the medical officer and nurse.

In the current study almost all patients with spinal cord injury and stroke received physiotherapy followed by occupational therapy. Literature found that both professionals and patients perceived physiotherapist to be the key to rehabilitation, whereas occupational therapists focus on hand- function, but together both physiotherapists and occupational therapists complement each other. Doctors were found to coordinate the team, yet reduce their input as patients move out of the acute phase into rehabilitation (Pellatt, 2007).

Previous studies have also reported that physiotherapy was more often provided to stroke patients than any other type of therapy (Jiménez Muro, de Pedro-Cuesta, Almazán, & Widén Holmqvist, 2000). In the current study all patients with spinal cord injury and apart from one patient with stroke received physiotherapy. Concerning occupational therapy, 96.87% and 95.45% of patients with spinal cord injury and stroke respectively, reported receiving this therapeutic service. The referral of patients to the appropriate professional or service could either be linked to patient's residual functioning within the context of the bio-psycho-social approach that guides treatment at the WCRC.

The reason why stroke patients often receive more physiotherapy than occupational therapy highlight the fact that rehabilitation in the acute and sub-acute stage is often still impairment based (Dobkin, 2004). In the current study the impairments among patients with stroke on admission were diverse in nature with the most common manifestations of muscle weakness,

abnormal tone and aphasia. Initially a greater emphasis is placed on motor- and functional recovery than on addressing the participation restrictions (Dobkin, 2004). The activities such as active exercises and re-education of gait are more often facilitated by physiotherapists. Subsequent to the functional gains, the focus shifts to the social and leisure activities which are addressed by occupational therapists (Blacker, Broadhurst & Teixeira, 2008; WHO, 2001).

Speech therapy is only provided to patients who have speech impairments. The results of the current study found that 50.75% of the sample presenting with stroke received speech therapy, even though literature highlights that approximately 20-30% of patients with stroke suffer from speech impairment (Dobkin, 2005; Rathore *et al.*, 2002). Firstly, the high frequency of speech therapy attendance could be link to the laterality of the stroke event, which suggests that patients with left hemisphere lesions (50.75% of the patient with stroke in the current study) are more likely to have speech impairment, and would therefore need the services of a speech therapist (Nys *et al.*, 2007). Lastly, the high numbers of patients receiving speech therapy could be that the speech therapist does not only address problems with the articulation of speech but also issues related to swallowing, feeding and cognitive disorders (Miller *et al.*, 2010; Pollens, 2004). Despite these justifications, more research is needed to clarify the full scope of practice of speech therapists at the WCRC.

Similar to the high frequency of patients receiving physiotherapy or occupational therapy, patients also consulted the social worker. As mentioned previously in various chapters, the consequences of stroke and spinal cord injury are vast and affect individuals in various aspects of social life. Therefore, the social worker plays an important role in helping the consumer with a stroke and SCI and the family make a positive recovery and adjustment to life during and after rehabilitation. They are considered an integral part of the rehabilitation team and focus on the life areas, which are compromised in most instances, such as

relationships, financial concerns, recreational and leisure needs, discharge plans and options, emotional reactions and many other areas of human functioning (Golden, Willits & White, 2000).

Apart from the professional services, the WCRC offers other recreational activities to the patients with stroke, but not all patients utilise these services. The effect of recreational activities as part of the rehabilitation process has not been investigated extensively, but available literature claims that the impact of the recreational and leisure activities enhances physical health, mental health, life satisfaction and psychological growth of persons with disabilities (Specht, King, Brown & Foris, 2002; Cassidy 1996). These activities are rather considered higher functional tasks, thus the utility of these services are based on sufficient functional improvement.

Almost 40% of the patients with stroke and 50% of those with spinal cord injury attended the "learn to swim sessions / aquatic exercises", under the direct supervision of the physiotherapist, and occasionally by the occupational therapist. Literature highlights that by combining land-based rehabilitation with aquatic physical therapy, better outcomes may be achieved in recovery of function in adults with acquired neurological impairments (Degano & Geigle, 2009). The current study findings provided evidence on the effect of a learn-to- swim programme /aquatic therapy on the functional outcomes of those patients with spinal cord injury. The bivariate analysis demonstrated that those who attended the learn-to-swim programme had a significantly higher functional outcome (p>0.013) at discharge than those who did not attend, whereas an insignificant difference between the mean functional outcome scores of the two independent samples (those who did attend versus those who did not attend) were found on admission.

Apart from the "learn to swim programme", almost one-third of the patients with spinal cord injury participated in the "wheelchair basketball" programme, of which studies have shown that a distinct relationship between leisure patterns and secondary medical complications. A study conducted more than twenty years ago found that the more sedentary a person is, more medical complications arise, and the less satisfied the person becomes with his or her leisure time. But as leisure satisfaction levels increase, medical complications decrease (Specht, *et al.*, 2002; Cassidy, 1996). More specifically, Stotts (1986) reported that individuals with paraplegia, (which constituted the majority of the patients with SCI) who are involved in wheelchair sports, are more successful in avoiding major medical complications. Secondary medical complications have a profound impact on state resources, which are often related to re-admission of patients with preventable secondary condition, which eventually culminate into an increase length of hospital stays and increase health care cost (Richards, Waites, Chen, Kogos & Schmitt, 2004; Johnson, Gerhart, McCray, Menconi, Whiteneck, 1998).

Structured recreational activities have been found to assist the integration of persons with disabilities in various life areas (Specht *et al.*, 2002). Community integration is pivotal to the rehabilitation outcomes of the WCRC. Even though the current study did not investigate the effect of recreational activities on the outcomes in the domain of participation, it should be noted that the introduction of the recreational and leisure activities as part of the rehabilitation process is considered as a positive step to facilitate integration of patients with physical disabilities within the major dimensions of participation (Conway, 2010). Further studies need to be conducted to determine the effect and impact of these programmes and could thus motivate for the appointment of recreational specialists at the WCRC.

