

EVALUATION OF THE REHABILITATION PROGRAM FOR PERSONS WITH COMPLETE PARAPLEGIA AT NETCARE REHABILITATION HOSPITAL



**Thesis presented in partial fulfilment of the requirements of the degree
of Masters of Medical Sciences (Majoring in Rehabilitation) at the
University of Stellenbosch**

**Supervisors: Gubela Mji
Surona Visagie**

November 2009

Declaration

By submitting this dissertation electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the owner of the copyright thereof (unless to the extent explicitly otherwise stated) and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Date: 16 November 2009

Copyright © 2009 Stellenbosch University

All rights reserved

ABSTRACT

Spinal cord injury is a devastating sudden cause of disability which renders a person paralyzed and dependent on care immediately after the incident. A person who has suffered a spinal cord injury requires an intensive rehabilitation program to achieve physical independence as well as reintegration into the community.

The aim of this study was to evaluate the rehabilitation program for patients with complete paraplegia at the Netcare Rehabilitation Hospital, a 120 bed private rehabilitation facility in Johannesburg, where rehabilitation for patients with physical disabilities is offered by an interdisciplinary team.

The rehabilitation program was evaluated in terms of effectiveness including the degree of physical independence the patients achieved and how well the program prepared patients for successful integration into the community.

The Functional Independence Measure (FIM), a standardized outcome measure that measures certain physical and cognitive functions and the Needs Assessment Checklist (NAC), an instrument designed to assess if the rehabilitation program is geared towards the patients' individual needs were used as outcome measure. FIM scores were determined on admission and discharge and NAC scores were determined at discharge.

A convenient, consecutive sample of sixteen patients with complete paraplegia (ASIA A), with a neurological level between T1 and T12, formed the study population.

Consistently high FIM and NAC scores in the area of physical functioning suggested that the rehabilitation program at Netcare Rehabilitation Hospital was effective in terms of providing patients with physical independence. However, NAC results showed that the patients were not completely ready to reintegrate back to their communities. Areas that were identified as particularly problematic were knowledge on follow up health care

services in the community, readiness for work and accessibility of the home and work environments.

Therefore it is recommended that the rehabilitation team re-evaluate the program and incorporate strategies with the aim to improve it's effectiveness in terms of preparing patients for community reintegration. It is also recommended that further research is conducted to assess the current success rate with regards to community reintegration and determine challenges to re-integration in order to assist with program panning.

Key terms: *paraplegia, rehabilitation, outcome measure, needs assessment, program evaluation*

OPSOMMING

'n Spinaalkoordbesering is 'n skielike oorsaak van gestremdheid wat die persoon verlam en afhanklik van sorg laat direk na die voorval. 'n Persoon wat 'n spinaalkoordbesering opdoen benodig 'n intensiewe rehabilitasie program om weer fisies onafhanklik te wees en ook om hom/haar voor te berei om weer by die gemeenskap in te skakel.

Die doel van hierdie studie was om die rehabilitasie program by die Netcare Rehabilitasie Hospitaal, 'n 120 bed private rehabilitasie fasiliteit in Johannesburg, waar rehabilitasie vir fisies gestremde persone deur 'n interdisiplinere span aangebied word, te evalueer.

Die program is geevalueer in terme van twee uitkomstes naamlik, die graad van fisiese onafhanklikheid wat die pasiënte behaal en tot watter mate die program pasiente voorberei vir herintegrasie in die gemeenskap

Die "Functional Independence Measure" (FIM), 'n gestandaardiseerde uitkoms skaal wat sekere fisiese en kognitiewe funksies meet en die "Needs Assessment Checklist" (NAC), 'n instrument wat ontwikkel is om te evalueer of rehabilitasie programme pasiente se spesifieke behoeftes aanspreek. Is gebruik om die rehabilitasie program te evalueer. Die FIM is met toelating en ontslag voltooi en die NAC is met ontslag voltooi.

'n Steekproef van sestien pasiente met volledige spinaalkoordletsels (ASIA A) tussen T1 en T12 het die studie populasie gevorm.

Deurgans hoë FIM en NAC tellings vir fisiese funksionering het daarop gedui dat die rehabilitasie program by die Netcare Rehabilitation Hospital effektief is in terme van fisiese onafhanklikheid van pasiente. Aan die ander kant het die NAC tellings daarop gedui dat die program minder suksesvol is wat betref die voorbereiding van pasiente vir gemeenskapsintegrasie. Spesifieke probleem areas sluit in kennis van waar om opvolg gesondheidsorg in die gemeenskap te bekom, gereedheid vir werk en toeganklikheid van die huis en werksomgewing.

Daar word aanbeveel dat die rehabilitasie span by Netcare Rehabilitasie Hospitaal die program herevalueer om die effektiwiteit van die program in terme van die voorbereiding vir gemeenskaps herintegrasië te verbeter. Dit word ook aanbeveel dat 'n opvolg studie gedoen word om die huidige sukses ten opsigte van gemeenskaps herintegrasië te evalueer en sruikelblokke te identifiseer ten einde die span te help met program beplanning.

Sleutelwoorde: *Paraplieë, rehabilitasie, uitkomsskaal, behoefte bepaling, Program evaluering.*

ACKNOWLEDGEMENTS

The author would like to express her sincere thanks and appreciation to the following individuals without whose assistance, support and guidance this thesis would not have been possible:

Ms Surona Visagie, supervisor, for not giving up on me, despite the long time I took to complete this thesis.

All the patients who willingly participate in this study and made it possible.

My colleagues at Rita Henn & Partners Inc, Rehabilitation Therapists, for their constant patience and support.

DEFINITION OF KEY TERMS USED IN THE STUDY

- Community integration:** A degree of community presence and participation for persons with disabilities that is no different from that enjoyed by persons without disabilities (Boschen, Miller, Noreau, Wolfe, McColl, Ginis, Prince, Joe & Konnyu 2008)
- Complete spinal cord lesion:** No sensation or voluntary muscle power below the neurological level of a lesion to the spinal cord (Nixon, 1985).
- Functional assessment:** Any attempt to measure objectively ability at the person level including activities of daily living, mental status, communication and sensorimotor ability (Ditmars & Gresham, 1997).
- Functional independence:** Optimal physical, sensory, intellectual, psychological and social functional levels (WHO 2000).
- Outcome measure:** Measurement tool used to document change in one or more patient characteristic over a period of time (Cole, Finch, Gowland, Mayo, 1994).
- Paraplegia:** Person with a spinal cord injury at the thoracic, lumbar or sacral level (T1-L5) that affects the lower limbs (Harvey, 2008).
- Physical independence:** Independence in activities of daily living, transfers, bed mobility and wheelchair dexterity (Eng & Miller, 2008).

Program evaluation:

A process of measuring to describe, predict and evaluate in order to provide benchmarks and summarize change related to the condition and care of individuals within a program (Wade 2004)

Rehabilitation:

Rehabilitation is a goal orientated and time limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functional level, thus providing one with tools to change ones life when and where necessary. The WHO definition of rehabilitation maintains that rehabilitation is the combined and co-ordinated use of medical, social, educational and vocational measures to enable the individual to reach the highest possible level of functional activity (WHO 2000).

CONTENTS

	PAGE
CHAPTER 1 BACKGROUND TO STUDY	
1.1. Introduction	1
1.2. Study problem	9
1.3. Motivation	10
1.4. Significance	11
1.5. Summary	13
CHAPTER 2 LITERATURE REVIEW	
2.1 Introduction	14
2.2 Spinal Cord Injuries	14
2.2.1 Epidemiology	15
2.2.2 Classification of spinal cord injuries	17
2.2.3 Outcome following spinal cord injury	17
2.3 Rehabilitation	23
2.3.1 Rehabilitation programs for SCI patients	27
2.4 Outcome measurement in rehabilitation programs	32
2.4.1 Outcome Measures	34
2.4.2 Measuring physical outcomes in SCI	36
2.4.3 Measuring participation in SCI	40
2.5 Measuring instruments used in current study	40
2.5.1 Introduction	40
2.5.2 The Functional Independence Measure (FIM)	42
2.5.2.1 Validity and reliability of FIM	43
2.5.2.2 Responsiveness	43
2.5.2.3 Feasibility	44
2.5.2.4 Shortcomings	44
2.5.3 Needs Assessment Checklist (NAC)	46
2.5.3.1 Validity and Reliability	47

2.5.3.2	Responsiveness	48
2.5.3.3	Feasibility	48
2.5.3.4	Shortcomings	48
2.6	Summary	49

CHAPTER 3 METHODOLOGY

3.1	Introduction	51
3.2	Aim of study	51
3.3	Study objectives	51
3.4	Study design	52
3.5	Study setting	52
3.6	Study population	52
3.6.1	Inclusion criteria	53
3.6.2	Exclusion criteria	54
3.7	Measuring instruments	54
3.7.1	Functional Independence measure (FIM)	54
3.7.2	Needs Assessment Checklist (NAC)	55
3.8	Pilot study	55
3.9	Data collection	56
3.10	Data analysis	58
3.11	Reliability and validity	58
3.12	Ethical considerations	59
3.13	Summary	60

CHAPTER 4 RESULTS AND DISCUSSION

4.1	Introduction	61
4.2	Demographic profile of the study population	61
4.2.1	Age distribution	61
4.2.2	Gender distribution	62
4.2.3	Marital status	62
4.2.4	Housing and living environment	63

4.2.5	Education level and employment status	63
4.3	Information related to the Spinal Cord Injury	64
4.3.1	Referring hospital	64
4.3.2	Level of lesion	66
4.3.3	Cause of accident	66
4.3.4	Length of stay in acute care and in rehabilitation	
	Hospital	67
4.4	Functional Independence measure scores	74
4.4.1	FIM admission scores	75
4.4.2	FIM discharge scores	76
4.5	Needs Assessment Checklist scores	78
4.6	Comparison of functional scores of FIM and NAC	79
4.6.1	Self care/Activities of daily living	80
4.6.2	Bowel and bladder management	82
4.6.3	Mobility	83
4.7	Additional categories of the NAC	85
4.7.1	Wheelchair and equipment	85
4.7.2	Community preparation	87
4.7.3	Discharge planning	88
4.7.4	Psychological issues	90
4.7.5	Prevention of secondary complications	91
4.8	Summary	91

CHAPTER 5 CONCLUSIONS AND RECOMMENDATIONS

5.1	Introduction	93
5.2	Demographic profile of participants	93
5.3	Length of stay	94
5.4	Effectiveness of program in terms of FIM scores	94
5.5	Effectiveness of program in terms of NAC scores	96
5.6	Comparison of FIM scores to the guidelines of the Consortium of Spinal Cord Medicine	97

5.7	Cost effectiveness	97
5.8	Funding for rehabilitation	97
5.9	Recommendations	98
5.9.1	Measuring instruments	98
5.9.2	Performance measurements of the rehabilitation Program	99
5.9.3	Rehabilitation program for persons with complete paraplegia at NRH	99
5.9.4	Recommendations to other SCI rehabilitation Programs	101
5.9.5	Recommendations to SASCA	101
5.9.6	Recommendations for further studies	101
5.10	Conclusion	102
5.11	Limitations of the study	102
REFERENCES		104
 APPENDICES		
APPENDIX A	Consent letter addressed to manager of hospital	110
APPENDIX B	Consent letter to Doctor in charge of patients	111
APPENDIX C	Consent form for participants	112
APPENDIX D	Functional Independence Measure (FIM)	115
APPENDIX E	Needs Assessment Checklist (NAC)	118

LIST OF FIGURES

Fig 2.1	Overview of the interaction between the different domains of the International Classification of Function, Disability and Health (ICF)	15
Fig 4.1	Age and gender distribution of study population	61
Fig 4.2	Level of lesion	66
Fig 4.3	Cause of spinal cord injury	67
Fig 4.4.	LOS in acute hospital	68
Fig 4.5	Length of stay in rehabilitation hospital	69
Fig.4.6.	Acute and rehabilitation hospital LOS	70
Fig 4.7	Scatter plot comparing LOS and discharge FIM score	71
Fig 4.8	Scatter plot comparing LOS and NAC score	71
Fig 4.9	Scatter plot comparing LOS and level of lesion	72
Fig 4.10	Scatter plot comparing LOS and cause of injury	73
Fig 4.11	Scatter plot comparing LOS to gender	73
Fig 4.12	FIM scores on admission and discharge	74
Fig 4.13	Scatter plot comparing FIM admission to FIM discharge scores	75
Fig 4.14	Admission FIM motor scores	76
Fig 4.15	Discharge FIM motor scores	77
Fig 4.16	Needs Assessment Checklist scores	78
Fig 4.17	Comparison of FIM and NAC Self-care Scores	81
Fig 4.18	Comparison of FIM and NAC Bladder and Bowel Scores	83
Fig 4.19	Comparisons of FIM and NAC Transfer and Mobility Scores	84
Fig 4.20	Knowledge on wheelchair & equipment scores	86
Fig 4.21	Community Preparation and work readiness scores	87
Fig 4.22	Discharge Planning scores	89
Fig 4.23	Psychological issues scores	90

LIST OF TABLES

Table 2.1	ASIA Impairment scale (AIS)	17
Table 2.2	Levels of outcome in Rehabilitation	25
Table 2.3	Rehabilitation program for SCI	28
Table 2.4	Outcome measurements used in SCI Rehabilitation	36
Table 2.5	Expected Functional Outcomes	39
Table 3.1	Determination of study participants	53
Table 4.1	Demographic data of study participants	66
Table 4.2	Maximum scores in FIM & NAC Physical Categories	79
Table 4.3	Comparison of FIM discharge and NAC motor scores	80

LIST OF ACRONYMS

ADL	Activities of daily living
AIS	ASIA Impairment Scale
ASIA	American Spinal Injury Association
BI	Barthel Index
CBR	Community Based Rehabilitation
CHART	Craig Hospital Assessment and Reporting Technique
CPA	Canadian Paraplegic Association
CPG	Clinical Practice Guidelines
DPO	Disabled people's Organisation
FIM	Functional independence measure
HADS	Hospital Anxiety and Depression Scale
ICF	International Classification of Function, Disability and Health
IMSOP	International Medical Society of Paraplegia
INDS	Integrated National Disability Strategy
ISCoS	International Spinal Cord Society
LOS	Length of Stay
NAC	Needs Assessment Checklist
NRH	Netcare Rehabilitation Hospital
NRP	National Rehabilitation Policy
NSCISC	National Spinal Cord Injury Statistical Center
RHMIMF	Rick Hanson Man-In-Motion Foundation
RNL	Reintegration to Normal living Index
ROMS	Rehabilitation Outcomes Measuring System
SA	South Africa
SASCA	Southern African Spinal Cord Association
SCI	Spinal Cord Injury
SCIM	Spinal Cord Independence Measure
SRFM	Self Reported Functional Measure
WCHP	Western Cape Health Plan
WHO	World Health Organisation

CHAPTER 1

BACKGROUND TO STUDY

1.1 Introduction

Spinal Cord Injury (SCI) is a relatively uncommon yet devastating cause of disability. A person who newly acquires a spinal cord injury is often faced with the sudden loss of all physical independence and has to be cared for by others. Impairments caused by SCI such as a loss of sensation, motor function and bladder and bowel function can have a severe impact on participation in life and can lead to a loss of social roles e.g. loss of job and income, loss of sport and leisure activities. All this can have a profound emotional and psychological effect on the person (Eng & Miller 2008). To facilitate physical independence once again and assist an individual with SCI to perform the former roles he/she played in society, a coordinated, comprehensive, outcome oriented and cost effective rehabilitation program is necessary (Landrum, Schmidt & McLean 1995).

Landrum et al (1995) states that medical rehabilitation seeks to enhance the residual functional abilities of people who have acquired a disabling impairment, such as SCI. According to Landrum et al (1995), medical rehabilitation includes a multi-disciplinary array of evaluative, diagnostic and therapeutic services rendered by doctors, nurses, physiotherapists, occupational therapists, speech and language therapists, prosthetists, orthotists, psychologists, social workers and other health care workers. The rehabilitation process attempts to address the patient's physical, emotional and other support needs. Evidence of the benefits of medical rehabilitation is documented typically in terms of the reduction in disability and is measured through numerous impairment and activity measures e.g. the Functional Independence Measure (FIM) (Hamilton & Fuhrer 1987) and the Bartel Index (BI) (Roth, Davidoff, Haughton & Ardner 1990) to name but two.

However, as is clear from the International Classification of Function, Disability and Health's (ICF) definition, rehabilitation in the fullest sense of the word incorporates much more than medical rehabilitation and should encompass all measures necessary to maximize physical and psychological health, including social, economic and vocational

aspects (WHO 2000). It is the opinion of the researcher that this all-inclusive rehabilitation is unfortunately not often practised in South Africa if one takes into account that according to the World Health Organization (WHO) 75-80% of disabled people in the African Region live in rural areas, where services for rehabilitation are either limited or unavailable (WHO 2000). This is despite a move from the South African government who tabled the White Paper on the Integrated National Disability Strategy (INDS) in 1997 and the National Rehabilitation Policy (NRP) in 2000 in an attempt to promote rehabilitation services as part of the essential health services in South Africa (Office of the Deputy President 1997; Department of Health 2000).

Rehabilitation for patients with SCI must be initiated in the acute phase and continues with extensive and specialised in-patient services during the sub-acute phase and Community Based Rehabilitation (CBR) after discharge (www.ilo.org/public/health/english/employment/skill). The researcher is of the opinion that CBR programs are lacking in South Africa and rehabilitation is often terminated on discharge from the rehabilitation facility.

The focus of SCI in-patient rehabilitation programs is on achieving physical independence in preparation for community integration (www.spauldingrehab.org; www.mssm.edu/rehab/spinal; Eng & Miller 2008) and accordingly, the Consortium for Spinal Cord Medicine in the USA have published clinical practice guidelines for health-care professionals which outline the expected physical outcomes following traumatic spinal cord injury (Consortium for Spinal Cord Medicine 1999). These guidelines are presented in full in chapter 2. Thus the focus of the clinicians is to ensure that each SCI patient achieves physical independence. Similarly the patient's most important need during rehabilitation is to be able to go home as physically independent as possible (Eng & Millar 2008). However, to be successfully integrated back into the community requires more than physical independence. Furthermore, physical independence in hospital does not necessarily translate into physical independence at home. In conjunction with the ability to perform physical activities patients need to overcome many contextual barriers, both architectural and from the natural environment, as well as

attitudinal. Furthermore, they must have sufficient understanding of the injury and its effects on their body and mind to take care of their own health and prevent the development of secondary complications. In all this they need support from the community, local, provincial and national government with regards to implementing building regulations, providing accessible transport as well as access to education and training – all areas that currently cause barriers to the integration of disabled people including those with SCI (Office of the Deputy President 1997). Primary health care services are especially important. However these services are often inaccessible or ill-equipped to deal with the complicated needs of a person with an injury to the spinal cord (Office of the Deputy President 1997; Boschen, Miller, Noreau, Wolfe, McColl, Ginis, Martin, Prince, Joe & Konnyu 2008).

It is the experience of the researcher, who has worked in both the public and private sector in the field of spinal cord injuries that currently SCI are managed in the following manner in South Africa: Individuals with spinal cord injuries are admitted to either private or public acute care hospitals where they are stabilised. During the acute post-injury phase, specialised management of spinal fractures and other injuries occurs concomitantly with the prevention of complications such as pressure sores, deep vein thromboses and infections. Multi-disciplinary rehabilitation programs designed to optimize physical independence and minimize medical problems begin during the initial stabilising phase and continue until discharge from rehabilitation some three or four months later. These programs are centred on physical gains and aim to achieve maximal physical independence, thus rather medical rehabilitation than the all-inclusive process as described by the ICF.

Historically all rehabilitation services in South Africa were provided by the public sector, but with a growing need for medical services in the private sector, private rehabilitation facilities developed during the 1990s. At present a number of private rehabilitation centres, where rehabilitation programs for patients with spinal cord injuries are offered, are available in urban areas throughout the country (www.lifehealthcare.co.za; www.netcare.co.za).

Netcare Rehabilitation Hospital (NRH), where this research was conducted, is a private rehabilitation hospital in Johannesburg, Gauteng, where a rehabilitation program for patients with paraplegia, amongst others, is being offered. It is the observation of the researcher that the spinal cord rehabilitation program at this private rehabilitation centre focuses primarily on impairments, activities and physical outcomes, with only superficial attention being given to social, vocational and psychosocial aspects of rehabilitation. Therefore it was the facility of choice for the study as the researcher is working at this facility and is interested in the outcome of rehabilitation programs at this facility in an attempt to improve the rehabilitation programs offered.

Patients with newly acquired spinal cord injuries are transferred to this rehabilitation facility once their injuries have been stabilised in an acute hospital and they are declared ready for rehabilitation by the resident doctors at the acute hospitals. This usually means that they have no medical complications and all fractures are stable. Statistics available at the hospital show that the average time before the patients are admitted for rehabilitation is usually one to two weeks post injury but can be as long as six weeks post injury where medical complications necessitate longer periods of acute care. The bulk of patients come from acute care private hospitals in the Johannesburg area.

Rehabilitation at NRH is provided by an interdisciplinary rehabilitation team which consists of a medical doctor, nurses, physiotherapists, occupational therapists, social workers, psychologists and a dietician. The hospital has a dedicated spinal ward where patients are cared for as well as therapy areas outside of the ward where patients receive physio- and occupational therapy and an outdoor area for sport and recreation. The patients frequently go on outings to shopping malls, the movies, etc to facilitate the community integration process as well as trips in the suburb surrounding the hospital to prepare them for safe traffic negotiation as well as to improve their wheelchair dexterity skills. Although the facilities in the hospital are wheelchair friendly, the rehabilitation team focus many of the activities in the rehabilitation program outside of the hospital where circumstances are not always that accessible to wheelchair users.

On admission to NRH, patients with SCI are assessed by the different team members and a goal-oriented rehabilitation program is planned by the whole rehabilitation team. A family/team meeting is held within the first week of admission to NRH to discuss and plan the program with the patient and his/her family and set goals together. The patient and his/her family have the opportunity to set their own goals in line with the progress of the patient e.g. planning of first weekend home, carer training, etc.

The length of hospital stay at Netcare Rehabilitation Hospital for the rehabilitation of a person with complete paraplegia is usually set at twelve weeks (86 days) by the rehabilitation team and a full admission report including the long-term goals to be achieved by the patient is sent to the funder. The first report to the funder is followed by a weekly comprehensive team report on the patient's improvement and the short-term goals for the next week of rehabilitation. The funding for rehabilitation is mostly the responsibility of the patient's medical aid. It is found that often the funder or medical aid is not willing to pay for twelve weeks of in-patient hospital stay and patients may be discharged from hospital before they have achieved a reasonable degree of physical independence. This in itself places a burden on the family of the patient as the patient needs caring and it prolongs the process of reintegration into the community.