5.3.4 Discharge destination

The goal of all rehabilitation services is to integrate persons with any health condition back into their home and community life and to resume previously enjoyed activities. The majority of the patients with stroke (82.08%) in the current study were discharged home with only 13.43% referred home with formal referral to other health care facilities including WCRC out-patient Department. Literature highlights lower frequencies of patients that were discharged home following in-patient rehabilitation (Rouillard, 2007; Somerford, Lee & Yah, 2004; Patel, Potter, Perez & Kalra, 1998). A study conducted at the WCRC found that 52.9% of patients with stroke were discharged home without follow-up, whereas the remaining patients (47.1%) were referred to the WCRC out-patient Department or other health care facilities.

Literature suggests that discharge destination of patients with stroke varies depending on functional and social factors (Bloemen-Vrencken, 2006), thus the ability to safely ambulate and the presence of intact bladder-and bowel function were found favourable determinants of being discharged home (Feigenson *et al*, 1977). There is some evidence from the current study to support the aforementioned relationship. More than 80% of the sample demonstrated intact bowel function and 93.93% of the patients had intact bladder function. However, the only negating factor to the literature that suggests that bladder and bowel function and safe ambulation are good predictors to be discharge. However, it is important to note that the aforementioned figure only depicts the number of patients who does not need any assistance, but neglects to take into account the patients that can ambulate safely and independently with the use of an assistive device. Therefore, the figure of safe mobilisation with or without the use of an assistive device could be larger.

The rehabilitation personnel at the WCRC utilises the outcome levels as an indicator of functioning in the domains of activity and participation. Almost three-quarters (72.36%) of the patients with spinal cord injury were discharged upon reaching an outcome level four or five. In short, those outcome levels refer to home and community integration and productive living respectively. The validity of those patients who have reached the desirable outcome levels (four and five) is evident in the discharge destination of which the majority (80.26%) of the patients were discharged home. However, it was noted that some patients did not comply with the criteria of those levels. A study conducted in the Netherlands found that similar results with regards to the discharge destination, of which 87.7% of patients with SCI are sent home or to a non-institutional residence following rehabilitation (Bloemen-Vrencken, 2006), whereas a study conducted in the US found that all age groups were equally likely to be discharged to a private residence (McKinley, Seel, Gardi &Tewksbury, 2001).

Previous research has revealed several shortcomings in the routine care of persons with SCI. One of the major conclusions was that follow-up care is not adequate (De Witte, 1991). Patients in the current study were discharged with residual disability (specifically related to mobility tasks, stair management and transfers), therefore one could agree that the coordination and tailoring of care post discharge from the rehabilitation unit is far from perfect, since more than 80% of patients with spinal cord injury were discharged home. This gap in the referral process should be corrected as it could perpetuate re-hospitalisation, which not only results in higher health care costs, but may also impede social reintegration.

In the light of no formal referral post discharge from rehabilitation, one particular study conducted in the Netherlands found that persons with SCI would like to receive extra support after discharge in the form of telephonic consulting hours, peer meetings and/or home visits (Bloemen-Vrencken, 2006). Some of the aforementioned support services are already embedded within the rehabilitation programme at the WCRC during hospitalisation. With the

emphasis on peer support, only 18% of the patient reported receiving this service during inpatient rehabilitation. In the light of the functional disability at discharge, perhaps these services could be extended to the post-discharge phase or appropriate follow-up services should be put in place to address the limitations in activities and participatory roles once the patient gain first-hand experience of those limitations in home and community life.

5.4 Rehabilitation Outcomes

This section discusses the outcomes of patients with stroke and spinal cord injury within the conceptual framework of the ICF. However, the first section describes the impairment status on admission.



5.4.1.1 Stroke

In the current study the most prevalent impairment was found to be weakness / paralysis on one side of the body, which affected 80.6% of the sample, irrespective of the 10% of cases which were undocumented. This finding is in agreement with a study done by Lawrence et al. (2001) among patients with acute strokes, which found the prevalence of upper-and lower limb weakness to be 77.4% and 72.4% respectively. Furthermore, a large body of literature has indicated and supported the higher prevalence of hemiparesis / weakness (Jette et al., 2005; Rathore et al., 2002). Studies conducted in the US by Jette et al. (2005) and in Japan by Isagoda and Nakamura (1995) reported the presence of hemiparesis / weakness in the entire study population.

In the current study 50.75% of patients were found to have aphasia. This was slightly higher than the 41% of patients with aphasia found by Umurubenshi and Rhoda (2010), but consistent with the results of Edwards et al. (2006), which suggest that between 30-60% of patients manifested with this clinical feature. The higher prevalence of aphasia in the current study could be due to the laterality of the lesion in patients with stroke. It was demonstrated that patients with left hemisphere lesions (right hemiplegia) are those who are most likely to have aphasia/speech impairment (Edwards *et al.*, 2006). The effect of aphasia is a noteworthy area of research in rehabilitation, as it has been found to influence and pose challenges to patients in other domains of human encounter. One particular study found that speech impairment contributed to patients experiencing restrictions in participatory roles and actions, and increase the risk of long-term disability (Barker, Reid & Cott, 2006).

Limited evidence is available concerning the number of patients developing spasticity or the relationship between spasticity and disabilities after acute stroke (Sommerfeld, Eek, Svensson, Holmqvist & von Arbin, 2004). The current study gathered data on abnormal tone among patients with stroke, and found that 76.13% fitted this category. The study conducted by Sommerfeld *et al.* (2004) found that spasticity was present in only 19% of the patients investigated three months post- stroke, and that the severity of disabilities were seen in almost the same number of non-spastic as spastic patients, whereas more that 80% of a cohort presented with reduced tone, was found by Barker and Mullooly (1997). This finding indicates that the focus on spasticity in stroke rehabilitation is misaligned with its clinical imperatives. This could also be the impetus behind the adoption of the outcome-based approach at the WCRC, which neglects treatment centred towards addressing impairments only.

In the current study 41.79% of patients presented with reduced sensation. The findings of the current study is in agreement with a hospital-based study conducted by Rathore *et al.* (2002), which found that 44.5% of patients presented with sensory impairment, whereas the first population-based study on acute stroke impairments found a prevalence of reduced sensory

awareness in 19.4% of the sample (Lawrence *et al.*, 2001). The problematic nature of assessing sensation, the lack of reliable outcome measures and the non-assessments could account for further variance in the prevalence of sensation. Literature highlights that normal sensory function is related to high activity levels (Sommerfield et al., 2004), especially related to functions of leisure, sexual activity and safety (Carey *et al.*, 1997).