The rehabilitation program at NRH for patients with paraplegia includes the achievement of the following physical activities:

- Independent bed mobility (rolling, sitting up in bed and shifting sideways in bed)
- Independent transfers to and from wheelchair (incl. bed, toilet, bath, car and floor)
- Independent dressing of upper and lower body
- Independent washing of upper and lower body
- Independent wheelchair mobility on all indoor and outdoor surfaces (incl. ramps, uneven surfaces, up and down curbs)
- Independent bladder management
- Independent bowel management

In addition to the above, the patients are also involved in the following to prepare them for community integration:

- Individual counselling and family counselling
- Sexual counselling
- Informative talks on the nature of their injury, pressure care, diet, prevention of complications and traffic safety
- Outings to shopping centres
- A home and work visit to discuss appropriate accommodations for wheelchair accessibility
- A driving assessment if appropriate
- The prescription of appropriate mobility equipment according to the patient's needs
- Peer counselling and support

On completion of the program the majority of patients are discharged to their homes which are mostly situated in the urban areas of Johannesburg.

The overall aim of the rehabilitation program for patients with paraplegia at NRH is to ensure that the patient achieves physical independence using a wheelchair and to prepare the patient for integration back into his/her community. While there is some emphasis on preparing the patient for participation and social roles the bulk of the program is impairment and activity focused and it is unsure if the program achieves its overall aim as stated above. The program does not assist the patients after discharge from hospital with the actual community reintegration process. It seems that the reason for this, as observed by the researcher, is mostly a lack of funding as no medical aid is prepared to pay for an extensive integration program or even vocational rehabilitation to ensure that the patient can return to meaningful employment. There are also very few CBR programs in the community to which patients can be referred for facilitation of the integration process. This means that on discharge, even though the patients might be physically independent, they are left to reintegrate into their communities by themselves. Furthermore, NRH does not provide a follow-up service and patients are advised to visit their general practitioner

for medical follow-up. Currently it is unknown what percentage of the patients fully and successfully reintegrated into their communities after discharge from hospital as no survey on this has been done since the start of the rehabilitation program at NRH in 1999.

That the emphasis of the rehabilitation program is on activities is further illustrated by the fact that the Functional Independence Measure (FIM), an activity measure, is the rehabilitation outcome measure currently in use in the program. From the FIM scores the team usually knows when a patient is independent in the activities as outlined by the Consortium for Spinal Cord Medicine in the USA (1999), but the FIM does not measure whether the patient has the knowledge to take care of his/her own health and prevent secondary complications, is equipped to face the many contextual barriers at home and in the community and is ready to reintegrate into his/her community.

Another worrying aspect of the rehabilitation program at NRH is that in the opinion of the researcher it is based on the medical model of disability. The rehabilitation process is driven by the service providers and disability is seen as a personal tragedy which should be cured or corrected and the person assisted to fit into society. Patients and families are not included in decisions regarding their treatment. While some moves have been made towards the inclusion of the patient in the planning of their rehabilitation at NRH i.e. including the patient and family in the goal-setting process, on the whole the program is still driven by the professionals. Therefore health issues are treated in isolation with little or no attention being given to other areas such as education, social circumstances and societal barriers that prevent inclusion and full integration into the community. Disability is not seen as a human rights issue and disabled people do not determine priorities and policy with regard to rehabilitation services at NRH as they should according to the social model of disability (Office of the Deputy President 1997). Through this study the researcher wants to emphasise these areas of omission and raise awareness within the rehabilitation team with regard to their importance in terms of community integration. If these aspects are not taken into account and addressed where necessary during rehabilitation, people with spinal cord injuries are unlikely to manage their own health

and wellness (prevent secondary complications etc.), reach their full potential and actively participate in their communities.

Another important factor in the rehabilitation of SCI patients is the increased lengths of stay compared to other types of rehabilitation patients and this has proven to be a challenge to the current system of reimbursement for medical services (Burnett, Cifu, Kolakowski-Hayner & Kreutzer 2001). With the escalating cost of health care came the need to justify the expenditure associated with rehabilitation through the use of measuring instruments that can indicate gains that will impact on the person's ability to perform his/her social roles. At NRH the funders (mostly medical aids) demand a weekly comprehensive progress report accompanied by scores from an outcome measure, in this case the FIM, to justify the length of hospital stay of the SCI patient.

Therefore rehabilitation programs, and in this instance more specifically spinal cord rehabilitation programs, need accurate methods of measuring improvement of human function over a reasonable period of time. Outcome management and measurement among individual service providers could serve to establish their basic credibility with payers and justify the payment for rehabilitation. Specific outcome management can assist service providers and in this case NRH to demonstrate to funders that although the cost of rehabilitation is high, the outcomes are superior as well (Landrum et al 1995; Cole, Finch, Gowland & Mayo 1994) and that outcome-oriented rehabilitation ensures a comprehensive, patient-focused service and cost-containment. In essence, the identification of a successful outcome justifies the rehabilitation professional's existence (Landrum et al 1995). An essential part of this move toward outcome oriented rehabilitation is outcome measurement and measuring the effectiveness of the rehabilitation program.

According to Kendall (1997) what one measures depends on the objectives of the program and why one is interested in comparing these over a period of time. If one is interested in measuring the effectiveness and efficiency of the service provided, then one must look for outcome measures that will measure that concept accurately. For the

current study the aim was to evaluate the outcome of the rehabilitation program for individuals with complete thoracic spinal cord lesions (complete paraplegia).

Effectiveness of a program has many facets e.g. patient satisfaction, functional outcome, successful community integration, whether patient's needs are met, cost effectiveness, personnel satisfaction etc. Within the limitations of this study the researcher has decided to concentrate on only two aspects of effectiveness i.e. the traditional physical independence and the preparation of the patient for community reintegration. For this reason the Functional Independence Measure and the Needs Assessment Checklist were selected as the measuring instruments in this study as these measured the independence of physical activities as well as the patient's opinion on how well the rehabilitation program prepared them for community integration.

1.2 Study problem

When the researcher, a physiotherapist at NRH, observed and analysed the rehabilitation program for patients with complete spinal cord lesions between T1 and T12 at Netcare Rehabilitation Hospital, the following questions arose:

- Is the program effective in terms of patient expectations (are the needs of the patients being met?)
- Do the patients achieve their optimal physical independence during the rehabilitation phase?
- Is the length of stay in hospital for rehabilitation justified?
- Is the maximum FIM score an indication that the person is ready for discharge from the hospital?
- Can this FIM score be seen as an indication that the patient's needs in terms of his/her rehabilitation have been met?
- Would another measurement tool, apart from the FIM, provide more reliable information on necessary length of stay and program effectiveness in terms of the patient's needs?

Currently the health professionals at Netcare Rehabilitation Hospital have no proof that the rehabilitation program for patients with complete paraplegia is meeting the needs of

the patient and that the outcome is justifying the length of stay and thus the funding thereof. Therefore the rehabilitation program needs to be evaluated in terms of the above questions. Findings must be incorporated into the program to ensure constant growth and improvement. Only when there is proof that the program is effective in terms of achieving optimal physical independence as preparation for successful reintegration back into the community, can the health care professionals justify the length of hospital stay, the costs of the rehabilitation and motivate the funding thereof.

The FIM instrument is the only rehabilitation outcome measuring instrument currently in use at the Netcare Rehabilitation Hospital. It is a task-oriented, objective activity measure. It does not indicate whether the needs of patients are met during the rehabilitation program and whether the patients are prepared for re-entry into the community. It is thus necessary to compare it to an outcome scale that is patient-oriented, and includes areas of community and social functioning such as the Needs Assessment Checklist. This is necessary as the researcher had observed that those patients with complete paraplegia achieve a high FIM score fairly quickly. This observation was confirmed by therapists at NRH. However, the patient is then not yet fully rehabilitated and often does not have a clear understanding about his condition, because only general functional activities have been addressed as the FIM only focuses on activities. It is therefore advisable to assess and compare findings from the FIM with another outcome measure to determine the usefulness of the FIM score in determining patient readiness for discharge.

1.3 Motivation

Traditionally rehabilitation treatment started with an evaluation and ended when the patient reached the highest possible level of physical independence. Time and cost was often not considered. Each discipline (medical, nursing, physiotherapy, occupational therapy and psychology) evaluated the patient, and performed standardized and non-standardized assessments of their choice. Therapists from each discipline set goals separately and the patient's ability to function within their own environment was frequently not assessed (Dittmars & Gresham 1997). Consideration of the patient's goals

and the intended outcome are addressed toward the middle or the end of the treatment program, if at all. This is all due in part to the medical model of rehabilitation, which is a model of cause, pathology and manifestation of disease and is generally considered to be limited to identification of characteristics of disease, rather than function (Dittmars & Gresham 1997).

An example is the rehabilitation program at NRH that was initiated in 1999 and has never been evaluated for effectiveness. Currently it is unknown if the patients reach optimal physical independence, if their needs are met and if the program is preparing the patients to be able to reintegrate into their own environments after discharge from hospital. Thus the study aims to determine the effectiveness of the program through measuring the patients' physical outcome at the termination of rehabilitation, as measured by the FIM and to measure whether the needs of the patients were met during rehabilitation, as measured by the NAC and thus how well they have been prepared for community integration by the program.

Furthermore, the rehabilitation team at NRH is experiencing that health care funders are dictating to the health care workers at NRH what length of stay they are willing to pay for, without considering patient outcome on termination of rehabilitation. This payer driven system is not to the advantage of the patient as the rehabilitation team is observing that the length of stay is not an indicator that needs have been met or that rehabilitation has been completed successfully. Hence it is becoming more and more important to use mutually acceptable outcome measures to ensure adequate funding until the patient has been rehabilitated optimally. With this study the potential of the Needs Assessment Checklist to be that instrument will be in part assessed.

1.4 Significance

The patient should receive maximum benefit from the rehabilitation program. Therefore, the objectives of the rehabilitation program at NRH are to enable the patient to be physically independent, to meet the needs of the patient and to prepare him/her to integrate back into society after discharge from hospital. Rehabilitation programs should

be constantly monitored and assessed by means of using outcome measures to establish whether the program succeeds in its aims. Currently this monitoring process is lacking at NRH. With this study the current program at NRH will be assessed to determine if it reached its objectives. The results of the FIM scores will be analysed to determine if patients are physically independent on discharge and the NAC is introduced to determine if the program addresses the needs of the patients and prepares them for social integration. Results will provide program managers with the necessary information to determine how well the program is functioning and also with information on which aspects of the program can be improved.

Thus feedback from the study could lead to program improvement with a resultant better service to the patient and improved patient outcomes.

Proven program efficiency and the ability to accurately predict the physical outcome of rehabilitation for people with spinal cord injury will assist with securing adequate funding for rehabilitation, as the medical insurance companies can authorise patient's rehabilitation time in hospital based on an outcome scale that shows the patient's improvement.

An effective rehabilitation program that meets the needs of the patients will diminish their risk for developing costly complications. Not only will this improve the patients' quality of life, but it will have a positive economic impact on the patients and employers as well as health care funders whose long-term costs would be minimized.

Should it be proven by clinical research that the rehabilitation program, as it is offered at Netcare Rehabilitation Hospital, is effective, it will establish NRH as a credible provider of a rehabilitation program for spinal cord injured patients with the medical insurance companies.

In the field of rehabilitation, development and refinement of reliable, valid, user-friendly, standardised rating scales are of major importance for quantitative evaluation of function,

for setting treatment goals and for monitoring the achievements of therapy (Catz, Itzkovitz, Steinberg, Philo, Ring, Ronen, Spasser, Gepstein & Tamir 2001). This study might also assist to establish whether the NAC is an appropriate outcome measure to evaluate the rehabilitation program for complete paraplegics at NRH as well as other settings.

1.5 Summary

Spinal cord injury is a devastating cause of disability which has an impact on the patient's physical, social and vocational roles. Rehabilitation for patients with SCI should be a goal-oriented and time-limited process and should address physical, psychological, social and vocational needs of the patient to prepare the patient to reintegrate successfully back into society. The rehabilitation program should also be coordinated, comprehensive and cost-effective. Currently rehabilitation programs for persons with SCI, like the one at NRH, focus to a large extent on physical independence, while other aspects necessary to facilitate community integration are often neglected. Therefore this study evolved to assess the effectiveness of the rehabilitation program for complete paraplegics, in terms of physical independence and preparation of the patient for reintegration into the community at Netcare Rehabilitation Hospital, using two outcome measures, the FIM to measure independence of physical activities, and the NAC, to measure the readiness of patients to reintegrate into the community.

CHAPTER 2

LITERATURE REVIEW

2.1 Introduction

In order to determine the effectiveness of a program as the researcher aims to do, it is necessary to have an understanding of the physical disability that the rehabilitation program is aimed at, the rehabilitation program being evaluated and other programs with similar objectives, the program effectiveness as well as ways of measuring effectiveness. Therefore these issues will be discussed in this literature review.

2.2 Spinal cord injuries

Damage to the spinal cord can occur if the blood supply is cut off, or if it is bruised by a bone fragment, or if it is crushed or severed (Eng & Millar 2008).

Persons with spinal cord lesions are confronted with motor and sensory impairments as well as bladder and bowel dysfunction, which cause activity limitations and participation restrictions. The nature and severity of activity limitations and participation restrictions are dependent on the severity and site of the lesion as well as the person's social roles and contextual factors (McKinley, Santos, Meade & Brooke 2007). In addition to the loss of sensation and motor function, individuals with a spinal cord injury (SCI) also experience other signs and symptoms that will lead to impairments which may affect them e.g. presence of pain, sexual dysfunction, gastro-intestinal problems, poor temperature and blood pressure regulation as well as decreased respiratory function. Numerous secondary complications may arise from SCI including deep vein thrombosis, heterotrophic ossification, pressure ulcers and spasticity (Eng & Miller 2008).

To put the effect of these impairments and complications on disability and function into perspective it is necessary to picture them within a larger framework that incorporates both the person's social roles and contextual barriers and facilitators. Such a conceptual framework is provided by the World Health Organization's International Classification of

Functioning, Disability and Health (ICF) (WHO 2000). As is shown in Figure 2.1 every one of these domains can influence the other domains. It is important to notice that there is no linear relationship between domains and that one might exist in isolation of the others.

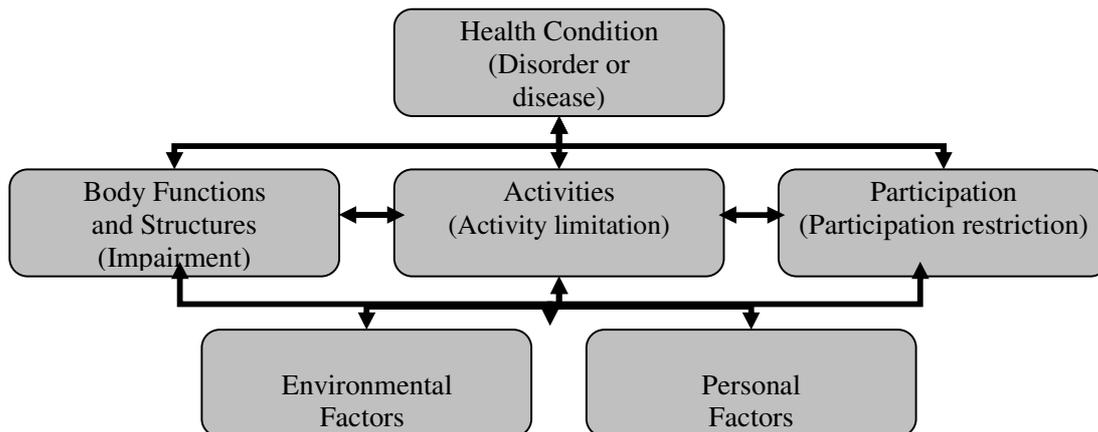


Fig 2.1 Overview of the interaction between the different domains of the International Classification of Function, Disability and Health (ICF)

With an impairment such as loss of motor function, as caused by SCI, the activity of walking is completely compromised, which means that the person is dependent on a wheelchair for mobility, in which case an environmental barrier like stairs at the entrance to the person's site of employment can cause a complete participation restriction in the area of employment. SCI often results in severe impairments which usually cause severe participation restrictions especially in the lives of persons where contextual barriers such as poverty, poor educational levels, poor infrastructure and poor access to health services are common.

2.2.1 Epidemiology

There are numerous causes for spinal cord lesions. These can be categorised as either traumatic (e.g. motor vehicle accidents, falls, violent incidents and sports injuries) or non-

traumatic (e.g. tumours, spinal stenosis or vascular incidents). For this study the researcher focused on patients with traumatic spinal cord injuries. Traumatic SCI are more common than non-traumatic ones. Eng et al (2008) reports from Canada that 81% of all SCI are traumatic in origin, while in Germany 75% of SCI results from trauma (Exner & Meinecke 1997), and in the Netherlands 48% (Schönherr, Groothoff, Mulder and Eisma 1999).

In the USA it is estimated that the annual incidence of spinal cord injury is approximately 40 per million with approximately 11 000 new cases each year of which 69% can be attributed to traumatic incidents (McKinley et al 2007).

The Quadpara Association of South Africa estimates a total of 400-500 new SCI individuals per year (Gore 2006). Unfortunately no prevalence figures are available for South Africa. Hart (2000) reports in a study done over an eleven year period that 90% of new spinal cord injuries are related to trauma while a statement in the South African Parliament by Mr V C Gore on 19 September 2006 reads as follows: “According to the Quadpara Association of South Africa, South African roads produce an average of 200 quadriplegics and paraplegics per annum (50% of all traumatic spinal cord injuries in SA)” (Gore 2006). Motor vehicle accidents thus seem to be the major cause of traumatic SCI in both South Africa as well as the rest of the world (Blackwell, Krause, Winkler & Stiens 2001). Schönherr et al (1999) reports a 20% incidence of industrial accidents causing SCI in the USA.

SCI can affect people from all walks of life. Males are more commonly affected with males accounting for almost 77% of the total SCI population (McKinley et al 2007; Eng & Miller 2008). Furthermore people of all ages are at risk for SCI, but the highest risk is in the young adult population with the average age at the time of the injury being 38 (McKinley et al 2007).

2.2.2 Classification of spinal cord injury

Internationally SCI are classified according to the American Spinal Injury Association (ASIA) International Standards for Neurological Classification of Spinal Cord Injury (American Spinal Cord Injury Association 2002). The ASIA Impairment Scale (AIS) is a five category scale (Table 2.1.)

Completeness of the injury is based on these ASIA standards where the absence of sensory and motor functions in the lowest sacral segments indicates a complete lesion and is classified as an ASIA A (American Spinal Cord Injury Association 2002).

Table 2.1. ASIA Impairment scale (AIS) (American Spinal Cord Injury Association 2002)

ASIA A	Complete injury where no sensory or motor function is preserved in sacral segments S4-S5
ASIA B	Incomplete injury where sensory, but no motor, function is preserved below the neurological level and extends through sacral segments S4-S5
ASIA C	Incomplete injury where motor function is preserved below the neurological level, and most key muscles below the neurological level have muscle grade less than 3 (active full-range movement against gravity)
ASIA D	Incomplete injury where motor function is preserved below the neurological level, and most key muscles below the neurological level have muscle grade greater than or equal to 3
ASIA E	Normal sensory and motor functions

Most patients make significant functional gains during in-patient rehabilitation but those patients diagnosed as ASIA A on admission are known to make the least functional gains (Waters, Yakura, Adkins & Sie 1992). Waters et al (1992) further reported that 73% of patients diagnosed on admission to hospital with complete paraplegia (paralysis from the chest down) will remain neurologically at an ASIA A level and will not show any neurological recovery one year post-injury.

2.2.3 Outcome following spinal cord injury

Comprehensive in-patient rehabilitation post spinal cord injury is crucial to prevent complications and an early death as well as to assist with community reintegration which is generally considered as the ultimate goal of in-patient rehabilitation for SCI individuals

(Schönherr et al 1999). Going home is a goal frequently established by newly admitted patients and Eng & Miller (2008) has found that 73% of all SCI patients in the USA will return home after rehabilitation.

A summary of the literature available on reintegration into the community after SCI describes three major dimensions of community integration (Boschen, Miller, Noreau, Wolfe, McColl, Ginis, Martin, Prince, Joe & Konnyu 2008). The first dimension involves basic requirements to be discharged from rehabilitation and includes primary health care, housing and income support. The second dimension involves personal maintenance requirements (to remain active in the community) and includes transportation, employment, education, sport and recreation. The last dimension, that of self-actualisation requirements (to claim an identity in the community) includes family adjustment, effective counselling, peer mentoring and social policies (Boschen et al 2008).

In terms of primary health care the first year post-injury is significant for survival as hospital readmission occurs frequently during this year with the most common causes for readmission being urinary tract infections, pressure ulcers, respiratory infections and musculoskeletal problems (Cardenas, Hoffman, Kirshblum, McKinley 2004). According to a multicenter study done in the USA, 55% of all SCI patients were readmitted within the first year post- injury with the above-mentioned complications (Cardenas et al 2004). According to Donnelly, McColl, Charlifue, Glass, O'Brien and Savic (2007) most persons with SCI receive primary care from their general practitioner after discharge from hospital, but in reality their needs in terms of health care are unmet as there is a lack of knowledge among the general practitioners about SCI. This is a contributing factor in the high percentage of secondary complications and readmissions (Donnelly et al 2007). Access to appropriate primary health care is one of the basic requirements to integrate successfully into the community according to Donnelly et al (2007).

Similarly at Netcare Rehabilitation Hospital SCI patients are referred to their general practitioners for health related problems after discharge from hospital and as the hospital

is only a rehabilitation facility, patients often do not get readmitted with complications to the hospital, but are admitted to an acute care private hospital. Thus there are currently no statistics available to determine what percentage of NRH patients get readmitted with complications. Furthermore, the researcher could find no statistics on the incidence or prevalence of secondary complications in the SCI population of South Africa.

The lack of statistics give rise to concern as the United Kingdom's National Spinal Cord Injury Statistical Centre (NSCISC 2004) reports that life expectancy after SCI is reduced and a 40 year old paraplegic who has survived one year post-injury has a life expectancy of ten years less than a person without a spinal cord injury.

Another of the basic requirements when considering community reintegration is accessible housing. In South Africa private housing is exempt from building regulations with regards to wheelchair accessibility and thus private houses are seldom accessible. Structural and other changes to houses, flats etc to make them accessible is often time consuming and expensive. That, in combination with the demand from medical aids to decrease length of in-patient hospitalisation, possibly causes a large percentage of SCI patients to be discharged to inappropriate housing arrangements that may have a negative impact on their reintegration either temporarily or long-term (Forrest & Gombas 1995).

As the full vision of community reintegration is not only to live in the community, but to be an integral part of it, successful reintegration relies on financial resources (Boschen et al 2008). These resources for the patient population from NRH usually come from insurance coverage, pension funds, savings, disability grants or employment. With the high percentage of unemployment of disabled people in South Africa, 99% according to the Integrated National Disability Strategy (INDS) (Office of the Deputy President 1997), it can be assumed that SCI patients' income is mostly from disability grants or the workman's compensation fund if they were injured while working.

As the majority of patients with traumatic SCI are young adults, return to work or school is extremely important, but in a survey in Canada among SCI patients in the first five

years post injury, 62% were unemployed (Canadian Paraplegic Association 1997). The same survey found that only 14% of patients are employed within three to six months of injury and that the level of education is a key factor in re-employment as a change in vocation is often necessary for meaningful employment after SCI. With 62% unemployment in a first world country like Canada it is clear that reintegration into the community is not optimal.

According to Jongbloed, Backman, Forwell & Carpenter (2007) the importance of returning to work has been recognised by Guttman as early as 1959 and since then many international studies have focused on identifying the factors that play a role in successful return to meaningful employment (Jongbloed et al 2007).

These factors can be categorised as follows:

- Demographic: age, gender
- Health or injury-related: level of lesion, secondary complications
- Pre-injury situation: education, type of work
- Post-injury opportunities: vocational counselling, job retraining, social support
- Physical environment: workplace accessibility, transportation

An accessible infrastructure and disability support were named as the two major areas that would improve the rate of employment (Rick Hanson Men in Motion Foundation 2004).

Unfortunately there are no comparative statistics available for South Africa, but according to the INDS it is estimated that 99% of disabled people are excluded from employment on the open labour market (Office of the Deputy President 1997).

The INDS (Office of the Deputy President 1997) points out that unemployment remains a fundamental problem affecting the majority of people with disabilities and their families. The government has undertaken a number of initiatives since 1994. These include introducing the new Labour Relations Act (1997) which provides some protection for both employees and job-seekers against unfair discrimination on the basis of their disability, particularly in the areas of unfair dismissal and hiring practices. The weakness of the Labour Relations Act lies, however, in the fact that this provision is not

enforceable, but rather provides employers and the courts with guidelines for appropriate practice (Office of the Deputy President 1997). The Employment Equity Act (1997) seeks to eliminate all forms of discrimination. Together with the Act there is a Code of good practice which is a guide for employers, employees (both applicants and existing employees) and trade unions on promoting equal opportunities and fair treatment for people with disabilities. Despite these documents, a study done by Global Business Solutions of over 100 large and small companies covering more than 150 000 employees found that less than 1% of the total workforce in South Africa is reported as having disabilities. Only 0.35% of new appointments appear to have been of people with disabilities (Global Business Solutions 2001).

For individuals with SCI to fully participate in the community it is vital for them to be able to travel between locations in the community. Transportation can include ambulation (walk or wheelchair), driving an adapted motor vehicle or public transportation (bus, taxi, train, plane) (Wehman, Wilson, Targett, West, Bricout & McKinley 1999). These authors report that due to the inability to walk, many individuals with SCI find it extremely difficult to travel in their communities and are often homebound, a factor that makes community reintegration including meaningful employment, impossible.

According to the INDS (Office of the Deputy President 1997) there is a need for rapid progress in developing a public transport system in South Africa that is flexible and accessible to people with disabilities. Transport for people with disabilities is currently largely restricted to those who are either associated with a social service agency (i.e. predominantly in the urban areas), or those who are able and can afford to drive modified private vehicles or employ the services of a chauffeur. In rural areas minibus taxis are the major mode of transport and the researcher had observed that while a person can be lifted into a minibus taxi for transport, the driver will charge an extra fee to transport the wheelchair as well.

Even though the INDS (Office of the Deputy President 1997) describes accessible transport as a human rights issue it also points out that the lack of accessible transport in

South Africa is still a serious barrier to the full integration into society of people with disabilities as the ability to use services or attend school or work, is largely dependent on the ability of people to get there. Even the proposed Gautrain, currently under construction between Pretoria and Johannesburg with the aim to provide transport to the daily commuters between the two cities, will not be accessible to wheelchair users according to their website (www.gautrain.co.za).

According to Boschen et al (2008) family adjustment also plays a significant role in the third dimension i.e. claiming an identity in the community. It is well known that family members require individualized support especially early on in the rehabilitation process to minimize unrealistic expectations and any misunderstandings regarding the consequences of SCI to ensure adequate support for the SCI patient. The family needs to feel effectively prepared for and involved in the treatment and especially the discharge planning process for successful integration of the SCI patient after discharge from hospital (Boschen et al 2008).

Together with the family support as part of reintegration, Boschen et al (2008) also advocate a peer support program in the community. Peer mentoring is being proposed as an effective liaison between rehabilitation and community integration by providing information, support and other resources. It is thought by Eckenrode & Hamilton (2000) that receiving support from a peer rather than a family member may provide a unique experience in the rehabilitation phase.

Another factor in this dimension is the existence of certain social policies in the country. Social policy is intimately linked to community reintegration as it provides the platform that can act as an enabler or barrier to reintegration for individuals with SCI (Boschen et al 2008). The INDS (Office of the Deputy President 1997) could be seen as such a policy for South Africa which supposedly is acting as an enabler to assist in facilitating community reintegration. There is, however, no evidence to determine the stage of implementation of the recommendations of the INDS (Office of the Deputy President 1997) that has been reached.

Another example of a policy which should be providing a strong platform for reintegration is the National Rehabilitation Policy, launched in 2000, which is intended to facilitate the establishment and the strengthening of rehabilitation services in the country. The policy provides for the whole spectrum of rehabilitation services, from community-based services to tertiary institution based rehabilitation services (Department of Health 2000).

2.3 Rehabilitation

The purpose of rehabilitation is to maximise an individual's physical, psychological and social potential in order to achieve previously held life goals. It should assist individuals to achieve an optimal independent and satisfying lifestyle in their own community (Schönherr et al 1999). The World Health Organization (WHO) emphasises above points in their definition which states that rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation must provide disabled people with the tools they need to attain independence and self-determination (WHO 2000).

Rehabilitation for SCI individuals is mostly done in institutions such as tertiary hospitals and rehabilitation centres as it is highly specialised. Donovan, Carter, Bedbrook, Young & Griffiths (1984) advocate that the best practice for SCI rehabilitation is an integrated, comprehensive system where expertise, facilities and equipment are focused on optimal patient care and cost-effectiveness, a fact that is still relevant today. They condemn the situation where SCI care is done in a general setting where the occasional patient is treated by the occasional doctor. Both Donovan et al (1984) and Smith (2002) found in respective studies that the most common complications in SCI patients were lowest when SCI patients were admitted early to specialized centres. The fact that was most striking was the absence of pressure sores in those individuals admitted to specialized centres versus the progressively greater incidence for those admitted to general care.

Webster and Kennedy (2007), also state that rehabilitation programs must focus on reducing medical complications, achieving functional independence, preparing for work, enabling and encouraging community participation and facilitation of ongoing personal relationships.

In South Africa SCI patients are treated in specialized centres which are mostly found in metropolitan areas, but patients from rural areas are often treated in general hospitals as there is no specialised care available in these areas. The Department of Health in South Africa emphasizes this in a document stating that the treatment of SCI injury begins at the outset and ideally these patients should be transferred to specialized centres geared up to manage spinal trauma. Morbidity (further injury to the spinal cord, pressure sores, pneumonia and urinary tract infections) will be reduced and so will the mortality and thus in the long term there will be money saved which would normally be used to treat complications related to inadequate care (www.doh.gov.za/mts/reports/spinal.html).

A further aspect of rehabilitation is Community Based Rehabilitation (CBR) as advocated by the World Health Organisation (WHO) and is defined as a strategy within the general community development for the rehabilitation, equalization of opportunities and social inclusion of all people with disabilities (WHO 2004). CBR can play a huge role in community reintegration after the SCI patient is discharged from hospital. However, CBR is not fully operational in South Africa and existing programs are too few and too scattered to comprehensively address the need of persons with SCI in the community.

According to Landrum et al (1995) rehabilitation services should ideally be provided along a continuum of care from entry into the health care system directly post injury through to community integration. Landrum et al (1995) describe six levels of outcome in the rehabilitation process which must be achieved along the continuum of care. These outcome levels represent the basic domains that patients include in their lives, such as health, personal maintenance, home management, community activities and productivity. The levels are summarized in Table 2.2.

Table 2.2. Levels of outcome in rehabilitation (Landrum et al 1995)

0	Physiologic instability	Immediately after onset of injury or illness when there are unmanaged medical diagnostic and management problems which need care in an acute care setting.
1	Physiologic stability	First and most basic outcome level, all major medical and physiological problems addressed and appropriately managed.
2	Physiologic maintenance	The achievement of preservation of immediate and long-term physiologic health.
3	Residential reintegration	Achievement of proficiency in self-care, mobility, communication, safety and home management to function in a residential setting.
4	Community reintegration	Achievement of an appropriate level of function within the community. Includes self-management, social competencies, community mobility, complex home-making capabilities, financial management, self-directed health monitoring and recreation.
5	Productive activity	Establishment of the individual in productive activities within his/her capacity may involve vocational, avocational or educational pursuits.

The Western Cape Health Plan 2010 has integrated these mentioned levels of outcome into the various service provision settings as follows:

- Levels 0-2 are usually achieved in acute hospitals
- Level 3 is usually achieved through in- or out-patient rehabilitation
- Levels 4-5 are usually achieved through community based rehabilitation (WCHP 2010, 2007).

During acute care and in-patient rehabilitation patients participate in an intensive full day program focusing on physical independence which usually includes nursing, physiotherapy, occupational therapy, respiratory management, medical management, recreation and leisure, psychology, vocational counselling, driving training, assistive device prescription, nutritional services, sexual health counselling and pharmaceutical services (Eng et al 2008), in order to achieve outcome levels 0-3. The rehabilitation

program usually continues with planning for discharge back to the community and reintegration into activities in the community (Eng et al 2008), i.e. achieving outcome levels 4-5.

According to the INDS (Office of the Deputy President 1997) rehabilitation services have traditionally been neglected in South Africa. The INDS states that access to appropriate rehabilitation services can make the difference between leading an isolated and economically dependent life and leading an economically independent life and playing an active role in society (Office of the Deputy President 1997). The INDS states that this goal must be reflected in policy on rehabilitation with the main policy objectives as follows:

1. to enable people with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric, and/or social functional levels;
2. to provide people with disabilities with the tools to change their lives and to give them a greater degree of independence;
3. to prevent secondary disabilities or to reduce the extent of disability;
4. to take into account the specific needs of different disability groupings. (Office of the Deputy President 1997)

As mentioned before, and after screening the website of the Department of Health in South Africa for reports on the implementation and status of the INDS (Office of the Deputy President 1997), there is a lack of evidence in the available literature in South Africa to determine how well these objectives have been implemented.

To create successful rehabilitation programs for SCI patients the programs should be based on holistic goals. In the literature much attention has been paid to the neurological outcome and physical independence after SCI. The degree of functional independence, including physical, social and psychological improvement however, is more relevant in predicting rehabilitation outcome and these aspects are often neglected (Schönherr et al 1999).

Similarly the INDS (Office of the Deputy President 1997) states further that rehabilitation is a cross-sectoral issue. Major stakeholders are Health, Welfare, Education and Labour, together with Disabled Peoples Organisations (DPO) and Non-Governmental Organisations (NGO). Services should be developed in collaboration with all relevant sectors. Currently intersectoral collaboration is still poor. Since 1996 the private health industry has joined the public sector in developing and providing rehabilitation for the physically disabled in South Africa. According to the website of the Southern African Spinal Cord Association there are currently eleven private facilities and twelve public facilities in South Africa providing specialised rehabilitation for individuals with SCI (SASCA 2009).

The Southern African Spinal Cord Association (SASCA) was formed in 1993 and is affiliated with the International Spinal Cord Society (ISCoS). SASCA sees its role to provide information to health care professionals and policy makers, promote the treatment and rehabilitation of the spinal cord injured, and network with governmental and non-governmental organizations, academic institutions and other service providers. This is an organization which is attempting to bridge the gap between public and private rehabilitation services in South Africa, enhance communication and collaboration between rehabilitation providers, government departments and non-governmental organizations. The association also seeks to ensure adequate rehabilitation programs for SCI patients in South Africa by hosting basic and advanced workshops in SCI rehabilitation every year and a scientific congress every second year which provide opportunity for health care professionals and the disabled community to report on the progress and advances made in SCI rehabilitation in South Africa. Unfortunately no documented evidence of the progress of collaboration in the past ten years could be found.

2.3.1 Rehabilitation programs for SCI patients

SCI rehabilitation involves a multitude of services and health professionals and is initiated in the acute phase and continues with extensive and specialised in-patient services during the sub-acute phase. As a patient with a newly-acquired SCI has lost the ability to feel, move, control bladder and bowel function and in general to take care of

him/herself, in-patient rehabilitation is an important stepping stone towards regaining and learning new skills for independent living (Eng et al 2008).

Finding specific descriptions of rehabilitation programs for persons with SCI in the literature proved to be difficult. There are, however, examples of what should be included in the rehabilitation program for spinal cord injured patients to be found on websites of rehabilitation centres. One such an example is found on the website of the University of Virginia, USA and is summarised by the researcher in Table 2.3 (University of Virginia Health System. Physical Medicine and Rehabilitation, 2008).

Table 2.3. Rehabilitation program for SCI

Patient need:	Example:
Self-care skills, including activities of daily living (ADLs)	Feeding, grooming, bathing, dressing, toileting, and sexual functioning
Physical care	Support of heart and lung function, nutritional needs, and skin care
Mobility skills	Walking, transfers, and self-propelling a wheelchair
Communication skills	Speech, writing, and alternative methods of communication
Socialization skills	Interacting with others at home and within the community
Vocational training	Work-related skills
Psychological counselling	Identifying problems and solutions for thinking, behavioral, and emotional issues
Family support	Assistance with adapting to lifestyle changes, financial concerns, and discharge planning
Education	Patient and family education and training about SCI, home care needs, and adaptive techniques

Another example of an SCI rehabilitation program is found on the website of the Mount Sinai Spinal Cord Injury Model System (www.mssm.edu/rehab/spinal). Their program includes:

- A team of dedicated professionals with expertise in all aspects of medical, surgical, and rehabilitative care of patients with all types of SCI,
- State-of-the-art in-patient rehabilitation facility with all therapy areas.
- Comprehensive in-patient rehabilitation therapies six days a week that emphasize individual treatment as well as group sessions
- Extensive educational classes for individuals with SCI and their families
- Peer support and mentoring program
- Five day a week out-patient day program (Do It!) designed to facilitate community reintegration
- Spasticity management with a variety of oral medications, botulinum toxin injections and intrathecal baclofen therapy
- Neuro-urological evaluations and management of neurogenic bladder
- Pressure ulcer management, including reconstructive surgery

Similarly the Spaulding Rehabilitation Hospital, Massachusetts, USA offers an SCI Rehabilitation Program which is individualized and adjusted to each patient's needs. Patients can receive from three to five hours of individual and group therapy five to six times per week.

The SCI Rehabilitation Program at Spaulding includes the following services:

- Intensive medical management
- Physiotherapy, Occupational Therapy and Speech Therapy
- Spasticity management
- Wound care management
- Urological management
- Psychological counselling
- Sexual counselling

- Pain management
- Interdisciplinary educational classes and support groups
- Peer visitor program. (www.spauldingrehab.org)

The above are general programs used in most rehabilitation facilities where patients with spinal cord injuries are being treated. When interviewed on 3 September 2008 both Dr R Campbell, Medical Director at Aurora Hospital, Port Elizabeth and Dr Lisa Harvey, from the Rehabilitation Studies Unit, University of Sydney, Australia, confirmed that their institutions follow the same outline of rehabilitation as mentioned in Table 2.1.

The Aurora Hospital is a private rehabilitation facility in South Africa just like Netcare Rehabilitation Hospital and uses the Rehabilitation Outcomes Measuring System (ROMS) as an outcome measure for their rehabilitation program. ROMS is a newly developed outcomes measuring scale based on the ICF on which there is currently no literature available.

It was highlighted in the above conversations that private rehabilitation facilities in South Africa follow a general rehabilitation outline as is found in the literature and that the rehabilitation units make use of outcome measurements to assess the effectiveness of their rehabilitation programs. However no published results on this could be found.

Similarly at Netcare Rehabilitation Hospital the SCI rehabilitation program includes the following:

- Medical care provided by two general practitioners and two neurologists
- Physiotherapy, Occupational therapy and Speech therapy providing five hours per day of individual and group therapy on an in-patient or out-patient basis
- Psychological counselling provided by the team of social workers and psychologists
- Urological management
- Spasticity and pain management
- Wound care management
- A comprehensive, interdisciplinary educational program for in-patients as well as their families including a peer support program

- Prescription of mobility equipment supported by a seating clinic with pressure mapping
- Discharge planning

When comparing the outline of the program at NRH with that found in the literature it is evident that the programs are on par and that the program at NRH covers all aspects of in-patient rehabilitation for SCI patients. Referring back to the outcome levels as described by Landrum et al (1995) and the Western Cape Health Plan 2010, the rehabilitation process in most of the examples mentioned as well as NRH focus on achieving levels 0-3 only by the time the patients are discharged from hospital. It is however observed that the community based rehabilitation necessary to achieve the final levels of outcome, namely community integration and productive activity are not yet in place in for patients from NRH. Therefore it is questionable if the process of community rehabilitation is successfully implemented.

In summary, if one looks at the dimensions needed for community reintegration it does seem that most programs, including the one from NRH, offer the basic requirements for discharge from hospital (maintaining good health and physical independence) but do not do well in preparing the patient to stay active in the community (use of transport, employment, etc) or assistance in claiming an identity in the community (family support, peer mentoring). The programs seem to be focused on assisting the patient to achieve physical independence in order to be discharged home and very few offer an ongoing program to assist with community reintegration.

This practice is in keeping with suggestions from Landrum et al 1995 and the Western Cape Health Plan 2010 which state that rehabilitation should be provided along a continuum of care and progress through six stages from physiological instability to productive activity. These authors propose that outcome levels one and two (physiologic stability and physiologic maintenance) are usually achieved in an acute care setting, while level three (residential integration is achieved during in-patient rehabilitation – as is done in the rehabilitation programs described above) and the final two levels i.e. community

integration and productive activity should ideally be achieved through community based rehabilitation while the person is already living in his/her home environment.

While these proposed guidelines are in line with the National Rehabilitation Plan (NRP) (Department of Health 2000) implementing it in SA is hampered by a severe shortage and overburdening of primary health care services to which CBR programs are mostly linked in SA. Therefore a situation has been created where specialised rehabilitation units provide what is often an excellent service which prepares the patient physically for discharge to his/her home environment, but neither the rehabilitation facility nor the community have programs in place to ensure progression through the final two phases to full integration and social participation.

Furthermore, very little is done to assess the effectiveness of rehabilitation programs at any of these levels of service provision.

2.4 Outcome measurement in rehabilitation programs

According to Cole et al (1994) an outcome measure is a measurement tool (instrument, rating form, or questionnaire) which is used to document change in one or more patient characteristics over time. It is an observation associated with a set time period. Outcome measures can be used to determine the impact of an overall treatment program on an individual or to assess treatment outcomes in conjunction with resources used in order to assess the effectiveness and efficiency of the service provided (Cole et al 1994).

Rehabilitation outcome measurement tools can be classified according to the ICF – see Figure 2.1 (WHO 2000). The advantages of using the ICF framework is that it is well recognised and used by the international community and it provides a standard language when discussing outcomes and other health related subjects (Salter, Jutai, Foley, Teasal 2005).

It is important to use suitable tools to measure outcome in rehabilitation and as the focus of in-patient rehabilitation for SCI patients at present at Netcare Rehabilitation Hospital is

centred on body functions, activities and participation, it is advisable to use a tool that will measure the outcome of these domains (Salter et al 2005). Within the ICF, activity is defined as the execution of a task or action by an individual, while participation is involvement in a life situation. Activity limitations therefore are difficulties an individual may have in executing activities and participation restrictions are problems an individual may have in involvement in life situations.

As patient outcomes will be measured in the hospital, which could be seen as a simulated environment, they may demonstrate the capacity to do the activities independently, but it is important to acknowledge the fact that patients may not have the ability to perform the same activities in their own environment. Therefore they may experience a participation restriction as it is described by the ICF (WHO 2000).

The activity and participation domains in the ICF are defined as learning and applying knowledge, completing general tasks and demands, communication, mobility and self-care, domestic life, interpersonal interactions and relationships, major life areas (e.g. education, employment, economic self-sufficiency) and community, social and civic life (e.g. recreation and leisure, religion and spirituality, human rights and political life and citizenship).

However, not all these aspects are covered in the in-patient rehabilitation program at NRH as outlined earlier in this chapter. Only learning and applying knowledge, completing general tasks and demands, mobility and self-care are included. Still the program states as an aim community integration of patients and therefore the outcome measures used in this study will focus both on measuring outcome in the activity domain and the participation domain as will be shown when discussing the outcome measurements used in this study in Sections 2.5.2 and 2.5.3.

Data collected through outcome measures can be used to evaluate the patients' progress and plan further treatment. It can also contribute to program evaluation by providing information regarding change between admission and discharge. Information gathered

through regular measurement can help to tailor rehabilitation programs to produce optimal results for patients in the most efficient way. Funds and other resources can also be allocated and utilised optimally (Cole et al 1994).

Thus on the level of individual patients, outcome measures ensure that management adhere to expected standards and, on a service level data from outcome measures can be used to justify the existence of the rehabilitation team to administrators and funding bodies (Cole et al 1994).

Outcome measurements are a way of assessing the quality of care and the data generated can be used to identify areas which need to be addressed to improve that care.

The above highlight the importance of the use of adequate outcome measures in the field of disability and rehabilitation to ensure that a rehabilitation program is achieving its goals.