Only 25.37% of the patients with stroke presented with cognitive impairment on initial assessment. Saxena (2006) recorded a higher prevalence of cognitive impairment which ranged between 40-50%. A strong relationship exists between cognitive impairment and the ability to perform ADL's and the fulfilment of social roles (Johnston, Sidney, Bernstein & Gress, 2003). One possible explanation for the observed heterogeneity of findings across studies could be the differences and challenges with the standardisation of assessing cognitive function (Wade, 1992). The current study also found approximately 20% of undocumented responses for cognitive status of patients with stroke. Thus, in order to optimise functioning of patients at the WCRC, the assessment of cognitive abilities of patients with stroke should be mandatory.

It is however important to note that impairments affect functional ability and participation. A study done by Jorgensen, Nakayama, Raaschou and Olsen (1995) found that independence in walking has been correlated with lower-limb strength. Apart from impairments influencing the acquisition of functional tasks, as illustrated by the ICF model, impairment could further have implications for participation. A study done by Desrosiers *et al.* (2003) found that leg impairments were also found to affect participation. Although a task-oriented approach is advocated (Carr & Sheperd, 1998) the role of impairment in achieving outcomes should also be considered.

5.3.1.2 Spinal cord injury

Consistent with the ASIA classification of neurological function, muscle weakness was defined as a muscle power less than grade three as graded by the Oxford scale (ASIA, 2002). Muscle weakness was found to be the most prevalent impairment following spinal cord injury, of which three-quarters (75%) of patients presenting with varying severities of muscle weakness (ranging between grade 0 and three minus). Other studies conducted in US and Croatia found consistent results with regards to the prevalence of muscle weakness one-year post spinal cord injury and on admission respectively (Moslavac, Dzidic & Kejla, 2008; Kirshblum, Millis McKinley, Tulsky, 2004).

Similar to the high prevalence of muscle weakness, sensory impairment was reported in almost 70% of the sample. Literature reports slightly lower rates of sensory impairment following SCI (Gupta *et al.*, 2009; Moslavac *et al.*, 2008). A study conducted in India among patients with non-traumatic SCI reported that less than one-third of patients experienced impaired sensation. The variance in the prevalence of sensation could be attributed to the severity and nature of the spinal cord injury, the validity and reliability of the test being utilised and the examiner's training on the outcome measure (Cuthbert & Goodheart, 2007). Sensory impairment had been found to impact on function quite profoundly. A study conducted among eight rehabilitation centres with a SCI unit found that musculoskeletal pain, as a somatosensory modality, was inversely related to functional outcome (p<0.001) (Post *et al.*, 2005).

Record-keeping on impairments status of patients with stroke and spinal cord injury was problematic as such a large number of clinically relevant impairments were marked undocumented. The process of record-keeping in the medical professions is paramount because of the substantial evidence of the patient's health status as well as the quality and the quantity of patient care. Besides the implication of neglecting the influence of impairments on the other domains of functioning, the lack of record-keeping about impairments and patient management on the whole, could result in medico-legal proceedings (Scott, 2000)

5.4.2 Activity Limitations of participants

5.3.2.1 Stroke

Activity limitations including self-care and mobility functions were assessed on admission and at discharge with the Barthel Index (BI), with a score range of 0-100. A higher BI score indicates better functioning. The mean intake Barthel Index score for this cohort of patients was 58.85. The participants in the present study had a much higher level of function than stroke patients in Thailand with a mean intake Barthel Index of 37.4 and patients in Belgium with scores of 20 (Kuptniratsaikul *et al.*, 2009; De Wit *et al.*, 2006). The scores were however similar to previous results from patients from the same research setting as the current study, with an intake Barthel scores of 57 (Rouillard, 2007). The present study sample demonstrated a statistically significant improvement in the Barthel Index scores between intake and discharge.

Apart from statistically significant findings, clinical significant change is of more value to the therapist and other relevant stakeholders as it detects meaningful change in the execution of functional tasks. Certain studies recommend that a change of more than 15% (more than 15 points on the BI score) as an indicator for clinical significant change that occurred in at least one, but up to three functional tasks as measured by the BI (Foley, Hillier, & Barnard, 2009). The current study found that the majority of the patients demonstrated clinical significant change between admission and discharge. It should be noted that the findings related to statistical and clinical significant change are similar when compared to studies conducted

among patients with stroke locally (Rhoda, Mpofu & De Weerdt, 2011; Rouillard, 2007) and internationally (Kuptniratsaikul *et al.*, 2009) as this provides evidence (level III) on the role of rehabilitation in the respectively study settings.

The long-term effects of disability are profound in a number of stroke survivors. In the present study 48.49% of the participants were still moderately to severely affected as measured by the severity scale embedded within the Barthel Index at discharge. A study conducted by Rouillard (2007) at the WCRC found that just more than half of the participants were in the category of moderate to severe disability (as measured by the BI) at discharge. In the context of the WCRC guidelines on discharge policies the high disability prevalence at discharge is, however, an alarming finding.

Even though almost half of the patients are still significantly affected by the disability, which could be understood as affected patients needing assistance with at least one activity of daily living, more than 80% of the patients were discharged home without any formal follow-up rehabilitation services or routine medical screening for complications. Therefore, the risk of long-term disability associated with restrictions in certain human experiences and possible preventative complications could become the challenges these patients experience post-stroke. The discharge process of the WCRC could be further challenged on an operational level, which embraces the patient-oriented approach to rehabilitation. Fundamentally this approach could be best understood within the ICF model which shifts the focus from measuring the normative to assessments of unique individual-specific difficulties encountered (both personal and environmental) and what an individual may need to become fully active and integrated members of society (Loeb *et al.*, 2008; WHO, 2001). Therefore these patients

who are experiencing disability in any sphere of functioning should be provided with the needed support to further their rehabilitation and enhance their functioning.

Although stroke survivors achieved high overall scores on the Barthel Index measure, there are certain activities that most of the patients are unable to perform independently. Stairs, mobility, transfer and dressing were the activities in the present study with the lower frequency of independently execution at discharge. The same results were found in an outpatient community health centre conducted by Rhoda *et al.* (2011) and in the WCRC inpatient population (Rouillard, 2007). Thus, the inability of patients with stroke to perform activities of daily living such as dressing and transfer independently highlights the dependency stroke patients, even those with mild impairment, have on others (Dowswell *et*

al., 2000).



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5.3.2.2 Spinal cord injury

The Spinal Cord Independence Measure III consists of three categories, namely, (1) self-care, (2) respiration and sphincter management, and (3) mobility. Similar to the Barthel Index score that was used for the stroke cohort, the maximal total score amounts to 100 and the higher scores indicate higher levels of functioning. The mean intake SCIM III score for this cohort of patients was 48.03. The participants in the present study had a much higher level of functioning than patients with SCI in Europe, with a mean intake SCIM II score of 32.00 (Wirth *et al.*, 2008). The latter study demonstrated change in functional status at three and six months with median SCIM II scores of 60 and 71 respectively. It is important to note that the mean LOHS of patients with spinal cord injury in the current study was 73.11, which converts to more or less two and a half months of hospitalisation, but the median SCIM III score was 67.07, which was higher than the score obtained after three months in the study

conducted by Wirth *et al.* (2008). Thus, the current study shows that the SCIM III is a sensitive tool for monitoring functional improvement during the early phase after injury (Wirth *et al.*, 2008). It was also found that although the SCIM is considered the gold standard of measuring functional outcome in patients with SCI, very few published studies utilised this measure.

Maximal outcome levels have not yet been achieved at the time of discharge from rehabilitation for this cohort of patients. Taking cognisance of the discussion on the length of hospital stay, the finding on the residual disability at discharge might even be more pronounced by the trend towards reducing the in-patient rehabilitation (Hall, Cohen, Wright, Call & Werner, 1999). The study conducted by Cardenas, Hoffmann, Kirshblum and McKinley (2004) further reported that persons with SCI with low motor scores on the Functional Independence Measure at discharge had a greater likelihood of being rehospitalised. Thus the finding of the current study on the activity limitations at discharge emphasises the importance of outpatient rehabilitation following discharge. The highest levels of independence were for the items respiration, feeding and grooming. These findings are consistent with the results from a study conducted in eight rehabilitation centres in the Netherlands (Post et al., 2005), except for the item relating to respiration. The reason for this being that the latter study utilised the FIM, which omits items related to respiratory function. Looking at individual items, the majority of the patients with spinal cord injury in the current study experienced high levels of limitation with mobility (walking) and stair management at discharge, nevertheless the difference was statistically significant between the points of data collection. Similar findings were found elsewhere (Wirth et al. 2008; Chan & Chan, 2005).

The high level of disability associated with mobility (specifically relating to walking ability) is slightly ambiguous as the nature and extent of the spinal cord injury were not taken into account, irrespective of the independent execution of mobility tasks using a wheelchair. The need for follow up rehabilitation post discharge is undoubtedly evident since studies found significant improvement in mobility, particularly in mobility outdoors up to six months after injury (Wirth *et al.*, 2008). It is hypothesized that the limited availability of assistance at home could either be the impetus for improvement in functional status or a barrier to engagement in functional tasks which were previously performed with assistance.

The FIM is undoubtedly the most common functional outcome measure utilised in patients with neurological conditions, but has been criticised for not assessing bed mobility (Middleton *et al.*, 2006). Since sensory and motor impairment are common in patients with spinal cord injury, specifically in the current study, the evaluation of bed mobility is essential for planning of rehabilitation services and for the prevention of secondary complications, which could have adverse effects on function and health in general (Richards *et al.*, 2004). Therefore, the use of the SCIM III should take precedence over other functional outcome measures since it takes into account aspects of functioning altered by a spinal cord injury.

In summary, the research setting adopted an outcome-based approach, thus the outcome levels as defined by Landrum, Schmidt and Mclean (1995) were used as collateral evidence of functional abilities of patients at discharge. With the majority of patients with stroke (92.54%) and spinal cord injury (98.68%) discharged at an outcome level 3 and higher, which loosely encapsulate residential integration with the emphasis on, but not confined to, self-care, mobility around home, effective communication, simple housekeeping, household planning and home management, whereas a level four and five refers to community

integration and productive activity respectively. Given the level of dependence of mobility tasks (as measured by the respective outcome measures), which is an explicit criterion of the outcome level three, insufficient evidence is available to justify the level of functioning (on the outcome levels) of patients with stroke and spinal cord injury at the time of discharge. Since the outcome-based approach could strongly be conceptualised within the ICF framework, the author cautions the use of the outcome-levels as the only indicator of functional ability, thus recommends the use of standardised outcome measures to serve as an adjunct.

5.4.3 Participation Restrictions of participants

Assessing community integration in an in-patient facility is difficult, as the term "community" is ever-changing and unique to each patient and it could only be effectively evaluated if the therapy sessions mirror the "community" of the patient with its entire social, architectural and attitudinal environment. To compensate for contextualising the community into the therapy session, patients are allowed to go home over weekends, which are thought to provide them with the opportunity to engage in the potential threats that community life could pose to them, and then address those perceived challenges in therapy, once they are back (Rouillard, 2007; Personal communication, J. A. Hendry, October 15, 2010). As illustrated in the results not the entire sample is from the Cape Metropolitan sub-district, thus not all patients had the opportunity to visit home and engage in the participatory roles over weekend-leave.

5.4.3.1 Stroke

The survey of living conditions among people with disabilities in Zambia was used as the generic measure of activity limitations and participation restrictions in both stroke and spinal cord injury populations. This scale was used in response to literature frequently suggesting that the constructs of activity and participation are blurred (Carpenter *et al.*, 2007; Jette, Haley & Kooyoomjian, 2003). For the purpose of this study the dimensions of participation were limited to interpersonal behaviours, major life areas and community, social and civic life (WHO, 2001).

It has often been found that although stroke survivors become independent in basic activities of daily living and mobility, which make them loosely independent in their homes, large numbers of them still remain unable to be independent in their communities. The results of the current study suggest that those who responded to the various participatory tasks experience a mild difficulty with keeping their job, being active members of their respective organisations and social clubs, and enjoying previously fulfilling leisure and recreational activities. Both local and international studies found that large numbers of patients are unable to return to work, unable to resume the role of caring for their families and unable to partake in social and leisure activities (Rhoda *et al.*, 2011; Rouillard, 2007; Desrosiers *et al.*, 2003).