2.4.1 Outcome measures

An adequate measuring system should be able to give information on efficiency, effectiveness and quality of the rehabilitation program it is being used for. In setting up a rehabilitation program the professionals need to focus on achieving the best results in the shortest possible time. Effectiveness is measured from two perspectives: improvement in status and prevention of further decline (Griffen 1995). A program is effective when meaningful change occurs. Efficiency, quality and effectiveness should be measured on an ongoing basis so that the results can be used to improve the service and motivate for resources (Martin & Kettner 1996).

In this study effectiveness of the program will be determined by the physical outcome of the patients who participate in the study, as well as through measuring if patients' needs have been met by the program.

Measuring instruments must also be assessed for usefulness and practicality in a setting by looking at certain characteristics like validity, reliability, responsiveness and feasibility (Martin & Kettner 1996).

Validity refers to the extent to which a measurement method measures what it is intended to measure. Thus validity depends to a large extent on the existence of a “gold standard” to provide a basis for comparison (Cole et al 1994). Reliability on the other hand, refers to the stability of a measuring instrument and how far it will give the same results when it is used on the same population in the same circumstances on separate occasions (Kendall 1997).

Responsiveness of the instrument is highlighted by the sensitivity to changes within patients over time (which might be indicative of therapeutic effects). Responsiveness is most commonly evaluated through correlation with changes in other scores, effect sizes, standardized response means, relative efficiency, sensitivity & specificity of change scores. Assessment of possible floor and ceiling effects is included as they indicate limits to the range of detectable change beyond which no further improvement or deterioration can be noted (Wade 2004).

Lastly, one should look at feasibility of the instrument which includes the extent of effort, burden, expense and disruption to staff/clinical care arising from the administration of the instrument. Together with this is availability of the tool or a representative version of the tool. The tool must be available and affordable to make it a feasible instrument to use in clinical practice and research (Wade 2004).

Furthermore, the instruments used should be acceptable to both staff and patients. According to Jutai & Teasell (2003), questions that should be asked are: How acceptable is the scale in terms of completion by the patient, i.e. is it culturally sensitive and applicable to the patient’s circumstances?

Scores must be interpreted. Questions often asked when using measuring instruments are: How meaningful are the scores? Are there consistent definitions and classifications for results? (Jutai & Teasell 2003)

As stated, the outcome measures that one uses depend on the setting and which aspects one wants to measure as well as what the information is to be used for, which in the case of this study is physical outcomes and preparation for community integration.

2.4.2 Measuring physical outcomes in SCI

The literature identifies four different types of outcome measures in the rehabilitation of SCI. These include measures that examine the effectiveness of health delivery as well as measures that assess functional, neurological and general health status of patients.

Typical examples of outcome measurement tools that are used to measure these things are given in table 2.4 (Wolfe, Mehta & Hsieh 2008). Table 2.4 shows clearly that even in 2008 morbidity, impairments and activities are mostly targeted for measuring while participation are not included in these outcome measures.

Table 2.4 Outcome measurements used in SCI rehabilitation (Wolfe et al 2008)

Outcome Measure Type	Specific Outcome Measure
Health delivery indicators	Length of stay, Hospital charges,
Functional status	FIM, BI, Motor assessment scales
Neurological status	AIS, ASIA motor scores, Frankel Index
Health status	Incidence of secondary complications

The literature reviewed by The Spinal Cord Injury Rehabilitation Evidence (Scire Version II) indicates a trend for progressively shorter Length Of Stay (LOS) over the past decade. Furthermore, it is found that higher SCI lesions have a longer LOS, but LOS is also dependent on the completeness of the lesion. Patients with incomplete injuries have longer LOS than complete lesions (Wolfe et al 2008).

Patterns of neurological improvement with the ASIA scale as outcome measure and functional improvement, with the FIM as outcome measure over the first few months, have been identified by several studies reviewed by Scire Version II and these studies usually examine the neurological and functional status and associated changes between admission and discharge (Wolfe et al 2008).

For the purpose of this study attention will be given to outcome measures that evaluate the functional status of the SCI patients as well as how prepared they are for reintegration into the community.

Functional outcome is often measured as a degree of physical independence, where independence is defined as the observed ability to perform an activity without the help of another person (with or without appliance or orthosis) (Schönherr et al 1999). i.e. the ability to perform certain tasks like dressing, eating, preparing food, driving etc for oneself. Physical independence has long been one of the cornerstones of SCI rehabilitation with both occupational and physiotherapy programs focusing on functional gains through exercises, the use of assistive devices and the retraining of activities (Schönherr et al 1999). As can be expected of the importance that has been attached to functional outcomes, there are numerous measuring instruments that can be used to determine physical improvement. Examples include the Barthel Index (BI) (Roth, Davidoff, Haughton & Ardner 1990), the Functional Independence Measure (FIM) (Granger & Hamilton 1996), the Rivermead Mobility Index and the Rivermead Activities of Daily Living scales, the Canadian Neurological scale, the Chedoke McMaster and the Motor Assessment Scale (MAS) (Wade 1994, and Dittmars & Gresham 1997).

Due to dissatisfaction with the well-known measurement scales like the FIM and BI which were not specifically developed for the SCI population, some researchers attempted to modify existing scales, e.g. the Spinal Cord Independence Measure (SCIM), which were developed from the Functional Independence Measure (FIM) and are, according to Catz et al (2001), more specific and relevant to the spinal cord injured population. The SCIM addresses the activities of daily living that are most relevant to the

well-being of the patients. It is a disability scale developed at Loewenstein Rehabilitation Hospital, Isreal, to assess the capacity of the individual patient with a spinal cord lesion. Just like the FIM, patients are scored by observation (Itzkovich, Tripolski, Zeilig, Ring, Rosentul, Ronen, Spasser, Gepstein & Catz 2002). Another scale which was developed from the FIM is the Self-Reported Functional Measure (SRFM) (Hoenig, Hoff, McIntyre & Branch 2001). The SRFM was developed to measure functional abilities in patients with spinal cord lesions by means of self-reporting.

In keeping with the importance that has been given to functional outcomes, outcome-based practice guidelines has been established by the Consortium for Spinal Cord Medicine in the USA to give guidance as to what functional outcomes in terms of physical independence can be expected for patients with various levels of spinal cord injuries. These guidelines were based on outcome studies and expert clinical judgement. The outcome-based guidelines are used to establish goals, provide information for quality improvement, and compare performance across facilities with similar populations (Consortium for Spinal Cord Medicine 1999).

Expected functional outcomes for persons with spinal cord lesions from T1 toT12, according to above-mentioned guidelines are shown in Table 2.5. The table also reflects the maximum level of physical independence as measured by the FIM that can be expected of a person with a motor complete SCI between T1 and T12 given optimal circumstances. It is pointed out by the consortium that differences in patient characteristics, the course of medical events, psychological, social and environmental support, as well as cognitive abilities can strongly influence outcomes (Consortium for Spinal Cord Medicine 1999).

Table 2.5 Expected Functional Outcomes (Consortium for Spinal Cord Medicine 1999)

Task	Expected Functional outcome	Equipment	Expected FIM score
Respiratory	Compromised vital capacity and endurance	Peak flow meter	
Bowel	Independent	Elevated padded toilet seat	6-7
Bladder	Independent	Catheter	6
Bed mobility	Independent	Double bed	6-7
Bed/wheelchair transfers	Independent	May require transfer board	6-7
Pressure /relief Positioning	Independent	Wheelchair pressure relief cushion Postural devices as indicated May require pressure relief mattress	
Eating	Independent		7
Dressing	Independent		7
Grooming	Independent		7
Bathing	Independent	May require shower/commode chair	6
Wheelchair propulsion	Independent	Manual rigid or folding lightweight wheelchair	6

However some dissatisfaction remained according to Tooth, Ottenbacher, Smith, Illig, Linn and Granger (2004), mainly because functional independence is activity focused. Thus even though a person might be physically well rehabilitated and score high on these outcome measures it does not mean that he/she will be able to perform his/her social roles again as the rehabilitation process did not take these roles, their requirements as well as contextual factors impacting on them into consideration. Furthermore these

measurements do not take the time and effort involved in performing the activity into consideration (Kennedy et al 2003).

While the above-mentioned scales still only measured physical independence (activity), Kennedy et al (2003) make it clear that the need for participation measurements that assess actual patient needs is becoming increasingly important.

2.4.3 Measuring participation in SCI

It has become increasingly important to address participation in rehabilitation programs and for a rehabilitation measure to assess whether a person has been given the necessary skills to reintegrate into his/her community after discharge from hospital. Furthermore it must be assessed whether the patient's needs have been met during rehabilitation in terms of his/her physical independence to prepare them for their roles and responsibilities within the community. This includes areas like own health management, productive activity, community mobility, social integration and leisure and sport activities, all aspects that should have been addressed during rehabilitation (WHO 2000; Landrum et al 1995).

In the literature only a few measuring tools are available to determine if the needs of the patients were met during rehabilitation and if the rehabilitation program has prepared them adequately for community re-integration. Besides the Needs Assessment Checklist (NAC), which was specifically developed to determine if patients' needs were met, there is also the Craig Handicap Assessment and Reporting Technique (CHART) (Whiteneck 1992), the Reintegration to Normal Living Index (RNL) (Wade 1992) and the ICF checklist on activities and participation with its performance qualifier (WHO 2000).

2.5 Measuring instruments used in current study

2.5.1 Introduction

The researcher decided, for various reasons as discussed below, to use the FIM and NAC to measure the effectiveness of the rehabilitation program at NRH with regards to physical independence, needs fulfilment and preparation for community integration.

As indicated above there are a variety of acceptable outcome measures available to evaluate functional status and progress of which the Functional Independence Measure (FIM) is one. The FIM was chosen for this research since it is widely accepted as a measure of functional status and outcome in medical rehabilitation. The International Spinal Cord Society (ISCoS) and the American Spinal Injury Association (ASIA) accepted the FIM as a standard measure of disability in those with SCI although it was originally designed as a generic measuring instrument of disability (Karamehmetoglu, Karacan, Elbasi, Demirel, Koyuncu & Dösoglu 1997). Furthermore it is frequently used to evaluate the outcome of rehabilitation in persons who sustained a complete spinal cord injury (Greenwald et al 2001; Kilkens, Post, van der Woude, Dallmeijer & van der Heuvel 2002). The FIM has also been used as a standardised tool to measure physical ability during research in SCI patients (Greenwald et al 2001). According to the ICF conceptual framework, the FIM can be categorised as a tool that measures activity (Salter et al 2005). Finally the FIM is in use as an outcome measure at Netcare Rehabilitation Hospital and therefore can be evaluated in terms of the appropriateness of its use in evaluating outcomes of SCI patients at NRH.

The Needs Assessment Checklist (NAC) was chosen because it was specifically designed and developed for the spinal cord injured population. It was developed at a spinal cord injuries unit in the United Kingdom and has been in use for the last ten years with good results (Kennedy & Hamilton 1999). The NAC focuses on the patient's needs during his time of rehabilitation and was specifically designed to determine individual patients' needs as well as measure participation whereas most other participation measures are generic tools with standardised questions (Kennedy & Hamilton 1999; Salter et al 2005).

The NAC provides a way of assessing rehabilitation programs and assuring that they are geared toward each patient's individual needs and that they provide the patient with the skills appropriate for his/her level of lesion and social roles. Patients' functional abilities are assessed by means of self-reporting as they complete the NAC by themselves. This method of rating outcomes is appealing in that it requires few resources to obtain scores, and it takes into account the influence of subjective factors (Kennedy & Hamilton 1999).

The NAC also addresses some of the dimensions of community reintegration e.g. housing, employment, and primary health care and could thus be used to evaluate the patient's preparation for reintegration into the community.

2.5.2 The functional independence measure (FIM) (Appendix D)

The FIM was developed to assess physical and cognitive disability in terms of burden of care and is used to monitor patient progress and assess the outcomes of rehabilitation. It is a staff-completed measure. It was developed as a standard measure of disability in six areas of functioning and comprises of 18 items, subdivided into two domains, a motor domain with 13 items and a cognitive domain with five items. Areas like independence in self-care, sphincter control, mobility, locomotion, communication and social cognition is covered. It was developed by Granger and Hamilton with the consensus of a national advisory committee that continues to oversee its use (Granger & Hamilton 1996). It is applicable to patients of all ages and diagnoses, and is widely used in rehabilitation centres worldwide (Granger & Hamilton 1996).

Scoring is done on a rating scale. Each of the 18 items of the FIM instrument has a maximum score of seven and a minimum score of one. Total scores can therefore range from 126 to 18. A score of seven indicates complete independence in performing a task while a score of one indicates complete dependence. It takes approximately 20-30 minutes to complete depending on the skill of the observer. To calculate the score after using the instrument takes less than a minute and can be done manually (Granger & Hamilton 1996).

It is intended to measure what the person with a disability actually does, and does not measure what the person ought to be able to do. The scale measures whether a person is able to carry out an activity independently and/or if he needs assistance from another person or a device. If assistance is needed, the scale quantifies that need. The FIM therefore focuses on burden of care and the level of a patient's disability (Heineman, Hamilton, Linacre, Wright & Granger 1995).

The perception of the patient is not involved, therefore the FIM is seen by Duckworth (1999) as a fairly objective instrument from the point of view of the rehabilitation team.

The data generated by the FIM instrument can be used to track the changes in the severity of disability during rehabilitation and can thus analyse the outcome of rehabilitation. Not only does it measure the changes brought forward with intervention, but the instrument also assists clinicians to be more goal-orientated and to predict certain outcomes of rehabilitation. The FIM has been shown to be able to predict disability costs (Heineman et al 1995). Carter and Hayden (2002) have also found in a study that an average increase of one FIM point from admission to discharge was associated with a 3% reduction in the expected cost of in-patient rehabilitation care. This is due to a reduced burden of care.

Improvements in functional abilities rated by the FIM instrument are regarded as important indices of recovery and, perhaps, the effectiveness of intervention. According to various studies done on rehabilitation efficiency, efficiency is related to the changes in the FIM score over a period of time (Ottenbacher, Mann, Granger, Tomita, Hurren & Charvat 1994). Higher FIM scores are associated with fewer minutes per day of help required from another person to complete basic daily living tasks.

2.5.2.1 Validity and reliability of FIM

Several studies have established the validity and reliability of the FIM (Ottenbacher et al 1994). Hamilton, Deutsch, Russell, Fiedler and Granger (1999) and Masedo, Hanley, Jensen, Ehde and Cardenas (2004) found that the FIM motor scales and total FIM score are reliable and valid measures of perceived functional independence in individuals with SCI.

2.5.2.2 Responsiveness

Based on the description that Mawson (1995) gives in terms of sensitivity (responsiveness), it could be said that the FIM instrument is sensitive to changes that may be induced by intervention from the rehabilitation team.

Each item or activity on the instrument has a definitive starting and end point with well-defined increments to indicate change in between. Any significant improvement in any of the activities will be noted, as the score will increase accordingly.

The FIM is however not sensitive enough to detect small changes in activities, because it only scores whether a person can perform a particular task or whether the task is performed independently and not how much effort and time is needed to perform the task. Improvements in the quality of the task/ performance are also not taken into consideration. These changes could be very important.

The FIM is noted for possessing significant floor and ceiling effects and being insensitive to small changes in performance. The FIM score may not capture all the change resulting from the rehabilitation program (Dittmars & Gresham 1997). For example, a patient with SCI may require the use of a wheelchair for the rest of his life and regard himself as completely independent. However, this patient would obtain a lower FIM score of "modified independence" because the wheelchair is classified as using a device.

2.5.2.3 Feasibility

The FIM is easy to use, takes only 30 minutes to administer and is widely accepted as an outcomes measuring instrument. However the FIM is copyrighted and must be bought to be used. Staff must be trained and pass examinations in its use in order for results to be valid which makes it an expensive tool (Granger & Hamilton 1996).

2.5.2.4 Shortcomings

The total score can be fairly meaningless without a comprehensive report on the progress of the patient. For example, a person with a complete mid-thoracic lesion could have a high score within a short time during rehabilitation, as he would be able to do more than 50% of the activities independently. However, it is the observation of the researcher that the necessary muscle strength and endurance needed for returning to the community often are still lacking.

The score also does not reflect all the skills necessary for independent functioning in everyday life outside of the hospital e.g. making use of transport, propelling a wheelchair on uneven terrain or returning to work.

The FIM only measures physical, mental, cognitive and social function and does not include economic and environmental function. This is a major shortcoming as it only measures a patient's abilities while in a facility (capacity) and not independent functioning in the person's own environment (performance) (Granger & Hamilton 1996). The cognitive items are found to be not informative for detecting changes over time in SCI; they can only serve as a crude cognition screening assessment and are therefore not relevant in SCI (Hall, Cohen, Wright & Werner 1999).

The FIM is not a comprehensive tool, but only a basic indicator. It only includes a minimum number of items or activities. It is not intended to measure all the activities that could possibly be measured.

The FIM does not state what level of functioning the treatment is expected to produce and therefore treatment effectiveness for an individual patient cannot be measured accurately. The FIM is performance based and Hamilton, Deutsch, Russell, Fiedler, Granger (1999) have found in a rehabilitation outcome study that intensity of rehabilitation therapies after SCI is not strongly associated with FIM gains.

Several researchers have used specific functional tests for specific activities to minimise the disadvantages, for example wheelchair dexterity is tested with several measures developed for testing it more appropriately (Kirby, Swuste, Dupuis, Macleod & Monroe 2002).

In summary the FIM is a well-established and comprehensive measure for its purpose i.e. to measure activity limitation, but has significant limitations when one includes participation. Therefore the NAC was introduced into the study to measure participation.

2.5.3 Needs Assessment Checklist (Appendix E)

The Needs Assessment Checklist (NAC) is a clinical assessment tool that has been developed at the National Spinal Injuries Centre, Stoke Mandeville Hospital in the United Kingdom as part of the in-patient rehabilitation program (Kennedy et al 2003). The NAC framework begins by defining problems for a specific population and specifies the critical input, the important steps to produce the desired effects, the mode of delivery and the expected outcome.

The checklist covers nine specific SCI rehabilitation domains and is made up of 216 behavioural indicators, namely: activities of daily living (29 indicators), skin management (14 indicators), bladder management (10 indicators), bowel management (7 indicators), mobility (17 indicators), equipment (33 indicators), community preparation (24 indicators), discharge coordination (32 indicators) and psychological issues (19 indicators). The checklist is so detailed in order to find out exactly where rehabilitation attention needs to be focused and to provide an indication of the existing skills that can be built upon (Kennedy et al 2003). By including some of these measures of rehabilitation, like community preparation, discharge coordination and psychological issues, the NAC attempts to measure the participation domain of disablement as defined in the ICF, in addition to its coverage of the activity domain which includes ADL, skin management, bladder and bowel management and mobility.

The Needs Assessment Checklist has three conceptual levels. The first is the statement of need such as the general domains (e.g. activities of daily living). The second is the goal (e.g. being independent in food management). The third level is the behavioural target (e.g. using feeding utensils at every mealtime). The patient's performance is assessed in one of five categories of independence, ranging from total dependence to total independence and includes a not applicable category (Kennedy & Hamilton 1999).

The NAC was developed to incorporate patient perceptions and each patient rates his/her own level of independence for each task/item. Each item receives a score from 0-3

(0= completely dependent, 1= mostly dependent, 2= moderately dependent, 3= completely independent or not applicable). Questions that are rated not applicable are scored as 3 because they are irrelevant to the individual's treatment and rehabilitation. Item scores for each subscale are totalled and a percentage achieved is derived, reflecting the patient's level of independence in each rehabilitation area. For each subscale total scores range between 0 and 100, and higher scores indicate a greater level of independence (Berry & Kennedy 2002).

The Needs Assessment Checklist assesses both physical and verbal independence. No distinction is made between verbal and physical independence enabling each patient to have the potential to achieve 100% independence (Kennedy & Hamilton 1999). Verbal independence would mean that a patient is able to instruct a caregiver to assist him/her in all areas of need. The measurement of verbal independence makes the Needs Assessment Checklist more sensitive to gains that are of relevance to the individual patient and nurtures greater patient independence.

It was also shown to be successful in terms of usefulness to staff, and in focusing the different team members on specific goals. The Needs Assessment Checklist has been found to be a clinically appropriate measure, which is popular with team members. Essentially, it is a measure of health status and outcome from a patient-centred perspective as it concentrates on the patient's beliefs about their achievements (Kennedy & Hamilton 1999).

Kennedy et al (2003) have stated in their study on goal achievement by adults with spinal cord injury, that there is a need for active, individually tailored rehabilitation programs and this is possible when the Needs Assessment Checklist is used.

2.5.3.1 Validity and reliability

Berry & Kennedy (2002) tested the reliability and validity of the NAC in a study done on 43 SCI patients. In this study the NAC was rated against findings with the SCIM 9 Version II and the Hospital Anxiety and Depression scale (HADS). High correlations

with benchmark measures of psychometric reliability and validity (SCIM and HADS) have demonstrated the NAC's concurrent validity. All correlated subscales produced very acceptable correlations, especially considering that some scales were not directly comparable. The overall findings of the study indicated that the NAC is a psychometrically reliable and valid clinical measure of rehabilitation outcome.

2.5.3.2 Responsiveness

In the same study by Berry & Kennedy (2002), the NAC was completed twice with the same patients within a week of each other. The significant difference found between the first and second completion contributed to demonstrate the NAC's sensitivity to change.

2.5.3.3 Feasibility

The NAC provides an assessment of the patient's own perceptions of their independence. This is in accordance with the recommendations of Slade (1994) where he advocates that assessment measures developed for clinical use should go beyond symptomatology and the behaviour observed by professionals, and incorporates the patient's perception. Although the checklist is quite lengthy, patients complete the checklist by themselves and on average it only takes 30-45 minutes to complete.

Patient ratings of the NAC also demonstrate a high level of satisfaction with the NAC from those who undertake the assessment, relating to the NAC's usefulness, clarity and personal relevance. They also felt that the NAC was helpful because of its level of detail (Berry & Kennedy 2002).

2.5.3.4 Shortcomings

Even though the questions of the NAC are simple and straightforward, it is still necessary to explain the scoring system in detail to patients. It is observed by the researcher that this seems to be the only shortcoming noted as the literature reveals no other (Berry & Kennedy 2002).