Returning to work post stroke is very low (Green & King, 2009; Rouillard, 2007), especially in the context of patients who are still employable. It was beyond the scope of the current study to determine the number of patients that returned to work post in-patient rehabilitation, however the achieved outcome levels at discharge were recorded as an indicator of those who reached a level of functioning essential for work, or elsewhere stated productive activity. Alarmingly, only 19.66% of patients with stroke and spinal cord injury fitted the category (outcome level 5). In a study conducted in Israel, of 39 participants who worked before their stroke, only one returned to work (Hartman-Maeir, Soroker, Ring, Avni & Katz, 2007). The finding related to return to work is indeed alarming as the majority of those with stroke were at an employable age and of the male gender, which are often the primary breadwinner and/or only income provider of the family. This could have implications that do not only affect the patient with stroke, but the family structure and financial strain, which often lead to other family members, part of the household, caring for the patient instead of seeking employment (Rouillard, 2007; Teasall, McRae, Finestone, 2000). Therefore, rehabilitation should be fashioned to address problems with returning to work, and even in the midst of the low level of employment prior to admission in the current study (21.67%), patients should be provided with the necessary skills and services to optimise opportunities for employment (UNCRPD, 2007).

The participation in leisure activities was found to negatively impact those with stroke (Desrosiers *et al.*, 2003). The present study found that those with stroke experienced a mild difficulty with the involvement in their personal leisure activities. A study conducted by Desrosiers *et al.* (2003) found that leisure patterns and participation were significantly lower in those patients with stroke than the control group that was matched on age, gender and living environment. One could argue that the reduction in leisure activities is attributable to the stroke event itself. Therefore, rehabilitation should be targeted towards fostering greater participation in leisure activities, with the ultimate goal of achieving improved community participation and quality of life.

5.4.3.2 Spinal cord injury

The results of the current study found that patients with spinal cord injury experience a moderate difficulty with walking (n=29) and moving around (n=12) within the social context

and a mild to moderate restriction to driving a vehicle (n=3), getting and keeping a job (n=15), and leisure and recreational activities (n=26). Although the aforementioned findings of the current study are not a full representation of the spinal cord injury population, it is, however, consistent with literature (Duggan & Dijkers, 2002; Noreau, Fougevrollas, Post & Asano, 2005). With special reference to participation constructs, a study conducted by Noreau and colleagues identified the most commonly affected life habits to be manifested in occupational activities and recreational activities, which were similar as the restrictions experienced in the current study (Noreau et al., 2005). Numerous studies found that level of achievement in participatory roles is closely associated with quality of life. (Carpenter et al., 2007; Schonherr, Groothoff, Mulder & Eisma, 2005). One particular study found that leisure intervention resulted in significant improvement in all domains of quality of life and leisure satisfaction compared to the control group. The maintenance of improved quality of life is paramount following spinal cord injury, not limited to the well-being of the patients only, but also for the reservation of state resources, which are often pressurised due to unplanned hospitalisations (DeVivo & Farris, 2011; Daniel & Manigandan, 2005). Since strong evidence supports leisure activities a tool to improve quality of life, further research should be conducted to establish the content of leisure activities and the frequency of these activities in order to develop efficacy models.

Returning to work following a spinal cord injury is a grave concern, since it lags well behind the general population (Anderson & Vogel, 2002). Despite the level and severity of the lesion, other factors have been found to predict return to pre-injury occupation or alternative employment. One of these factors relates to formal education, in which those with a higher level of education and having a less-physical job, are more likely to return to work with less restrictions (Jang, Wang & Wang, 2005; Vestling, Tufvesson & Iwarsson, 2003). Given the educational bracket of the sample of patients with stroke and spinal cord injury (more than 90% of patients with no tertiary education) in the current study and the physical nature of their pre-injury occupation, it is unsurprising that these patients will face challenges with regards to keeping their work. Notwithstanding the fact that employment is the most important indicator of participation and is associated with higher quality of life, the need for post-injury education, even among individuals who have extensive training and education at the time of injury, is imperative.

Peer support programmes have been put in place at the WCRC to facilitate the community integration of patients with spinal cord injury, but similar to the other recreational activities as part of the rehabilitation process, only a few patients with spinal cord injury (18%) and stroke (12%) utilised this service. Peer support programmes, linking people with recent SCI and stroke with others who have more experience of managing and coping with SCI over time, are being increasingly implemented with the aim of facilitating participation after SCI (Carpenter *et al.*, 2007). Therefore, if participation is such a challenge for patients with SCI, more patients should receive peer support, but only on the premise that programme evaluation finds these programmes effective.

In essence, participation is a unique individual response to integration of environmental, personal, and cultural factors with the tangible presence of living with a disability. As demonstrated in the results most patients were referred directly from the secondary and tertiary hospitals, which unambiguously imply that those patients have not experienced community life and have not been functioning within the other dimensions of participatory roles since the onset of the health condition. Thus, the measurement of certain participatory outcomes could be questioned in an in-patient rehabilitation context.

Growing evidence underscores the issues of participation over the continuum of an individual's life rather than rehabilitation outcomes post-injury (Carpenter *et al.*, 2007).

Therefore, the need arises to fully encapsulate the burden of stroke and spinal cord injury and other health conditions, for the effective planning of health care services-, the implementation of preventative strategies-, and the reservation of scares resources along the continuum of the disabling health condition.

5.5 Factors predicting functional outcome at discharge

5.5.1 Stroke

The continuous score on the Barthel Index was used to determine the factors that predicted a favourable outcome. On bivariate testing, only the functional status on admission, as measured by the Barthel Index, had been identified as the factor which influences outcome of stroke at discharge. A direct relationship exists between activity scores, which suggest that the higher the functional score on admission the greater the score at discharge. This prediction corroborates with findings from other studies (Kuptniratsaikul *et al.*, 2009; Duncan *et al.*, 2005). A study by Hoffmann, McKenna, Cooke and Tooth (2003) and Thommessen, Bautz-Holter and Laake, (1999) found that activity score (using the Barthel Index) was the greatest predictor of functional status and social activities, which influences life satisfaction and quality of life of individuals.