2.6 Summary

Spinal cord injuries are devastating occurrences in people's lives with life-changing results. Acquiring a sudden traumatic SCI renders the person paralysed and dependent on others for all care. Due to the nature of such an injury, patients with SCI need a comprehensive rehabilitation program to regain physical independence and prepare them to be reintegrated into the community. While the ultimate goal of rehabilitation for SCI individuals is successful reintegration into the community, rehabilitation programs internationally and locally seem to focus mostly on physical independence and preparation for community integration does not always get the attention it needs during an in-patient rehabilitation program. Rehabilitation for SCI in South Africa is mostly done in institutions with little attention to out-patient programs or community based rehabilitation to assist patients to reintegrate into the community.

To ensure that rehabilitation programs succeed in the ultimate goal of community reintegration it is therefore important to evaluate rehabilitation programs in terms of their effectiveness in assisting SCI patients to regain physical independence and prepare for reintegration. Measuring instruments on functional outcomes abounds, but there are fewer instruments to measure community integration or preparation for community integration.

Despite its disadvantages the FIM can be used to measure functional outcomes in people with spinal cord injuries. It is a frequently used, standard, reliable and valid measure. Another advantage is that results are centrally computed and can thus be compared to FIM results from around the world. However, since it is task-oriented and not patient-oriented, it is not always appropriate to use as an indicator of patient progression and length of stay for a spinal cord injured patient. The fact that it only measures certain physical activities makes it unsuitable for use in evaluating how well a spinal cord injured patient is prepared for reintegration into his community.

The Needs Assessment Checklist on the other hand, addresses much more than the basic physical activities that the FIM measures. It gives adequate information in terms of how

well the patient has done during his/her rehabilitation program and how prepared he/she is for integration into the community.

CHAPTER 3

METHODOLOGY

3.1 Introduction

In this chapter the methodology of the study will be discussed under the following aspects: aim, objectives, design, setting, population, measuring instruments, pilot study, data collection, data analysis, reliability and validity.

3.2 Aim of the study

The aim of the study was to evaluate if the rehabilitation program for patients with complete paraplegia at Netcare Rehabilitation Hospital was effective in terms of the outcome of patients with complete paraplegia, with regards to physical independence and preparing them for reintegration into the community.

3.3 Study objectives

The objectives of the study were as follows:

1. Describe the demographic details of the study population
2. Determine if there were any relationship between length of stay and outcome according to the Functional Independence Measure and the Needs Assessment Checklist as well as the demographic details
3. Assess the effectiveness of the rehabilitation program in terms of the functional outcome of the study sample according to Functional Independence Measure and Needs Assessment Checklist scores by comparing the scores of the two outcome measures
4. Compare outcome of the study population according to the Functional Independence Measure with expected outcome according to the Clinical Practice Guidelines (CPG) of the Consortium for Spinal Cord Medicine
5. Assess the outcome of the rehabilitation program in terms of preparing the patients for community integration according to Needs Assessment Checklist scores

6. Make recommendations to Netcare Rehabilitation Hospital on the rehabilitation program for complete thoracic spinal cord injuries based on the findings of this research

3.4 Study design

This was a descriptive study to evaluate whether the rehabilitation program of Netcare Rehabilitation was effective with regard to the patients achieving physical independence and preparing the patients for reintegration into the community.

3.5 Study setting

The study was conducted at Netcare Rehabilitation Hospital, a 120 bed private rehabilitation facility situated in Johannesburg, South Africa. The focus of the hospital is to offer rehabilitation services to patients with physical disabilities, such as traumatic brain injuries, spinal cord afflictions, cerebrovascular accidents, amputations and multiple injuries. The patients are admitted to the hospital from various acute private hospitals in the area, once the referring doctors are satisfied that the patients have achieved outcome level 1 (physiological stability). The rehabilitation services within the hospital are offered by a rehabilitation team consisting of medical doctors, nurses, physiotherapists, occupational therapists, speech therapists, social workers, psychologists, dieticians and orthotists/prosthetists who work together on an inter-disciplinary basis as discussed in Chapter 1.

3.6 Study population

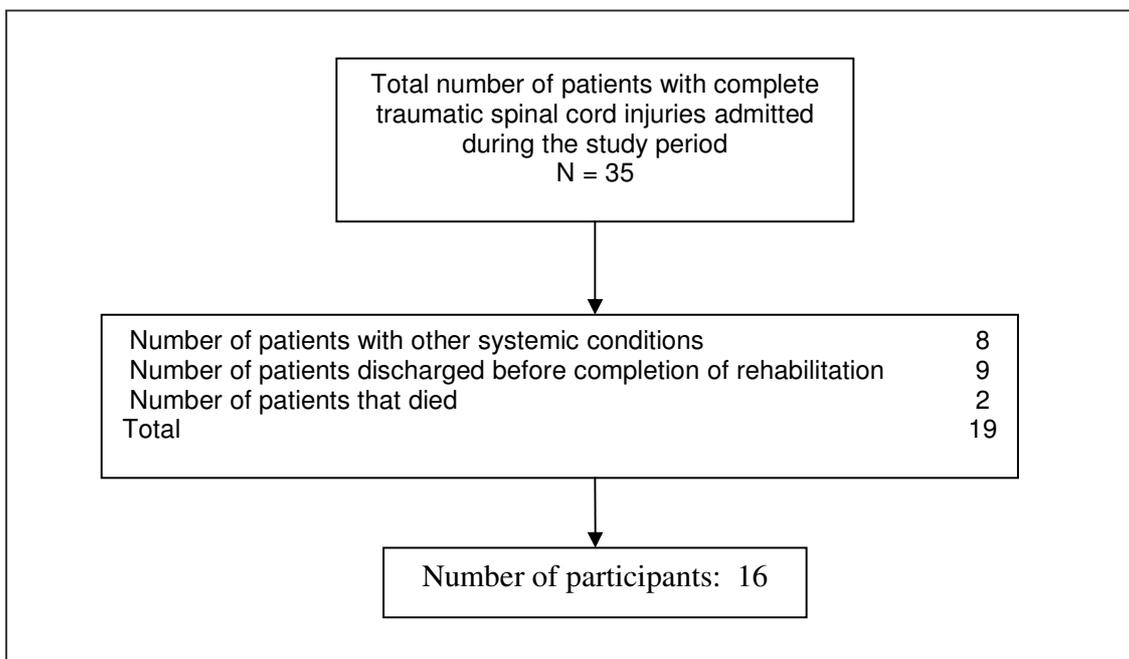
The study population consisted of a convenient sample of all patients who were diagnosed by the medical doctor at NRH with complete, traumatic, thoracic spinal cord injuries and were admitted to Netcare Rehabilitation Hospital between 1 April 2004 and 31 December 2007. Only patients admitted to NRH were considered for the study as the purpose of the study was to evaluate the rehabilitation program at NRH. A total of 35 patients who were diagnosed as above were admitted during above-mentioned period. Of these, 16 met the inclusion criteria of the study. Since 16 is already a very small number of participants for analysing quantitative data no further sampling was done. Table 3.1

provides a schematic representation of the study population and shows how the final number of 16 participants was determined.

Only patients with complete traumatic thoracic lesions were considered for the study to ensure a homogenous population. This was done to ease comparison to literature findings as well as comparisons with the CPG.

By including only trauma as cause of the lesion any patients with systemic diseases that could have an effect on physical endurance and rehabilitation outcome were excluded.

Table 3.1 Determination of study participants



3.6.1 Inclusion criteria

- All patients with a complete traumatic spinal cord lesion between T1 and T12 and classified as ASIA A, as diagnosed by a medical doctor at NRH, admitted during the study period
- All patients who were admitted for rehabilitation for the first time at Netcare Rehabilitation Hospital
- All patients who consented to participate in the study

3.6.2 Exclusion criteria

- Patients who previously received some rehabilitation at another facility
- Patients that did not complete the estimated length of stay in which to complete the rehabilitation program due to financial limitations or the development of complications
- Patients with injuries/conditions that could have influenced the outcome of rehabilitation including:
 - fractures/injuries to the upper limbs
 - fractures/injuries to the lower limbs
 - decreased range of movement of any joints of the upper or lower limbs that will limit their ability to transfer from a bed to a wheelchair
 - pre-existing cardiac or other systemic conditions that will influence endurance

3.7 Measuring instruments

The following two measuring instruments were used:

3.7.1 Functional Independence Measure (FIM) (appendix D)

As discussed in Chapter 2 the Functional Independence Measure (FIM) is a valid, reliable and sensitive instrument that measures the functional independence of a person on 18 items or activities that are scored on a seven point scale. The FIM data form makes provision for collection of some demographic data and further demographic data that the researcher required were added to the FIM, thus no separate demographic data coding sheet was used. Data was collected on the prescribed form (see Appendix D). The FIM was used as a measuring instrument primarily towards realising objectives 1,2,3 and 4 i.e. the determining of the relationship between LOS and FIM scores, determining the physical outcome of the patients, comparing physical outcome to the CPG and additionally to gather demographic data of study participants and realising objective 1. The FIM is currently being used as the measuring tool at NRH and was thus the tool of choice to use in this study. NRH is subscribed to use the FIM and is paying a monthly license fee, which include using it for research purposes in this setting.

3.7.2 Needs Assessment Checklist (NAC) (Appendix E)

The Needs Assessment Checklist has been discussed in Chapter 2. It is a valid, reliable and sensitive assessment tool which provides a way of assessing and assuring that rehabilitation programs are focused toward each patient's individual needs and that the rehabilitation program provides the patient with the skills appropriate to the level of their lesion and their needs. Data was collected on the prescribed checklist attached as Appendix E. The NAC was used to determine whether the needs of patients have been addressed by the rehabilitation program and whether patients were prepared for community integration, thus primarily towards realising objective 5, but also towards realising objectives 2 and 3. The NAC was chosen for this study because it was developed specifically for the spinal cord injured population and covers the activities necessary for the patient to be physically independent as well as the aspects that are necessary to help them integrate into the community. It was used only on discharge of the patient from the facility as some of the NAC categories address specifically the readiness for discharge from the hospital and are not applicable while the patient is still participating in the rehabilitation program.

3.8 Pilot study

A pilot study was conducted with three patients, who were part of the main study population, to test if the measuring instruments were user-friendly, understandable and if they gathered the information needed to meet the objectives of the study. Although it is not optimal to include the pilot study's participants in the main study it was done because such a large number of participants did not complete their rehabilitation and had to be excluded from the study.

All participants in the pilot study met the inclusion criteria. Two were English speaking and one was non-English speaking. The non-English speaking person was included to ensure that the NAC could be used through an interpreter. Of the two English speaking participants one was male and one female.

The three participants were scored on the FIM on admission and discharge. On discharge they were asked to complete the NAC. The NAC form was discussed with the English speaking participants and time was given to fill it out. With the non-English speaking participant, the form was discussed with the interpreter who then relayed the information to the participant. The interpreter, Mr J Mondhlane, a registered physiotherapy assistant, was chosen for this task as he is knowledgeable in the rehabilitation program and has 38 years experience working with patients with spinal cord injuries. He was trained to assist with translating the Needs Assessment Checklist by the researcher. Scoring the participants on the FIM proved to be without problems as the researcher is skilled in performing the scoring.

With observing the completing of the NAC the following were noted. The English speaking participants took less than 30 minutes to complete the form. Both reported that the form was easily understandable and the method of scoring was clear to them. The non-English speaking participant also took less than 30 minutes to complete the form. He reported that the questions put to him by the interpreter were easy to understand and he was able to score himself with no difficulty.

No changes were made to the data collection instruments.

3.9 Data collection

To prevent any inter-rator bias all data was collected by the researcher. The 16 patients with traumatic thoracic spinal cord injuries that were admitted to Netcare Rehabilitation Hospital between 1 April 2004 and 31 December 2007 and who adhered to the inclusion criteria of the study were asked to participate in the study on their admission to Netcare Rehabilitation Hospital. The aims, objectives and study procedures were explained to them. They were given the opportunity to ask questions and once they were satisfied they were asked to sign the written consent form (Appendix C).

Once they signed the consent form the researcher completed the FIM with regards to demographic data and admission scores. This was done three days after admission in the

spinal ward at the patient's hospital bed. The researcher is experienced in the use of the FIM and has been using it regularly for eight years. She was trained to use it and passed an international examination on using it. A discharge FIM score was done by the researcher one day before the final discharge date of the patient. Again this was done in the spinal ward using the patient's hospital bed and the ward's bathroom. As with all assessments done in the ward, the curtains were drawn around the bed to ensure patient privacy and no interruptions. The researcher was not involved in the rehabilitation program of any of the 16 participants.

After the discharge FIM score was done each participant was asked to complete the Needs Assessment Checklist. This was also done on the day preceding the final discharge of the patient from hospital. The checklist and the scoring were explained individually to each participant by the researcher and they were allowed to fill it out with no time constraints. Participants could select a time that was convenient to them, and were provided with a private, quiet room without interruptions, for completing the NAC. Non-English speaking participants were assisted to fill out the NAC data form by the researcher and an interpreter. The same interpreter was used for all three participants who wanted the NAC translated into Zulu. The NAC document was not translated formally before the study commenced.

In summary the following data was collected and documented on the appropriate data coding forms of the FIM (Appendix D) and NAC (Appendix E) respectively:

- ***Demographic Data:***
Age, gender, marital status, occupation, housing, urban or rural environment, educational level, employment, transport
- ***Medical information:***
Referring hospital, level of injury, cause of injury, funding for rehabilitation
- ***FIM score:***
Admission
Discharge

- *NAC score:*
 - Discharge
- *Total length of hospital stay (LOS)*

3.10 Data analysis

Data was entered onto an excel spreadsheet and analysed with the assistance of a statistician and STATISTICA Version 7. Results were discussed and presented through figures and tables as applicable.

FIM and NAC scores were compared to each other and discussed in terms of program effectiveness. Length of stay was compared to mean FIM and NAC discharge scores to detect a relationship. Specific tests (Spearman; ANOVA) were done to determine statistical significance of selected findings e.g. the relationship between LOS and mean FIM discharge and admission scores. A p value of < 0.05 was seen as statistically significant.

3.11 Reliability and validity

- The FIM and NAC are both reliable and valid instruments. (See discussion in Chapter 2)
- The research was performed by a single researcher to prevent any inter-rator bias from occurring
- The researcher was not involved in the rehabilitation program of any of the 16 participants
- The NAC was individually discussed with each participant and ample time for questions was given to them prior to completing the form
- There was no time constraint in filling out the NAC
- A private room was available to the patients for filling out the NAC
- The NAC was not translated and one interpreter trained by the researcher was used to assist with filling out the forms for the three Zulu speaking participants

3.12 Ethical considerations

- A proposal was submitted to Committee C of the University of Stellenbosch for ethical clearance before the study commenced. This proposal was accepted by the committee (N04/03/060).
- Written permission was obtained from the manager of NRH and the doctor in charge of the patients to perform the research in this setting.
- A written consent form was signed by each participant after the study had been explained to them and any questions that they had were answered to their satisfaction.
- Participation in the study was entirely voluntary and participants knew that they could refuse to participate or stop participating at any time without that decision having any adverse impact on their continued treatment at NRH.
- Hard copies of data were kept in a locked cupboard and only the researcher had access to it. This will be destroyed once the final report has been accepted.
- Data on spreadsheets did not contain the names or identifying particulars of patients and only the researcher, supervisor and statistician had access to the spreadsheets.
- All participants in the study were assured that all information disclosed by them will be confidential and that their treating therapists will in no way have access to the information they disclosed.
- The confidentiality aspect was explained to the interpreter by the researcher before he assisted in completing the Needs Assessment Checklist with the participants.
- Where data will be made public, as in publications, it will be presented in such a way that no individual person will be identifiable.
- The results of this study will be discussed in detail with the management and rehabilitation team of NRH to ensure the implementation of the recommendations made in section 5.9.3.

3.13 Summary

This study was aimed to evaluate the rehabilitation program for patients with complete paraplegia at a private rehabilitation facility using two measuring instruments, the FIM and NAC, to assess the effectiveness of the program in terms of the functional outcome of the participants in the study.

CHAPTER 4

RESULTS AND DISCUSSION

4.1 Introduction

In chapter four the results of the study will be presented and discussed according to the objectives of the study. A total of sixteen patients participated in the study. All the patients sustained traumatic spinal cord injuries and were admitted to Netcare Rehabilitation Hospital for rehabilitation following stabilization of their injuries in an acute hospital.

4.2 Demographic profile of the study population

4.2.1 Age distribution

The mean age of the study population was 32 years with ages ranging from 21 to 47 years. It is clear from Figure 4.1 that the majority of participants (87%) were young adults with ages from 21 to 40 years. These findings correlate with recent literature reviews. Wyndaele & Wyndaele (2006) report in a study that the mean age of new SCI injured patients is 33 years, while Blackwell, Winckler, Steins and Krause (2001) found it to be 31.7 years. McKinley et al (2007) report a mean age of 38 years in a study done on 175 patients admitted with traumatic SCI.

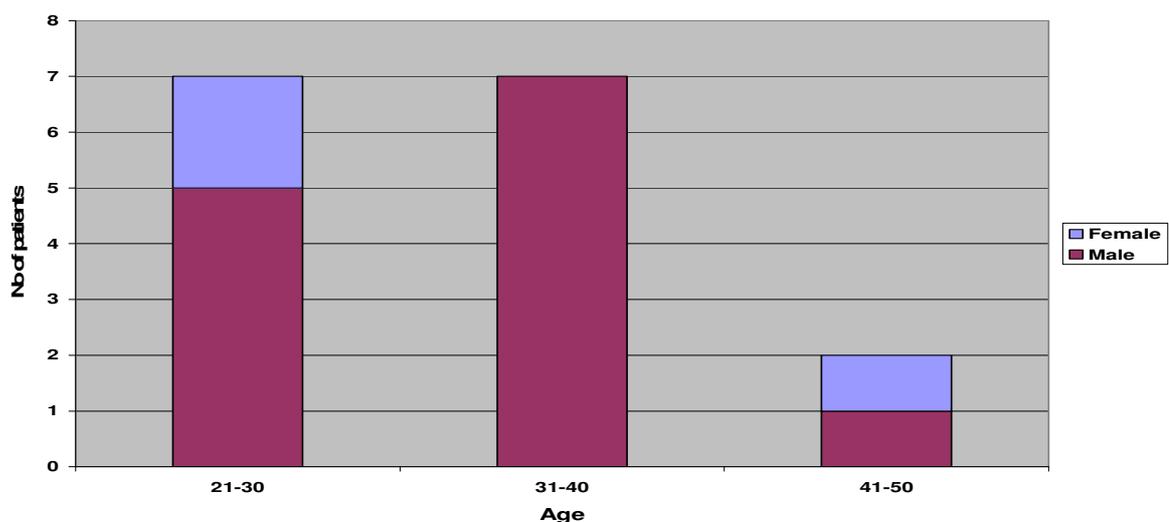


Fig 4.1 Age and gender distribution of study population

The majority of the patients in this study were young adults, an age group that would need to return to meaningful employment after rehabilitation to reintegrate successfully into the community. According to the literature discussed in Chapter 2, the unemployment rate within the spinal cord injured population is fairly high even in developed countries (62% in Canada). With the INDS estimating that 99% of disabled persons in South Africa are unemployed, it seems unlikely that the majority of these patients will return to some form of employment, which will make full integration into the community difficult (Office of the Deputy President 1997).

4.2.2 Gender distribution

Thirteen patients (81.25%) were male and three were female (18.75%) (See Fig. 4.1). This translates into a ratio of almost four male participants for every one female. Again the literature reports the same gender distribution. Wyndaele and Wyndaele (2006) report a distribution of 3.8:1 males to females and Blackwell et al (2001) report the ratio between male and female as 4:1.

4.2.3 Marital status

Table 4.1 shows that eleven patients (69%) were married and five single (31%). USA statistics report 51% of all SCI patients are married and 15% are divorced at the time of the accident while 29% are single (Berkowitz M, O'Leary P, Kruse D & Harvey 1998). As there are no divorced people in this study it seems that the statistics are once again in line with SCI populations in the rest of the world.

Studies have shown that marital status is a powerful predictor of community reintegration, as being married and thus having a spouse as support system assists with successful rehabilitation and community integration, as reported by Kreuter (2000).

Several studies have focused on the issue of marital status before and after the onset of the injury. Divorce rates for persons with SCI have been reported to be anywhere from 8% to 48% (Kreuter 2000). Thus, marital stability is a concern in the successful reintegration into the community of a person with a spinal cord injury (Kreuter 2000).

4.2.4 Housing and living environment

All sixteen patients are from urban areas and reside in houses. Two of the patients stayed in houses which belong to mining companies. This is potentially problematic, because if they cannot return to work for those companies they might also lose their housing. It might also mean that they will return to a rural area as mine workers often migrate to Gauteng from rural areas in order to earn a living and should it become impossible for them to work they go back to the rural communities that they have come from. Should this be the case the rehabilitation of these two patients might be especially inadequate with regards to community integration as circumstances in rural areas differs dramatically from those in urban areas and they require quite different types of wheelchairs and wheelchair mobility skills to name but two. All mining patients are however followed up by the social services of the mine and should they have to be repatriated to their original communities their reintegration will be monitored by the mining houses. Furthermore five participants are dependent on public transport to access the community. This will probably impact negatively on their ability to integrate into the community as the lack of accessible public transport in SA is well-known and was discussed in the literature review as well (Office of the Deputy President 1997).

4.2.5 Educational level and employment status

Although a very small group of participants, their educational levels and employment status differs strongly from general figures in Gauteng as well as international figures on patients with spinal cord injuries (Hart 2000). As Table 4.1 shows, all participants, except one who is a student, were employed, six had higher education while five of the others completed grade 10 and five grade 12. International figures report that 40% of SCI patients have less than a high school education, 50% have a high school education and only 6% have a tertiary education (Dawudu 2008). General figures for Gauteng indicate an unemployment rate of 31.8% and an illiteracy rate of more than 10% (Gaffey 2007). These discrepancies can probably be explained by the fact that the patients in the study accessed private health care and all either have medical insurance or medical costs were covered by Workman's Compensation Fund which, in South Africa is an indication

that they are part of a small advantaged group that enjoy most of the privileges which are usually associated with developed countries.

Data indicates that the type of employment of nine participants was classified as administrative (Table 4.1). It is dangerous to draw conclusions when one has so little information. However, one should expect these people to be able to resume their previous employment with the necessary workplace alterations; therefore it is particularly worrying that seven patients indicated that they need adaptations at work, but that nothing had been done about that at the time of their discharge from hospital. In the light of the high general unemployment figures in SA and the even higher unemployment figures for persons with disabilities it is essential that these issues are addressed as a matter of priority during rehabilitation. The Canadian Paraplegic Association (CPA) (1997) also reports in a study that education is a key factor in returning to employment. Higher education or increasing education following injury results in more success with employment. This could also be an indication that this particular study group could reintegrate successfully as the general level of education is fairly high (Table 4.1).