Patient -related characteristics such as age and gender among those with stroke were found to be statistically insignificant on bivariate analysis. It was particularly surprising that age was not found to be a significant factor, as a negative association between age and functional outcomes is often reported in literature (Kwakkel, Wagenaar, Kollen & Lankhorst, 1996). The stroke population at WCRC is unique as the profile differs from other populations worldwide. Not only were the mean ages in the sample lower than in overseas European countries, but age was seen as normally distributed, when one would expect it to be skewed to the older ages. Only 16% of the patients with stroke were aged above 65 years. It could be argued that the negative manifestation of age is more evident with increasing age, which is often related to an increase in co-morbidities and where normal aging is more apparent and responsible for reduced functional ability and not the onset of the stroke per se.

No clear effect was found with regards to length of hospital stay, income, impairment variables and inherent factors such as age and gender. The small sample size is expected to have limited power of the analysis (Domholdt, 2000). However, the bivariate analysis gave insight into the factor that was found to influence functional outcome at discharge. Therefore, the assessment of functional abilities on admission is essential for planning of the appropriate health professionals that should be involved in the rehabilitation of the patient, in order to optimise functional recovery and to a certain extent objectively answer frequently asked questions by the patient and their families. On the contrary, the results that demonstrated insignificant correlation between independent variables and the functional outcome score at discharge could be evidence to place less emphasis and spend less of the scarce resources on the strategies that are implemented to address those variables.

5.5.2 Spinal cord injury

The current study identified four factors namely age, length of hospital stay, functional outcome on admission and bladder -and bowel incontinence as predictors of functional status at discharge. These factors were considered individually during the bivariate testing and also together during the multivariate analysis.

The current study found age to be inversely related to functional outcome (as measured by the SCIM III). Numerous case control studies conducted by Scivoletto *et al.* (2003) and Seel,

Huang, Cifu, Kolakowsky-Hayner and McKinley (2001) found that gains for independence of daily living measures were significantly greater (p<0.001) for the younger age group and the young to middle age group respectively. The achievement of better functional outcomes in the younger age group could be due to the traumatic nature of the lesions, which have been associated with a higher probability of sustaining complete motor lesions of the thoracic and lumbar levels, whereas non-traumatic lesions are more common in older patients and have higher frequencies of incomplete tetraplegia (Scivoletto et al., 2003).

Apart from age affecting functional outcome in spinal cord injured patients, numerous studies found length of hospital stay to be a predictor of functional outcome at discharge (Sipski et al., 2004; Scivoletto et al., 2003). The current study found a significant correlation between LOHS and functional outcome at discharge (spearman's rho-0.28; p=0.0346), which in this instance could be the result of the sample consisting of more paraplegics (76.31%) than tetraplegics (Post et al., 2005). Although the mean length of hospital stay in the current study between those with paraplegia (68.53; SD 50.5) and tetraplegia (85.62; SD 40.6) was statistically insignificant, the difference of 17 days has clinical meaning and relevance as cost of healthcare are usually estimated based on the length of hospital stay in days (Winslow, Bode, Felton, Chen & Meyer, 2002). The inability to detect the significant difference in LOHS between those with paraplegia and tetraplegia could be due to the large standard deviation, which could be influenced by the small size that reduces the power of analysis. The shorter length of hospital stay as an indicator for better functional outcomes should be analysed with caution, as it could simply imply that those with paraplegia reach their injuryspecific outcomes sooner than those with tetraplegia, due to the initial level and severity of the injury and age.

On bivariate analysis, functional outcome on admission was found to predict functional outcome at discharge. Those with tetraplegia are usually more affected on the level of body structure and function, thus suggesting that those with tetraplegia are clearly more functionally impaired than paraplegics (Wolfe *et al.*, 2010; McKinley, Santos, Meade & Brooke, 2007; Post *et al.*, 2005). The results of the current study indicated the significant difference in the functional outcome between those with paraplegia and tetraplegia on admission (p=0.023) and at discharge (p=0.007).

In the current study, the presence of bladder -and bowel incontinence predicted functional outcome. Studies found that bowel incontinence is related to distress in patients with spinal cord injuries and were also found to be a major physical and psychological problem (Glickman & Kamm, 1996). A study conducted by Hicken, Putzke and Richards (2001) found that individuals with impaired bowel -and bladder control reported lower quality of life on several domains compared with those with independent control of bowel -and bladder. The implication of bladder and bowel incontinence could cause restrictions to social integration, which could be manifesting in improved difficulty of creating new relationships (Hicken *et al.*, 2001).

Results from the backward elimination multiple logistic regression indicated that functional outcome-and the presence of bladder -and bowel incontinence on admission predicted outcome at discharge. Literature often reports multiple predictor models consisting of functional ability on admission and number of medical complications as an indicator of functional outcome, without explicitly referring to bladder -and bowel incontinence (Burnett, Kolakowsky-Hayner, Gourley & Cifu, 2000). Based on theoretical principles, discharge planning should be guided by functional outcome and not health care cost. On the basis of

this investigation, with the author aware of the limitations of this model (small sample size and which led to the inclusion of only certain variables), the functional outcomes at discharge could be predicted. This model provides health providers and patients to aid in the identification of factors which could impede functional outcomes and the opportunity to aggressively manage and appropriately refer patients to other relevant professionals. Since the functional outcome on admission accounted for 46% of the variance in the overall functional score at discharge, it is recommended that rehabilitation professionals administer the Barthel Index and the SCIM III on admission, which are easy tools to use, in order to set realistic goals and decide on the appropriate rehabilitation services and processes for the patient.



5.6 Summary of Chapter

This chapter addressed the results of the study, which related to the research questions. Despite the demographic and socio-economic changes with regards to health and health-related issues in South Africa the last decade, the demographic profile of the participants fits the characteristics of patients with stroke and spinal cord injury in Sub-Saharan Africa. With regard to the process of rehabilitation, consistent results have been found in terms of rehabilitation services available to patients, with the emphasis on the multidisciplinary approach, and the utilisation of those services. However, the recreational activities/services, as part of the rehabilitation programme, were rather under-utilised despite the literature indicating its benefits, thus the efficacy of those activities and services should be determined before additional manpower and services are made available. The determined length of hospital stay for both stroke and spinal cord injury added to the controversy on global standards. Since downward trends in the length of hospital stay are noted on the global arena,

the study findings are well aligned. The current study found similar findings for the majority of patients that are discharged home following in-patient rehabilitation, but the discharge setting could be criticised based on the functional limitations and restrictions still exhibited by patients at discharge. Unsurprisingly, both diagnostic groups demonstrated significant functional gains following in-patient rehabilitation, but mobility, which encompass walking, stairs climbing and wheelchair dexterity, still remained an area of limitation of most patients with stroke and spinal cord injury at discharge. The latter findings are in agreement with literature, thus intervention strategies and the alignment of rehabilitation services have become top priority. Participation restrictions experienced by patients were similar to studies conducted in the same context. These restrictions were manifested in the sphere of social interaction with friends and family, occupational life activities, and leisure and recreational activities. Functional ability on admission was found to be a favourable predictor for functional ability of both diagnostic groups at discharge. In addition literature supports the other factors which predicted functional outcome of patients with spinal cord injury at WESTERN CAPE discharge.

CHAPTER SIX

SUMMARY, CONCLUSIONS, LIMITATIONS, SIGNIFICANCE, AND RECOMMENDATIONS

6.0 INTRODUCTION

In this chapter, a final summary of the study is provided. The most important findings of the study will be highlighted in the conclusion with possible confounding limitations of the study. Finally, the significance and recommendations emerging from the study are outlined.

6.1 SUMMARY OF THE STUDY

The aim of the current study was to determine the process of rehabilitation and the outcomes of patients following in-patient rehabilitation at a centre in the Western Cape. The study employed a longitudinal and observation study design to determine the outcomes of patients with stroke and spinal cord injury between admission and discharge, whereas a crosssectional design was used to collate information pertaining to the demographic,socioeconomic- and medical characteristics, and process of rehabilitation. In addition, a document review of the patients' medical records was also conducted to collate elements related to the impairment status of patients on admission, rehabilitation outcome levels achieved at the two data collection intervals and the discharge planning of patients.

The results indicated that the mean age of the patients with stroke was 52.95, which is approximately 15 years younger than what is found in developed countries, but consistent with results from sub-Saharan Africa. The mean age of patients with spinal cord injury was 34.14, which is consistent with literature. This study recorded more males in both stroke and spinal cord injury populations. It was also found that only 21.67% of patients were employed prior to the disease onset, with more in skilled or semi-skilled positions.

With regards to the process of rehabilitation, most of the patients with stroke were referred from secondary level hospitals, while the majority of patients with spinal cord injury were referred from tertiary level hospitals. Most patients with stroke and spinal cord injury were managed by the rehabilitation professionals as recommended by literature confirming the superiority of the multidisciplinary/interdisciplinary approach. Only 39.39% and 46.87% of patients with stroke and spinal cord injury respectively were referred to the learn-to- swim programme, whereas much lower numbers of patients engaged in the other recreational activities provided at the centre, despite evidence claiming the benefits of these interventions. The results indicated a mean length of hospital stay of 51.62 and 73.11 days of patients with stroke and spinal cord injury respectively, which is consistent with the downward trend observed in literature. At least 80% of both patients with stroke and spinal cord injury were discharged home following in-patient rehabilitation without formal referral to out-patient rehabilitation facilities.

The results on the outcome of patients found the most common documented impairments among those with stroke to be manifestations of muscle weakness (80.60%), abnormal tone (76.13%) and aphasia (50.75%), whereas those with spinal cord injury presented mostly with muscle weakness (75.00), bladder incontinence (71.05%) and sensory impairment (69.74%). At the level of activity, patients with stroke still experienced limitations in mobility and stair climbing. Patients with spinal cord injury were found to experience limitations in mobility (indoors, outdoors and moderate distances), stair management and wheelchair transfers to a car and from the floor at discharge. Both stroke and spinal cord injury populations and discharge.

Patients with stroke were found to experience a mild difficulty with participation restrictions, with special reference to keeping their job, being active members of their respective organisations and clubs and enjoying previously fulfilling leisure and recreational activities, whereas those with spinal cord injuries experienced a mild to moderate restriction in driving a vehicle, getting and keeping a job, and leisure and recreational activities.

The admission activity score, as measured by the respective outcome measures, was found to be a predictor of functional abilities (as measured by the same outcome measure) at discharge, of both stroke and spinal cord injury populations. In addition, age, length of hospital stay, attendance to the learn-to-swim programme and bladder -and bowel incontinence were found to be predictors of functional outcome of patients with spinal cord injury at discharge.

6.2 CONCLUSIONS

The results of the present study illustrated that the mean age of stroke was approximately 10-15 years younger than what was found in developed countries, but consistent with studies from developing countries. In addition, the perceived co-illnesses or medical conditions were rather low among the cohort of patients with stroke.

The recreational activities or services as part of the rehabilitation programme have not been extensively utilised by the patients with stroke and spinal cord injuries, despite the growing evidence of these activities that facilitate social integration. Literature suggests that patients should have considerable functional abilities in order to benefit from or utilise the "learn to swim", "wheelchair basketball" and other programmes. However, the current study found that patients are admitted with considerable residual disability. One could conclude that patients are incapable of utilising the services in order to benefit from them. Therefore, the

timing of introducing these services should be better matched with the functional abilities of the patients, or perhaps these services should be provided on an out-patient basis once patients are actively fighting the barriers to social integration.

The length of hospital stay was less than what was recommended for optimal outcomes of both diagnostic groups, using the activity and participation domain of the ICF as the reference framework. Most patients in both diagnostic groups were discharged home without any referral to further their rehabilitation along the continuum, irrespective of their activity limitations and participation restrictions at discharge. One could conclude that these patients will experience the same limitations in function and participation restrictions with possible future preventative physical- and psychosocial complications, which will make them dependent on others for assistance.

Literature highlights that mobility (i.e. walking, stair climbing and wheelchair dexterity) is a predictor for participation and is also closely related to quality of life. The most prevalent activity limitation in both diagnostic groups was related to mobility, which included walking, stair management and ability to propel a wheelchair over long distances. The point of concern is, however, that these patients will experience participation restrictions in the life situations which require of them to mobilise safely and independently. For further reiteration, the cohort of patients with stroke and spinal cord injury reported participation restrictions especially relating to return to work and leisure and social activities, which usually require of them to mobilise safely.