4.3 Information related to the Spinal Cord Injury

4.3.1 Referring hospital

Table 4.1 shows that all patients were referred from private acute care hospitals and the majority of them (88%) were situated in the greater Johannesburg area. Only two other patients were referred from outside the Johannesburg area.

Table 4.1. Demographic data of study participants

Patient No	Age	Gender	Cause	Diagnosis	Married	Housing	Referring hospital	Employment	Educational level	Transport	Funder
1	29	Male	MBA	T11 Paraplegia	No	Urban house	Milpark	Administration	Grade 12	Own	Med aid
2	30	Male	Gunshot	T5 Paraplegia	Yes	Urban house	Milpark	Administration	Grade 12	Own	Med aid
3	26	Female	Industrial	T11 Paraplegia	No	Urban house	Union	Security officer	Grade 10	Public	WCA
4	34	Male	Industrial	T11 Paraplegia	Yes	Mining house	Krugersdorp	Mine worker	Grade 10	Public	WCA
5	43	Female	MVA	T5 Paraplegia	Yes	Urban house	Milpark	Housewife	Tertiary educ	Own	Med aid
6	37	Male	MVA	T11 Paraplegia	Yes	Urban house	Union	Administration	Grade 10	Public	Med aid
7	28	Male	MVA	T6 Paraplegia	Yes	Urban house	Milpark	Administration	Tertiary educ	Own	Med aid
8	31	Male	MVA	T5 Paraplegia	Yes	Urban house	Milpark	Administration	Grade 10	Public	Med aid
9	21	Male	Gunshot	T6 Paraplegia	No	Urban house	Milpark	Student	Grade 12	Own	Med aid
10	36	Male	MVA	T12 Paraplegia	Yes	Urban house	PTA East	Administration	Grade 12	Own	Med aid
11	47	Male	Fall	T12 Paraplegia	Yes	Urban house	Union	Administration	Tertiary educ	Own	Med aid
12	32	Male	MVA	T8 Paraplegia	Yes	Urban house	Milpark	Administration	Tertiary educ	Own	Med aid
13	31	Male	Gunshot	T4 Paraplegia	Yes	Urban house	Milpark	Medical doctor	Tertiary educ	Own	Med aid
14	38	Male	Industrial	T11 Paraplegia	Yes	Mining house	Krugersdorp	Mine worker	Grade 10	Public	WCA
15	26	Female	MVA	T12 Paraplegia	No	Urban house	Kroonstad	Professional nurse	Tertiary educ	Own	Med aid
16	25	Male	Industrial	T8 Paraplegia	No	Urban house	Olivedale	Administration	Grade 12	Own	WCA

4.3.2 Level of lesion

In accordance with the study inclusion criteria all participants suffered a complete, thoracic spinal cord lesion. Lesions of the study population varied from the level of T4 to T12 (See Figure 4.2 for further details) and all were classified as complete lesions (ASIA A). Figure 4.2 show that 50% of participants suffered a T11 or T12 lesion while the other 50% suffered lesions from T4 to T8. According to Blackwell et al (2001) the most common lesion in the thoracic area is at the level of T12, which accounts for nearly 50% of all thoracic lesions.

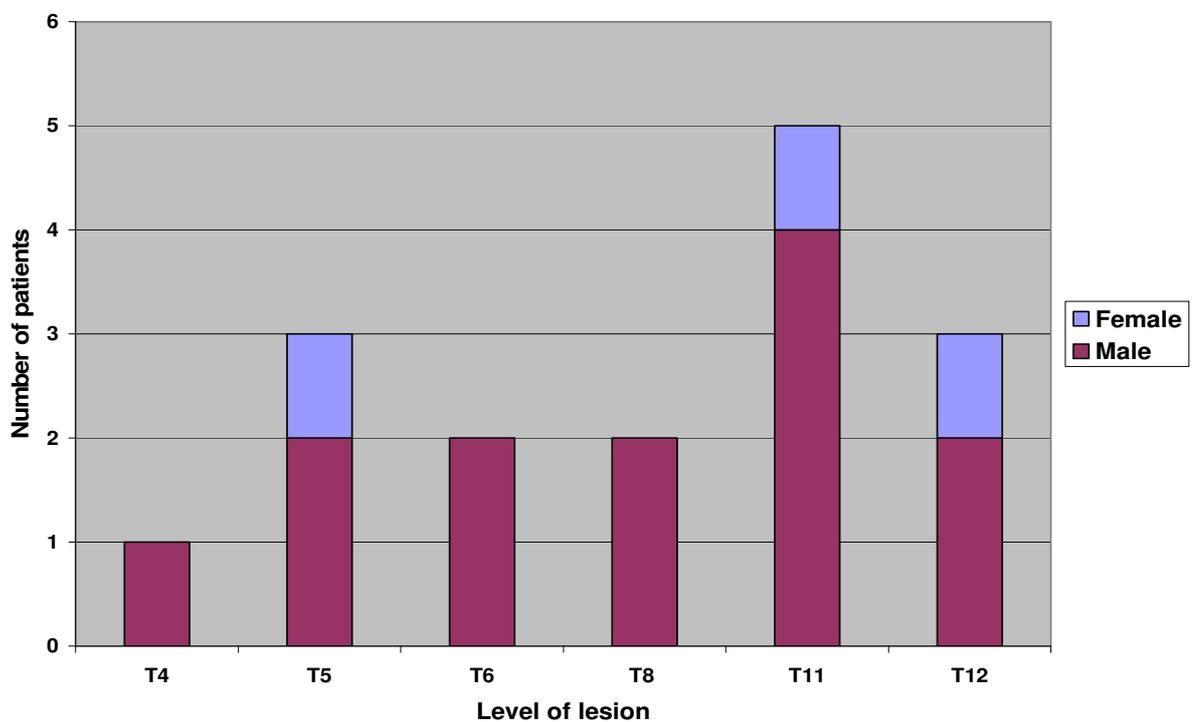


Fig 4.2 Level of lesion

4.3.3 Cause of accident

Although all injuries were of a traumatic nature different types of trauma resulted in the injuries. Motor vehicle accidents were the highest cause of injury with eight participants having sustained a motor vehicle accident. This was followed by industrial accidents (4), violence (3), and one patient fell from a height (Figure 4.3).

According to a study by Blackwell et al (2001) the leading cause of new SCI lesions are motor vehicle accidents. In a study done by Schönherr, Groothoff, Eisma and Mulder (1999) it is reported that 20% of their study population suffered industrial accidents, this is also in accordance with the current study findings where 25% of the patients had industrial accidents.

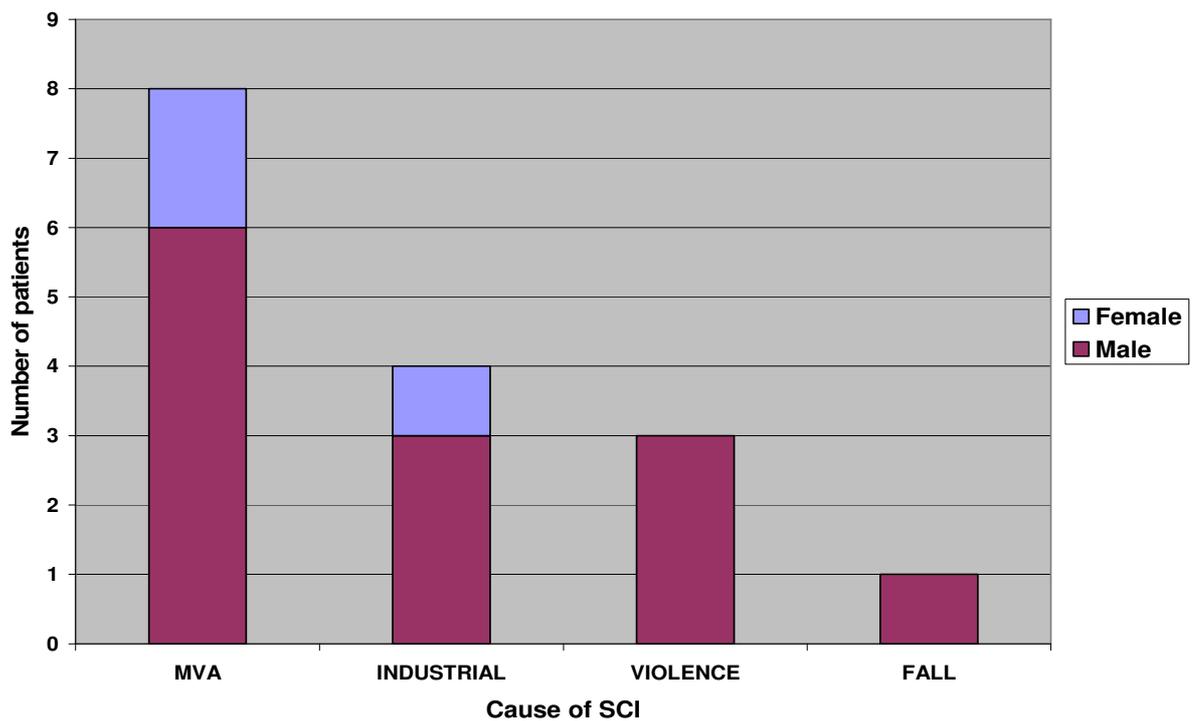


Fig 4.3 Cause of spinal cord injury

4.3.4 Length of stay in acute care and in rehabilitation hospital

Most of the patients participating in the study (9) were admitted to the NRH within two weeks after their injury, and a further three were admitted within the first month after their injury. It is thus assumed that outcome level 1, that of physiologic stability were achieved within the first four weeks in 75% of the patients (Figure 4.4).

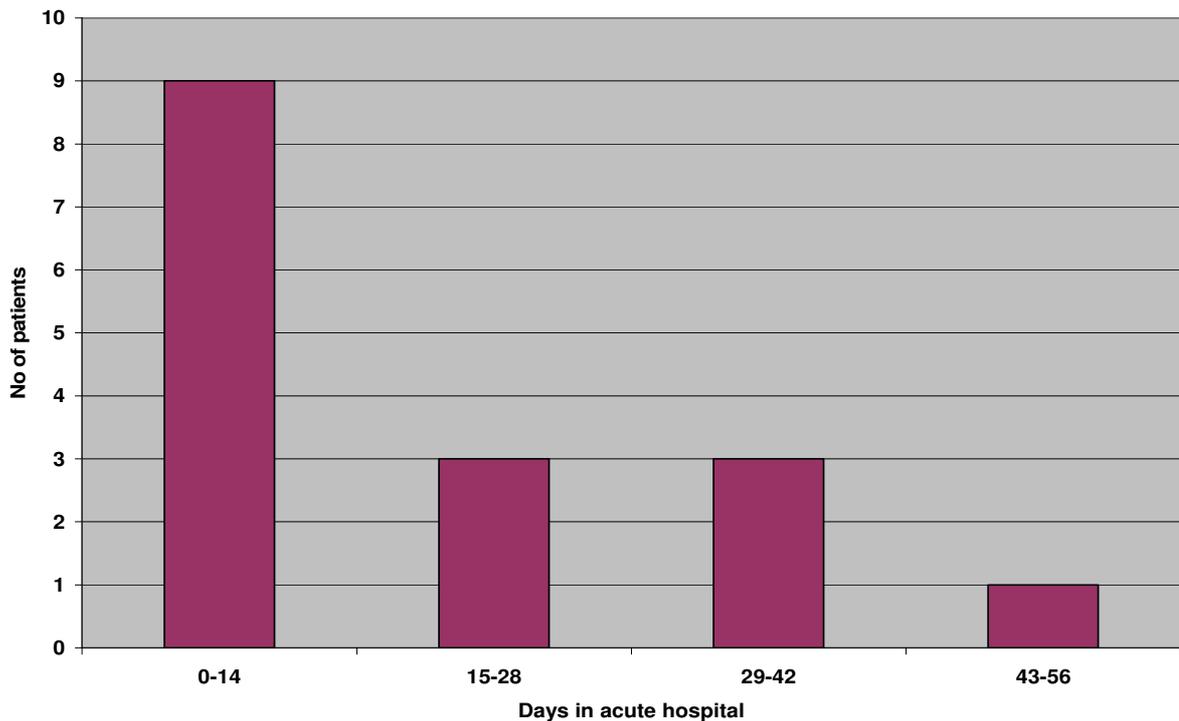


Fig 4.4. LOS in acute hospital

The mean length of stay (LOS) in NRH while participating in the rehabilitation program was 95 days with the length of stay ranging from 51 days to 124 days as shown in Figure 4.5.

Literature findings on length of stay for patients with complete thoracic lesions vary. A study by Greenwald, Seel, Cifu and Shah (2001) reports a mean LOS of 72.16 days while another study, reporting on complete paraplegics below T1, finds a mean stay of 250 days (Schönherr et al 1999). The second study was done in the Netherlands and its aim was to measure the functional outcome of patients with SCI in order to evaluate the rehabilitation programs for these patients, similar to the goals of the current study. The report however does not comment on why the length of stay was so much longer than that reported in other studies and the researcher could find no methodological differences that could explain it.

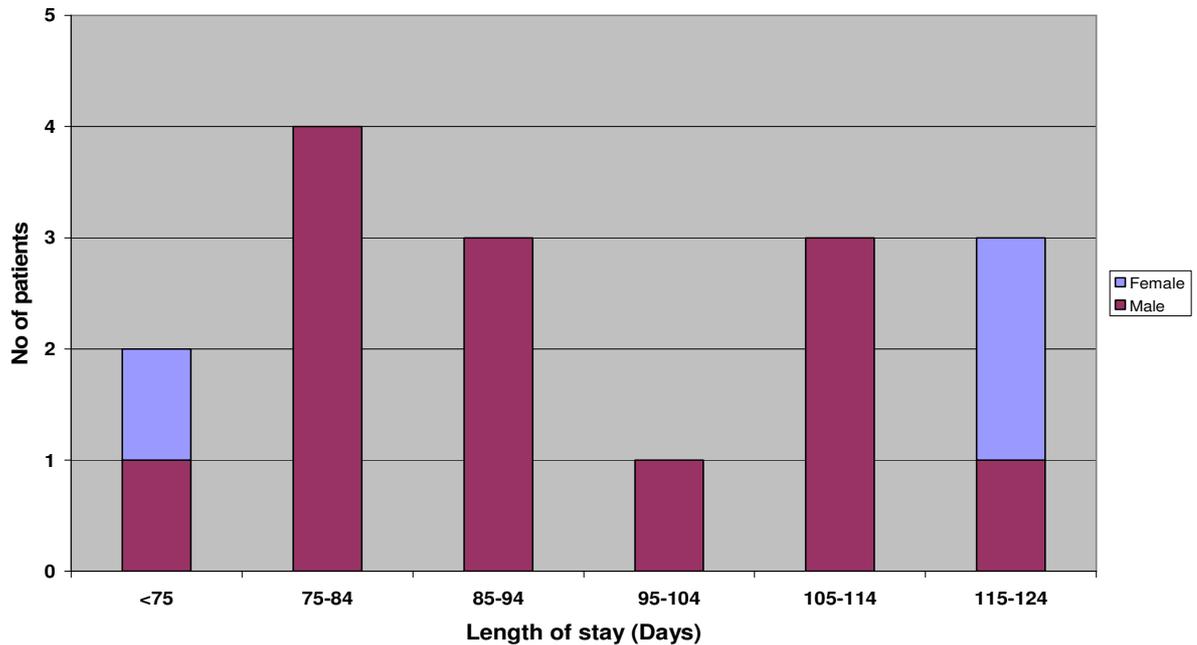


Fig 4.5 Length of stay in rehabilitation hospital

As is indicated by Figure 4.5 ten patients stayed longer than the expected 84 days as set out by the rehabilitation program, of which six stayed more than 20 days longer. Reasons for this were not assessed in the current study and the finding will be further discussed in Chapter 5. The stay in the acute hospital had no significant effect on the stay in the rehabilitation facility as demonstrated by Figure.4.6. The majority of the patients had a fairly short stay in the acute hospital (less than four weeks) and their stay in the rehabilitation hospital compared with the patients who had a longer stay (more than four weeks) in the acute hospital. One patient who spent 53 days in the acute hospital had a much shorter stay (51 days) in the rehabilitation hospital. Table 4.1 indicates that this participant, a professional nurse was referred from a hospital outside the greater Johannesburg area.

The combined LOS in hospital ranges from 83 to 152 days with a mean of 113 days. The LOS in both acute and rehabilitation hospital is demonstrated by Figure 4.6.

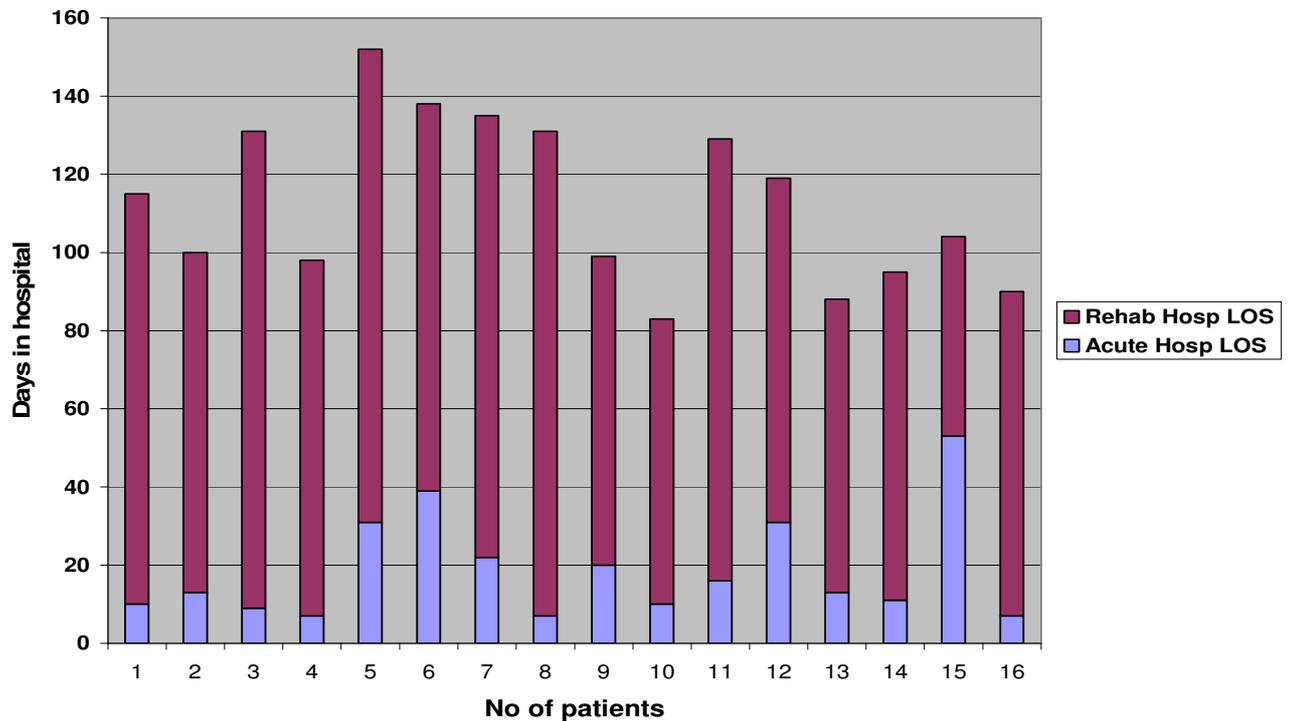


Fig 4.6 Acute and rehabilitation hospital LOS

According to the scatter plots (Figures 4.7 and 4.8) there was no correlation between length of stay and either FIM ($p = 0.05$) or NAC ($p = 0.26$) scores. As Figure 4.7 shows, a short LOS of 51 days resulted in an average FIM score of 80 while a much longer LOS like 91 to 121 days resulted in high, average and low FIM scores. However, a p value of 0.05 as shown by the Spearman correlation, which is utilized in this instance as data is not normally distributed, can be seen as marginally significant and indicates that one might be able to draw some inference of FIM admission scores with regards to LOS. However this must be further investigated before any conclusions are drawn or the information is used to make clinical predictions e.g. to medical aids.