6.3 LIMITATIONS

- The study design only provided level III evidence regarding the rehabilitation process and the outcomes of patients with stroke and spinal cord injury due to the longitudinal and observational nature of this study, with the omission of a control group.
- Patients who were incapable of performing a three step command due to receptive aphasia were excluded from the study, which could have led to systematic bias and inaccurate data.
- Very low frequencies of patients with stroke and spinal cord injury were re-admissions. However, the data on functional activities and participation could have biased the results because these patients generally have a have more favourable functional outcomes on admission and the participation results could mostly reflect the patients that were at home and in the community before their rehospitalisation.
- This study did not sub-classify completeness of injury and level-specific outcomes of patients with spinal cord injury. This limitation could present will barriers to the planning of appropriate services for sub-category or each spinal cord injury.
- In the current study 15% of patients with spinal cord injury were lost to follow-up due to sporadic discharge. Since these patients resided mostly in neighbouring provinces (or 50kms away from the WCRC) it was consider labour intensive in terms of time and financial constraints to follow these patients up.
- Since impairments following the onset of the health condition were not routinely recorded, the current study did not objectively assess the full spectrum of impairments related each health condition, which could have profound implications on the planning and implementation of services to match the needs of the patients.
- Certain data were obtained from medical records of patients and there were many missing data. Missing data were handled by case deletion, which have reduced the sample sizes.

6.4 SIGNIFICANCE OF THE STUDY

The importance of this study for physiotherapists and other medical professions that play an active role as part of the interdisciplinary team is emphasised by the current role of rehabilitation and the call for establishing institutional guidelines on certain processes and protocols to be followed for different health conditions. On a more individualistic level, this study could answer some of the questions so often asked by the patient and his/her family such as, "How long will I stay?", "Will I be able to go home?", and the all inevitable question, "Will I be able to walk again? The study of the process of rehabilitation and the factors influencing activities of daily living such as walking could provide a reference framework for the institution to identify factors that could prolong the length of hospital stay, and factors which hinder the independent execution of activities that are essential to the patient. Therefore, additional services should be made available to these patients presenting with unfavourable characteristics.

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The activity and participation measure and the archival review on impairment status that was used across the two diagnostic groups, identified dimensions not often addressed by rehabilitation, and quantified the high prevalence of specific activities and participatory roles still restricted at discharge. The findings advocate for the alignment and adaptation of rehabilitation to better match the all inclusive needs of the patient and to ensure improved outcome in the disability constructs affected by the health condition. The author is clear on the fact that the findings of this study cannot be generalised to the patients with similar health conditions reported on in this study to other countries, South Africa and the WCRC due to methodological limitations. However, this study could be used as a reference framework to compare findings for future studies.

6.5 RECOMMENDATIONS

The recommendations are based on the evidence of the study and are applicable to stakeholders on national level, patients, heads of therapeutic staff and rehabilitation professionals at the Western Cape Rehabilitation Centre.

6.5.1 Recommendation for the Department of Health

Part of the re-engineering of the Primary Health Care Plan of South Africa, the current Minister of Health prioritised the health needs of the country, with the most important vision of enhancing the life-span and longevity of South African citizens. Since the mean age of patients with stroke was rather low, the recommendation is that all citizens should visit family physicians regularly for medical screening and identification of preventable and treatable illnesses. In addition, Health Promotion Programmes should be implemented in the public setting in order to increase awareness of the risk factors for stroke. This recommendation should be operationalised on community level, with the ultimate goal of reducing mortality and morbidity rates in the younger age groups.

6.5.2 Recommendations for the rehabilitation programme at the Western Cape Rehabilitation Centre

1) Most patients in the stroke and spinal cord injury diagnostic groups were discharged home despite the activity limitations and participation restrictions still manifesting at discharge. The recommendation is that all patients with an outcome level 1-4 should be discharged to an outpatient facility for follow up rehabilitation purposes.

2) The results of the study demonstrated that not all patients engaged in their participatory life roles and actions since the onset of the health condition. Therefore, this finding re-iterates

the aforementioned recommendation of planning the appropriate referral destination of the patient at discharge because only post discharge will they attempt to perform their normal participatory roles, which will identify their barriers to participation.

3) Primary care providers, particularly physiotherapists and occupational therapists, should develop and implement home and community-based rehabilitation interventions that target the patients with stroke and spinal cord injury in order to optimise integration and reduce the possibility of rehospitalisation.

4) Based on the results of the study less than half of the patients received peer support during the length of hospital stay. The United Nations Convention on the Rights of Persons with Disabilities advocates for peer support to be part of the rehabilitation programme, with the core motive of facilitating the reintegration of patients back into the community. The recommendation is that all patients should receive peer support during the length of hospital stay, only once the evaluation of the role of peer support as part of the rehabilitation programme, has been found as a favourable component on outcomes of patients in the research setting.

5) This study did not evaluate the role or contribution of recreational activities (learn to swim wheelchair basketball etc.) on the outcome of patients. Since only a few patients utilised these services, follow-up studies should determine the impact of these of services on patient outcomes before its implementation as part of the rehabilitation programme.

6) The records on the documented impairment status of patients on admission were poor. Complete record keeping is essential for planning of health care services and proof of interventions for medico-legal purposes. It is important that the staff at the Western Cape Rehabilitation Centre keep correct and complete records relating to all aspects of assessment and treatment.

6.5.3 Recommendations for further research

According to the hierarchy of evidence observational studies would only provide Level III evidence. Randomised controlled studies, which would provide a higher level of evidence, should be conducted to address some of the issues highlighted by this baseline study. Some of the research questions that could be addressed by using randomised controlled trials, could include; do the recreational activities such as learn to swim, wheelchair basketball and peer support services translate into better outcomes of the patients?

Most patients in both diagnostic groups experienced limitations in mobility tasks at discharge. Follow-up studies should investigate whether an extended length of hospital stay would address the limitations in mobility with collateral information on the expenses of such an extension.

The researcher would also like to recommend that a mixed-method study be conducted, which determines and explores the activity limitations and especially participation restrictions patients face following in-patient rehabilitation at the WCRC.

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