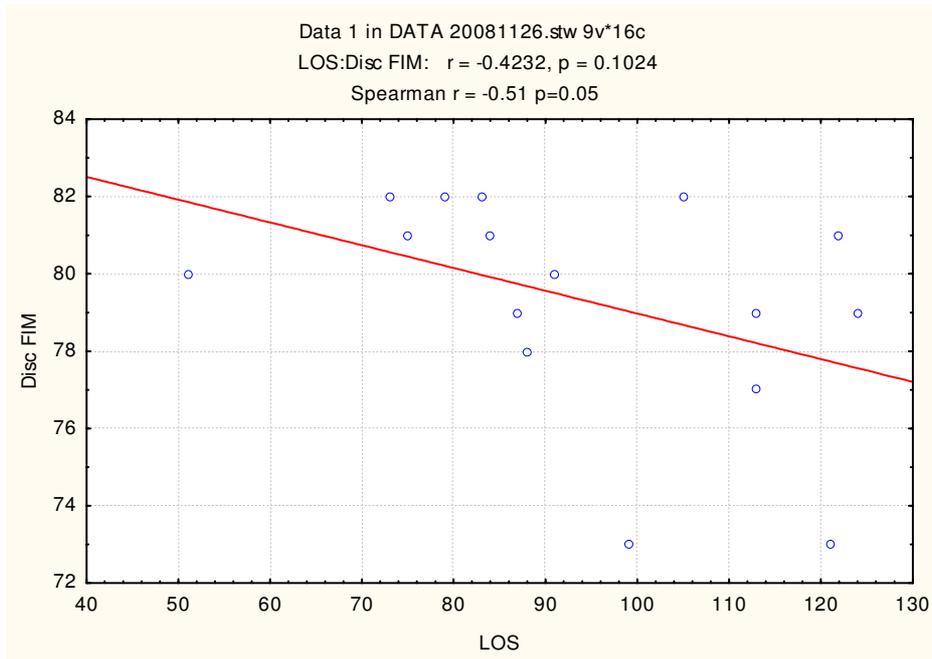


Fig 4.7 Scatter plot comparing LOS and discharge FIM score

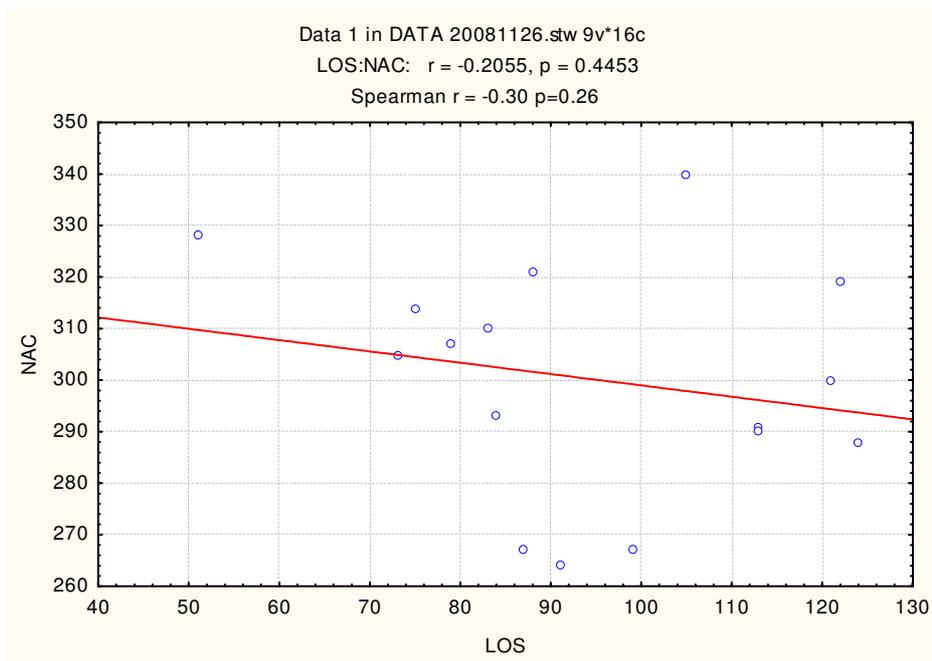


Fig 4.8 Scatter plot comparing LOS and NAC score

Furthermore LOS was compared to level of lesion as is shown in Figure 4.9. Although no significant statistical relationship could be found, Figure 4.9 shows a definite decrease

in mean LOS as well as distribution of LOS from the higher to the lower lesions with a slight discrepancy at T11. Mean LOS decreases with 30 days from 110 days for T5 lesions to 80 days for T12 lesions. This is important to keep in mind since 30 days of hospitalization amounts to an approximate cost of R70 000 as stated by Mr M Motsoane, Manager of Netcare Rehabilitation Hospital in an interview on 14 November 2008. Again these results might be useful if utilized carefully in situations where predictions on LOS must be made e.g. in motivations for rehabilitation funding to medical aids. These findings are in a way to be expected as a lower lesion leaves more residual muscle control in the trunk of the patient which has a positive impact on function, which was used to a large extent to determine readiness for discharge in this population.

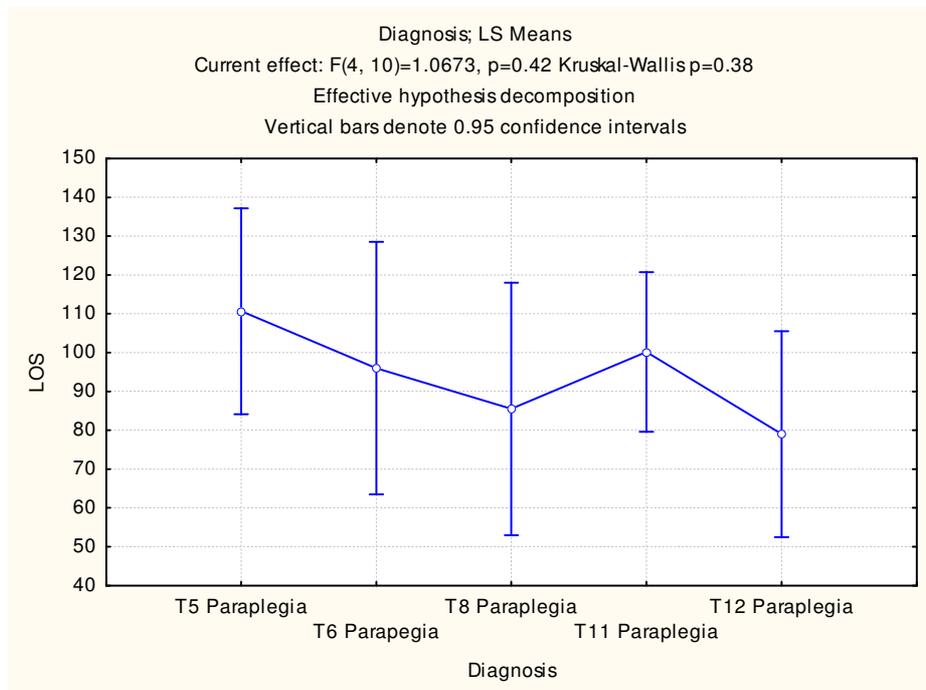


Fig 4.9 Scatter plot comparing LOS and level of lesion

On comparing LOS to cause of injury and gender no statistically significant or clinically important results were found (See Figures 4.10 and 4.11).

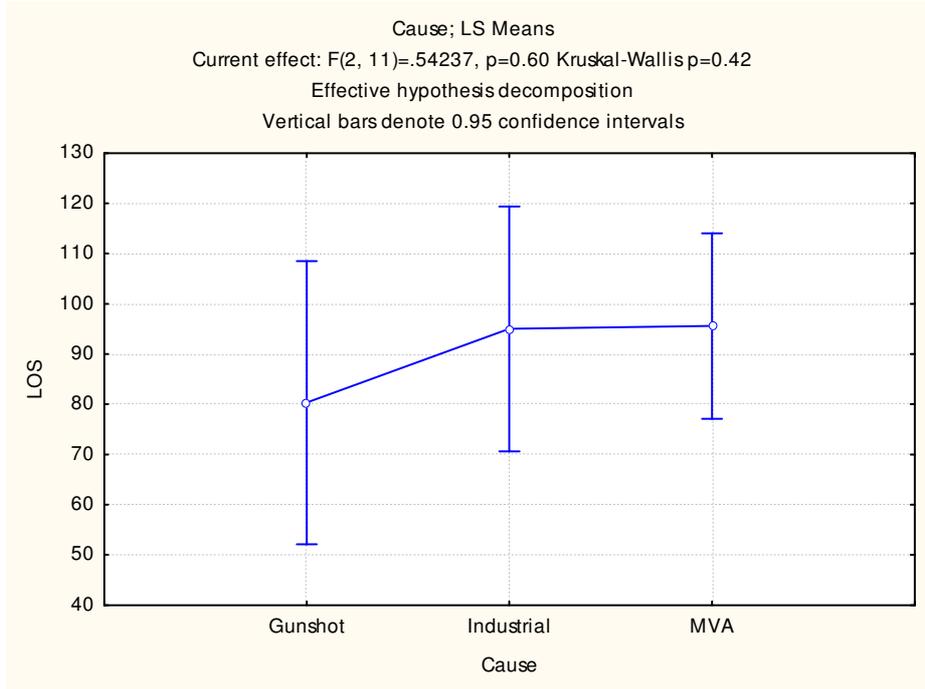


Fig 4.10 Scatter plot comparing LOS and cause of injury

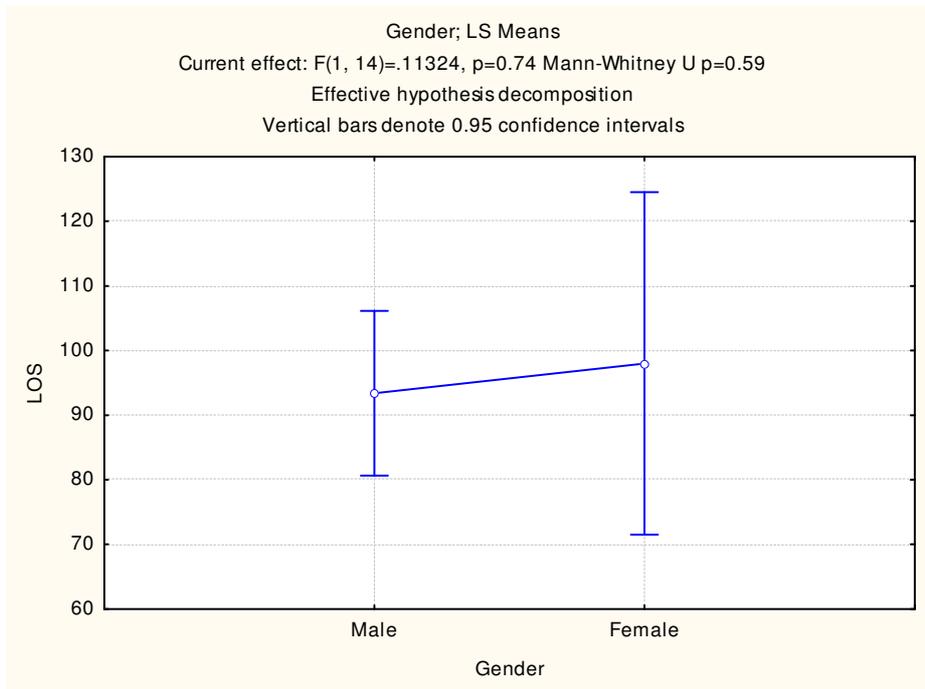


Fig 4.11 Scatter plot comparing LOS to gender

4.4 Functional Independent Measure (FIM) scores

All patients were scored using the FIM on admission and discharge. In order to compare findings with findings reported in the literature, one has to look at only the motor scores and not include the cognitive scores as well, since most studies utilizing the FIM as outcome measure in SCI look only at the motor score. This is understandable since an injury to the spinal cord should not affect cognitive status except if the patient suffered from a concurrent head injury or had a cognitive impairment prior to the SCI.

The initial (admission) FIM motor score in the current study ranged from 23 to 27 with a mean of 24.3 out of a possible 91 and the discharge FIM scores ranged from 77 to 82 with a mean of 79.3 out of a possible 91 (Figure 4.12). The mean gain in FIM motor score was 55. Greenwald et al (2001) report a mean FIM motor score of 26 on admission and 56 on discharge with a mean gain of 29 and another study done by Bode and Heineman (2002) reported an initial motor score of 45.6 and discharge score of 86.5 with a mean gain of 40.9. Both these studies report only on paraplegics with complete lesions between T1 and T12. Therefore the findings from this study on FIM scores are comparable to findings reported in the literature. Since the mean gain in FIM score is far higher than that reported by Greenwald et al (2001) and is similar to that of Bode and Heineman (2002), it reflects well on the rehabilitation program being assessed.

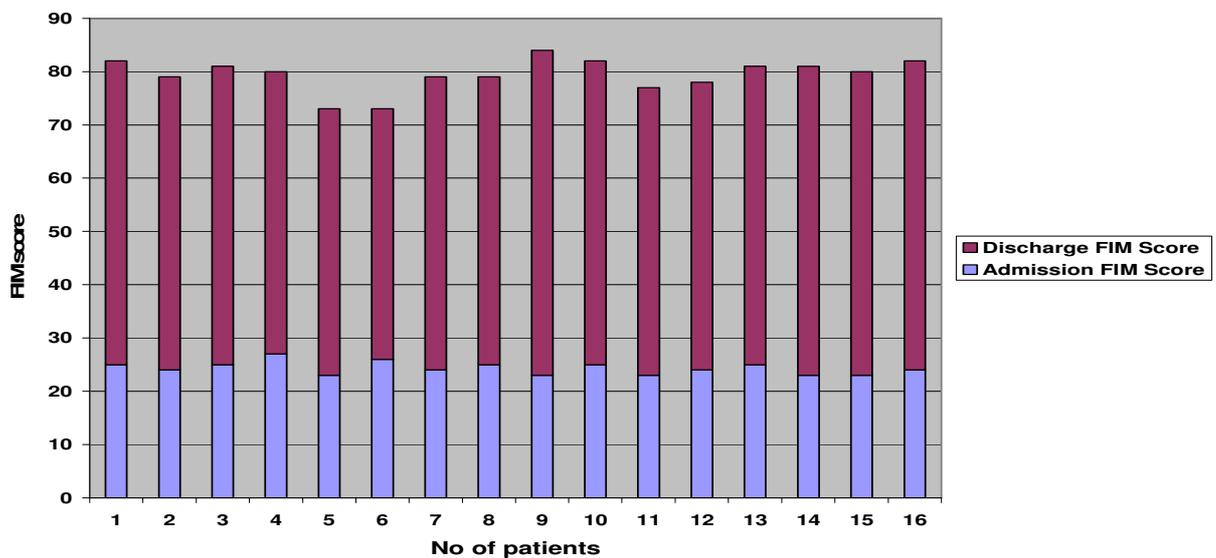


Fig 4.12 FIM scores on admission and discharge

As the scatter plot (Figure 4.13) shows, there was no relationship between admission and discharge FIM scores. A low admission score of 23 resulted in low, average and high discharge scores and similarly higher admission scores like 25 and 26 also resulted in low, average and high discharge scores.

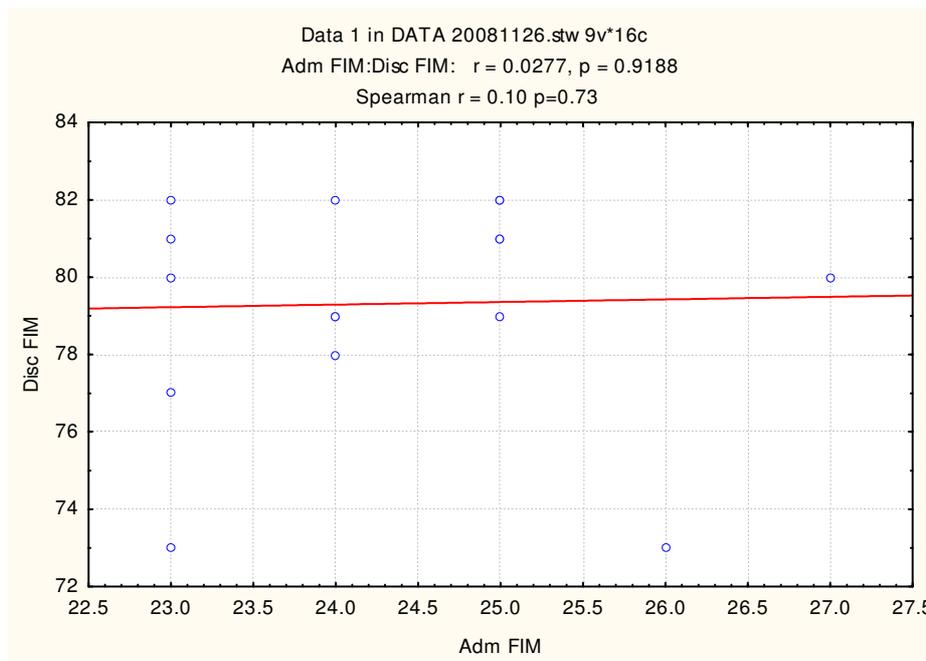


Fig 4.13 Scatter plot comparing FIM admission to FIM discharge scores

4.4.1 FIM admission scores

It is interesting to note that most of the patients had a FIM score of between 23 and 27 on admission with a mean score of 24.3 (Figure 4.14). When looking closely at the different domains in the FIM, one notes that the scores come only from the self-care domain which includes eating and grooming, two activities that for most patients with complete paraplegia are not affected much and which they can do independently from very early on. There was also no correlation between the LOS at the acute hospital and the initial FIM score. Patients who were referred for rehabilitation within the first two weeks after their injury had similar scores to those who were only referred four weeks or longer after the injury.

In the bladder and bowel, transfers and mobility domains, all areas where a patient with paraplegia will have to learn completely new skills, the patients all scored the lowest possible score on the scale which is one out of seven. This explains why admission FIM motor score is very similar for all patients and also similar to that reported by Greenwald et al (2001). Of interest is the relative high admission mean score of 45.6 reported by Bode & Heineman (2002). The researcher could find no explanation for it in the journal article.

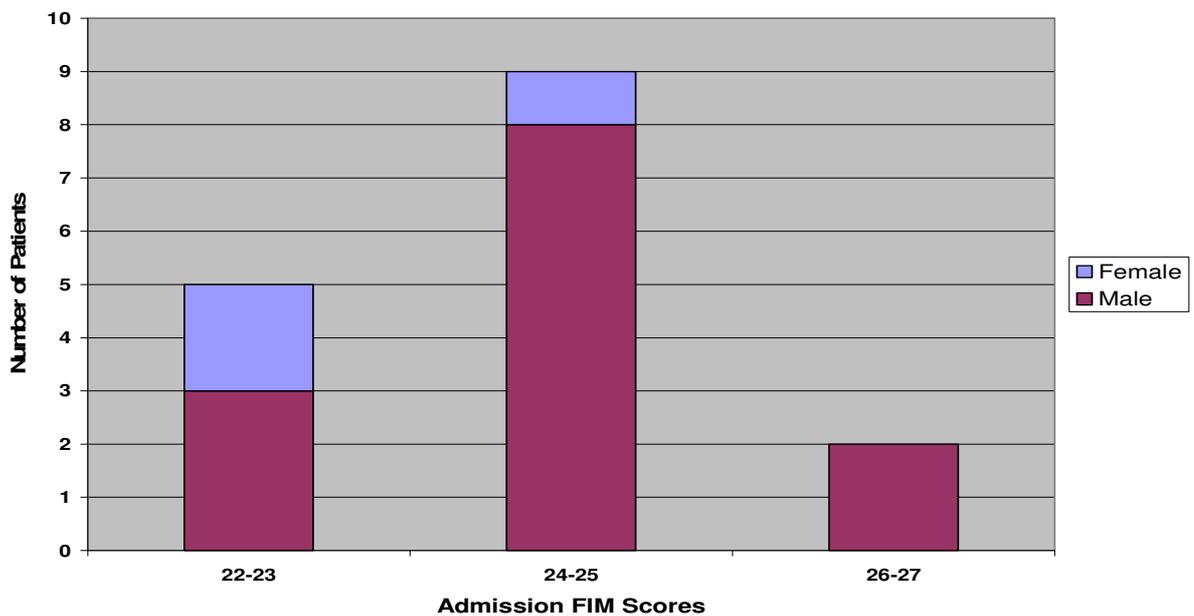


Fig 4.14 Admission FIM motor scores

Neither gender ($p = 0.32$) nor level of injury ($p = 0.35$) or cause of injury ($p = 0.74$) had any significant impact on FIM admission scores.

4.4.2 FIM discharge scores

Discharge FIM scores varied from 70 to 84 while most patients scored between 80 and 84 out of a possible 91. The mean FIM discharge motor score was 79.3 (Figure 4.15). Most categories in the FIM showed gains in the mean score with the biggest improvements in the bladder and bowel as well as the transfers and mobility categories. It is unfortunately impossible for a paraplegic to have a maximum score of 91 as they can only score six out of seven for mobility. This is because they use a wheelchair for mobility and if a person

uses an assistive device to perform an activity he/she cannot score higher than six out of seven for that activity on the FIM. The mobility category in the FIM also includes managing at least six stairs independently, an activity virtually impossible for a wheelchair user. This is another example of why the FIM is not entirely suitable for measuring the outcome of patients with complete paraplegia even if it is accepted as such by various spinal cord associations and authors on the subject (Schönherr et al 1999). The highest score that a patient with complete paraplegia can achieve on the FIM motor score is 84. While no patient in the current study achieved that, seven scored between 81 and 82. Twelve patients (75%) scored more than 79 and only two patients (13%) scored less than 75.

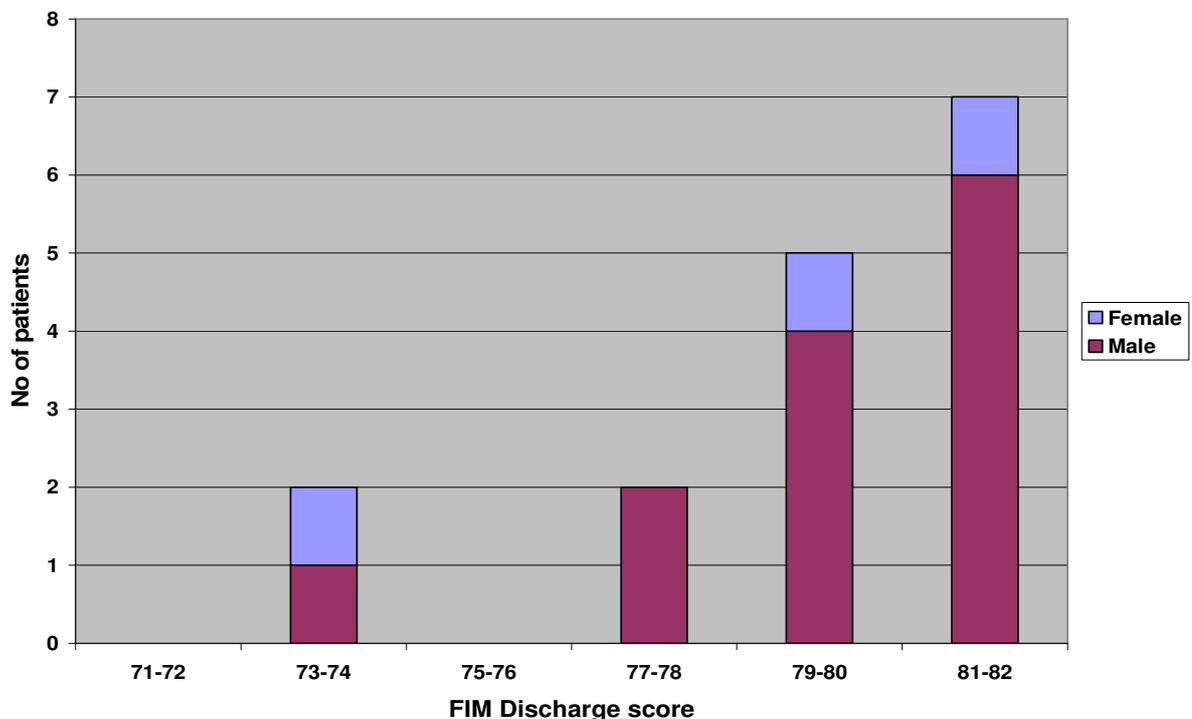


Fig 4.15 Discharge FIM motor scores

Once again no relationship could be found between gender ($p = 0.4$), cause of injury ($p = 0.13$) and level of injury ($p = 0.74$) and FIM discharge scores.

The positive gains in FIM scores of the patients included in this study indicate that the patients achieved high levels of physical independence during the rehabilitation program.

One of the goals of an effective rehabilitation program is to ensure physical independence and according to the FIM scores the program at Netcare Rehabilitation Hospital has achieved this objective within this study population.

4.5 Needs Assessment Checklist (NAC) scores

As discussed in Section 2.5.3 patients' needs are assessed in eight areas through the NAC. This includes four areas on physical activity, which in this study will be compared to FIM motor scores, three areas related to home, community and work integration and one area related to psychological aspects. The NAC scores ranged from 264 to 340 with a mean of 300 out of a possible 347 (Figure 4.16). No comparative literature could be found. The findings from the NAC will be discussed in two sections; firstly the physical aspects will be discussed and compared to FIM findings simultaneously, then the other areas addressed by the NAC which are not addressed by the FIM will be discussed.

Once again no significance could be found between gender ($p = 0.19$), level of lesion ($p = 0.67$) and cause of injury ($p = 0.95$) and NAC scores.

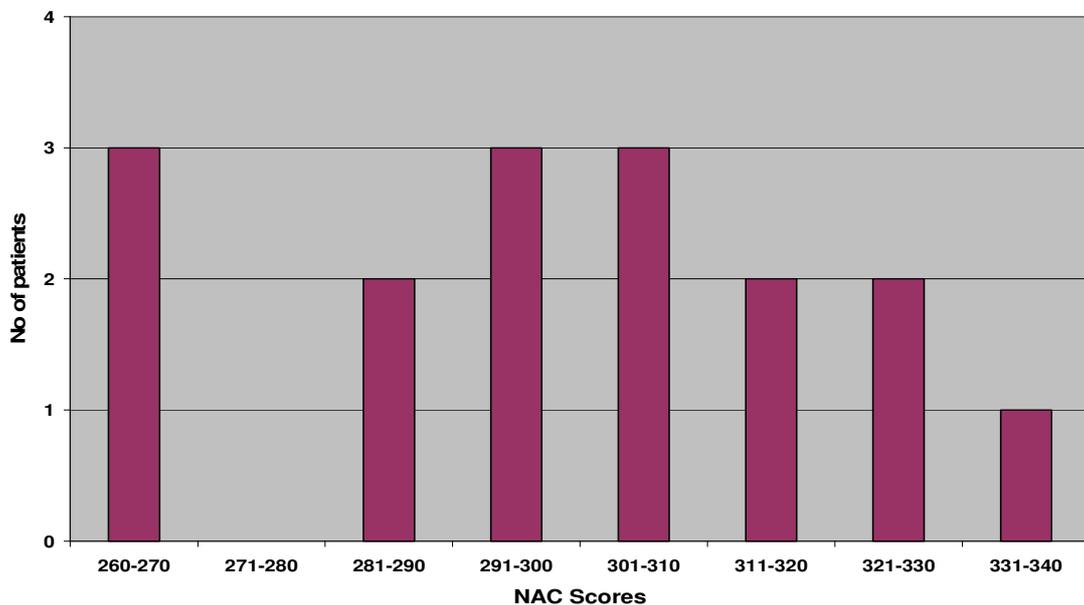


Fig 4.16 Needs Assessment Checklist scores

4.6 Comparison of functional scores of FIM & NAC

The FIM and NAC measure similar physical categories. In the FIM these categories are depicted by the motor scores. The specific areas that are assessed in the FIM are listed in Table 4.2 with similar areas from the NAC alongside. The maximum score possible in each category is also shown in the table.

For the purpose of comparing the scores, some of the categories were combined in order to ensure that the same activities were compared. By combining some categories it was possible to compare three physical categories. For the FIM, transfers were combined with locomotion as the NAC measures these categories under mobility. Likewise the bladder and bowel management category of the NAC were combined as the FIM scores these under sphincter control.

Table 4.2 Maximum scores in FIM & NAC physical categories

MAXIMUM SCORES IN FIM & NAC PHYSICAL CATEGORIES			
FIM		NAC	
SELF CARE		ACTIVITIES OF DAILY LIVING	
Eating	7	Food management	15
Grooming	7	Facial hygiene	15
Bathing	7	Personal hygiene	24
Dressing upper	7	Dressing upper & lower body	30
Dressing lower	7		
Toileting	7		
Total	42		84
SPHINCTER CONTROL		BLADDER & BOWEL	
Bladder	7	Bladder management	30
Bowel	7	Bowel management	21
Total	14		51
TRANSFERS & LOCOMOTION		TRANSFERS & MOBILITY	
Bed, chair, wheelchair	7	Transfers inc bed, toilet, bath,	33
Toilet	7	Shower, car	
Bath, shower	7	Wheelchair mobility	
Wheelchair	7		
Stairs	7		
Total	35		33
Total FIM score	91	Total NAC score	168

The value of comparing the discharge scores of these two instruments lay in the fact that the FIM scores were determined by the researcher while the NAC were scored by each individual patient. Therefore a comparison can be used to determine whether objective and subjective scoring in these areas corresponded. When the FIM scores were given, the discussion indicated that these scores were as high as could be expected and thus a good reflection on the effectiveness of the program. However the FIM scores are objective and the subjective patient scores are necessary to determine if patients also perceive the physical aspects of the program as effective. A summary of the various aspects of the scores in each category is given in percentages in Table 4.3 for the purpose of comparing them. In the following discussion FIM scores are compared to the guidelines from the Consortium of Spinal Cord Medicine (1999) as well.

Table 4.3 Comparison of FIM discharge and NAC motor scores

Variable	Descriptive Statistics (Data 2 in DATA 20081126.stw)						
	Mean	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
FIM Selfcare	95.50	97.00	90.00	100.00	93.00	97.00	3.52
NAC Selfcare	98.94	100.00	94.00	100.00	99.00	100.00	2.02
FIM Bladder & Bowel	85.56	86.00	79.00	86.00	86.00	86.00	1.75
NAC Bladder & Bowel	91.06	97.00	51.00	100.00	91.00	100.00	13.81
FIM Mobility	76.19	77.00	66.00	80.00	74.00	80.00	4.69
NAC Mobility	95.13	97.00	82.00	100.00	92.50	100.00	5.57
NAC W/C	85.69	98.00	33.00	100.00	74.50	100.00	21.78
NAC Community	80.19	84.00	55.00	100.00	64.50	90.50	14.64
NAC Disc Plan	61.25	56.00	35.00	100.00	44.00	73.50	20.83
NAC Psyc issues	88.38	91.00	73.00	100.00	79.00	97.00	9.97

4.6.1 Self-care/Activities of Daily Living

These scores include the motor FIM scores in the Self-care category and the NAC scores in the Activities of Daily Living category as explained in Table 4.2. The mean percentage for the FIM self care score was 95.5 %, with a median of 97 while the NAC mean percentage was 99% and the median was 100%. As Figure 4.17 indicates only three patients scored 100% on the FIM, but eleven patients scored themselves to be 100% in activities of daily living on the NAC.

The expected FIM outcome according to the Consortium for Spinal Cord Medicine (1999) is 6-7 out of 7 (86-100%) for self-care activities. Thus the results of this study correlated well with the expected FIM scores for patients with these specific lesions as all patients scored between 90 and 100%. Again there was evidence that the rehabilitation program at NRH allows patients to achieve physical independence.

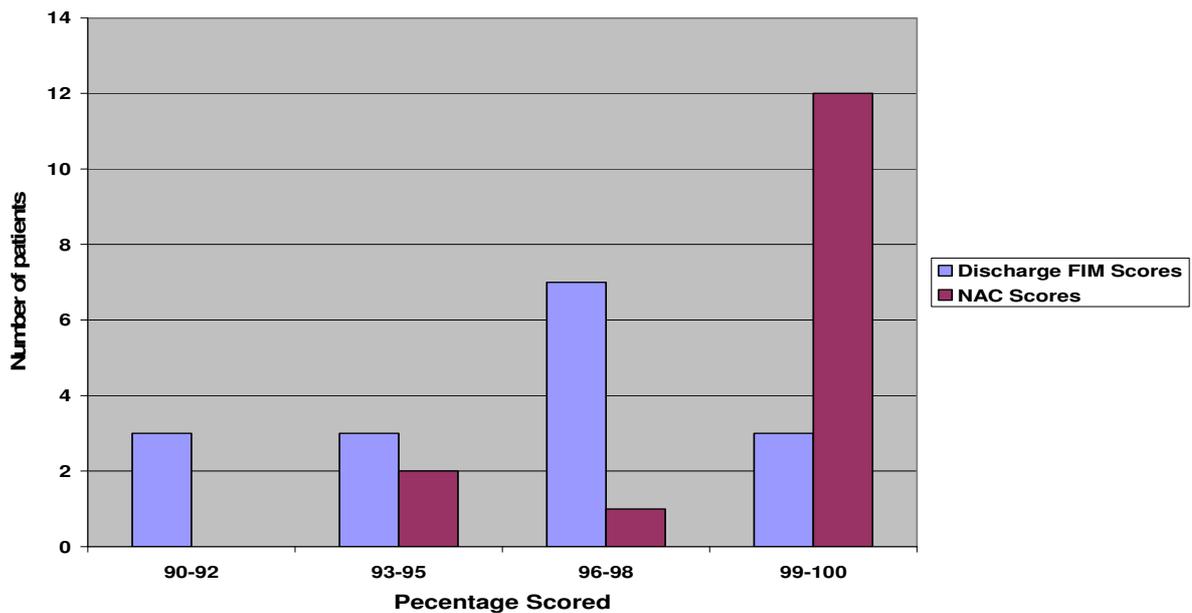


Fig 4.17 Comparison of FIM and NAC Self-care scores

It is evident that the patients' perception of their independence in self-care is better than what was reflected in the FIM scores which were done by the researcher while observing them while they performed self-care tasks. No patient scored themselves lower than 93% while three patients were scored lower than that by the researcher. The patients indicated by scoring themselves high that they feel that they are competent in self-care and could cope with these tasks by themselves and thus that the rehabilitation program addressed these areas sufficiently. From the patients' perspective they were thus satisfied with the level of independence they had achieved.

4.6.2 Bowel and bladder management

To be able to get a full score on the FIM for bladder management, one has to be able to empty one's bladder with no assistive devices. As patients with paraplegia are taught to empty their bladders with the aid of a catheter in the rehabilitation unit where the study was performed no paraplegic could get the maximum score of seven for this category. Therefore, even if the patient is independent in managing his/her bladder, it is not possible to get the maximum score. This might possibly explain the lower mean (85) of the FIM when compared to the mean of the NAC (91) as shown in Table 4.3.

The expected FIM score for bowel management according to the Clinical Practice Guidelines (CPG) is 6-7 out of 7 (86-100%) and 6 out of 7 (86%) for bladder management. The majority of patients in this study were scored between 81 and 90% in these categories and the results are therefore similar to the expected CPG outcome (Consortium for Spinal Cord Medicine 1999).

This is one of the areas where the FIM demonstrates that it is not responsive enough to use for patients with spinal cord injuries as it did not clearly illustrate the patient's independence. On comparison of NAC and FIM scores in these categories, patients again score themselves higher in terms of independent bladder and bowel management than the researcher. Twelve patients felt they were independent in their bladder and bowel management and therefore competent to care for themselves after discharge from the hospital (Figure 4.18). The NAC score range (51 to 100) was also much wider than that of the FIM (79 to 86) which went towards showing lack of responsiveness on the part of the FIM.

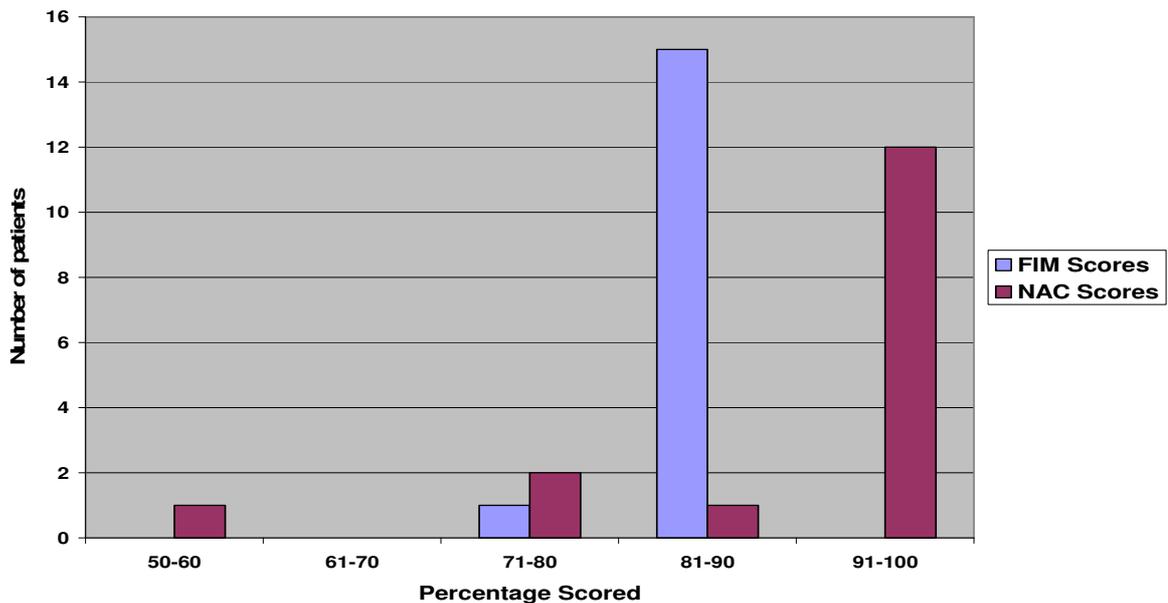


Fig 4.18 Comparison of FIM and NAC bladder and bowel scores

4.6.3 Mobility

For the mobility FIM scores, the patients were observed while doing transfers in hospital to their beds, the toilet, a bath and a car. They were also observed while propelling a wheelchair on a level surface for 50m. The FIM does not take into consideration any outdoor surfaces that a paraplegic has to negotiate to be independent in wheelchair mobility, which is a weakness of the FIM.

The expected FIM score for transfers from bed to wheelchair is 6-7 out of 7 (86 to 100%) according to the CPG and 6 out of 7 (86%) for wheelchair mobility on a level surface. The lower FIM scores (66 to 80% (see Table 4.3) that patients got in this category could be because the patients were scored on four different transfers while the CPG only uses one transfer i.e. bed to wheelchair, which is the easiest of the transfers, in their guidelines.

On comparing the FIM and NAC scores it is again noted that the NAC mean (95) is much higher than that of the FIM (76). No patient was scored more than 80% independent in transfers and mobility, while no patient scored him/herself lower than 80% independent

in the tasks that were part of this category. In fact fifteen patients felt that they were completely independent in transfers and wheelchair mobility, as the 100% NAC score indicates, and therefore once again competent to care for themselves after discharge from hospital (Figure 4.19).

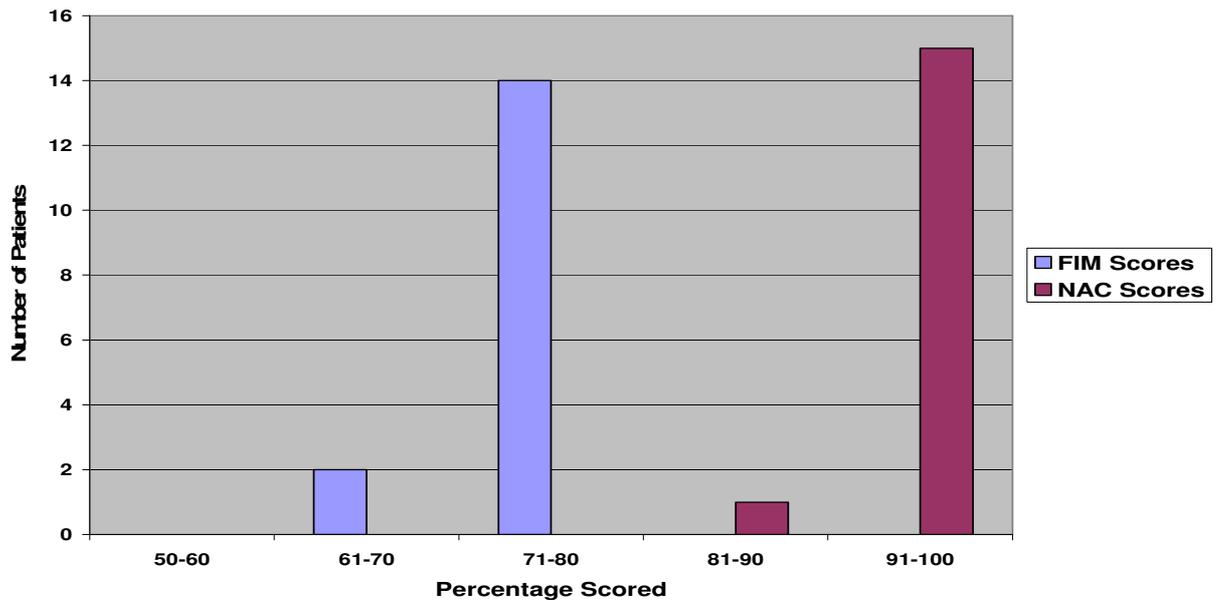


Fig 4.19 Comparisons of FIM and NAC transfer and mobility scores

From the results of this study it is clear that the rehabilitation program was effective in terms of addressing patients’ needs for physical independence. Both objective scores from the FIM as well as subjective NAC scores indicated a high level of effectiveness in this area and this was confirmed by the favorable comparison of FIM scores with the expected scores from the CPG (Consortium of Spinal Cord Medicine 1999).

While one cannot ignore the possibility that the higher NAC scores can be due to the fact that the participants wanted to please the researcher with high scores it is unlikely in the light of the lower scores that were given in other NAC categories (see Section 4.7) by these same participants.

4.7 Additional categories of the NAC

Apart from the physical categories scored in the NAC there are additional categories which score the patient's ability to care for him/herself as well as discharge planning and readiness to integrate back into the community.

These categories are the following:

- Wheelchair and equipment
- Community preparation
- Discharge coordination
- Psychological issues
- Prevention of secondary complications e.g. pressure sores (NAC 2.1, 2.2, 2.3 & 6.3)

4.7.1 Wheelchair and equipment

This category determines the patient's knowledge about his/her mobility equipment, for example the make and model of the wheelchair and pressure care cushion as well as knowledge on the maintenance of the equipment. The mobility equipment is prescribed according to each patient's needs in terms of age, body build, transport, and mobility needs. All patients get different wheelchairs to try out to assist them in making an informed decision. Before they make a final choice, they are allowed to go home for a weekend with the chair of their choice to check on the maneuverability of the chair in their houses as well as the ease with which it can be transported. Should their living circumstances change dramatically at a later stage, however, e.g. a move from urban to rural equipment might however not be suitable anymore. As the patient has to score him/herself, this category also gives some indication if the patient is ready to take care of his/her mobility equipment.

The majority of patients (twelve) scored themselves as having more than 80% knowledge of their equipment and the maintenance thereof with ten patients actually scoring themselves more than 90% (Figure 4.19). This, as well as a mean score of 85 and a median of 98 (Table 4.2) reflects well on the rehabilitation team and program, whose task

it is to ensure that each patient knows his/her equipment to the extent that they know how to take care of it and when to replace it. It is a concern, though, that two of the sixteen patients scored themselves less than 50% and two patients scored themselves between 60 and 70% (Figure 4.20). A possible explanation for this is that patients are often still in denial about their disability during rehabilitation and tried to distance themselves from their mobility equipment. Accepting a wheelchair also means that they need to accept their disability as permanent. The other possible reason could be that the rehabilitation team neglected to inform and educate the patients about their equipment. The study, however, did not establish the specific reasons for this and it would need some further investigation. Another aspect that was lacking in this assessment is that patients were not asked whether they found the equipment suitable for their needs. Choosing a wheelchair after testing, might only mean that they choose the best available option and not necessarily that this option really addresses their needs optimally.

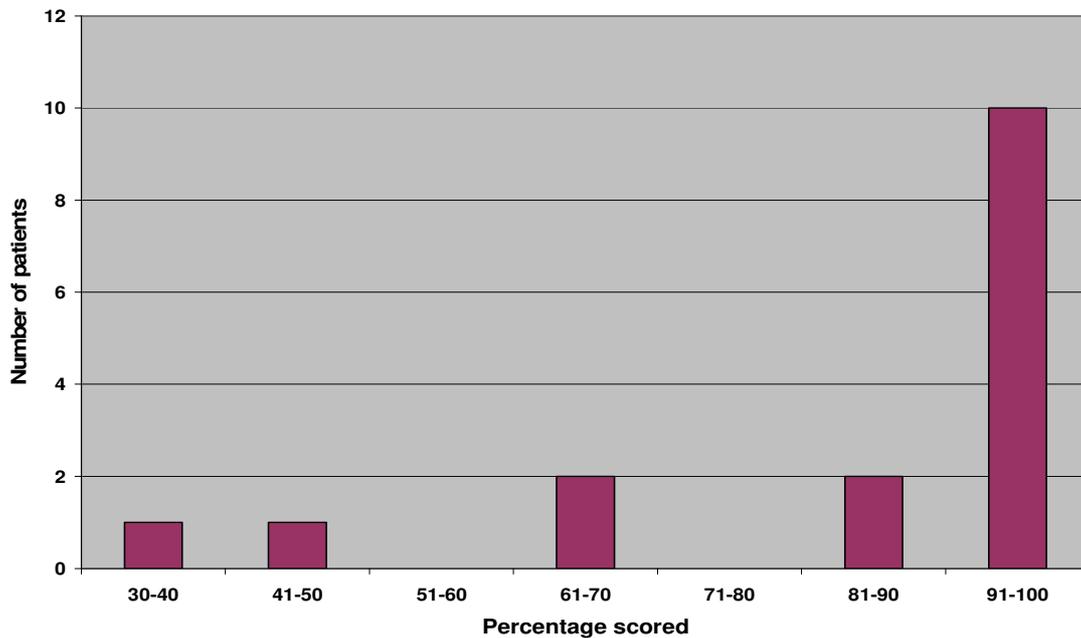


Fig 4.20 Knowledge on wheelchair & equipment scores

Since mobility equipment is crucial for a paraplegic who relies on his wheelchair for most of his independent mobility, no patient should not have adequate knowledge about their equipment on discharge from the hospital.

4.7.2 Community preparation

This category includes social activities, employment, community preparation as well as driving and transport issues. It includes the patients' participation in the patient education program, whether they went out of the hospital on a social event and whether they made any plans to return to work. This category can be used to determine if the patient is ready to be discharged from the hospital and if the rehabilitation team and program has prepared the patient adequately to reintegrate into the community and work environment.

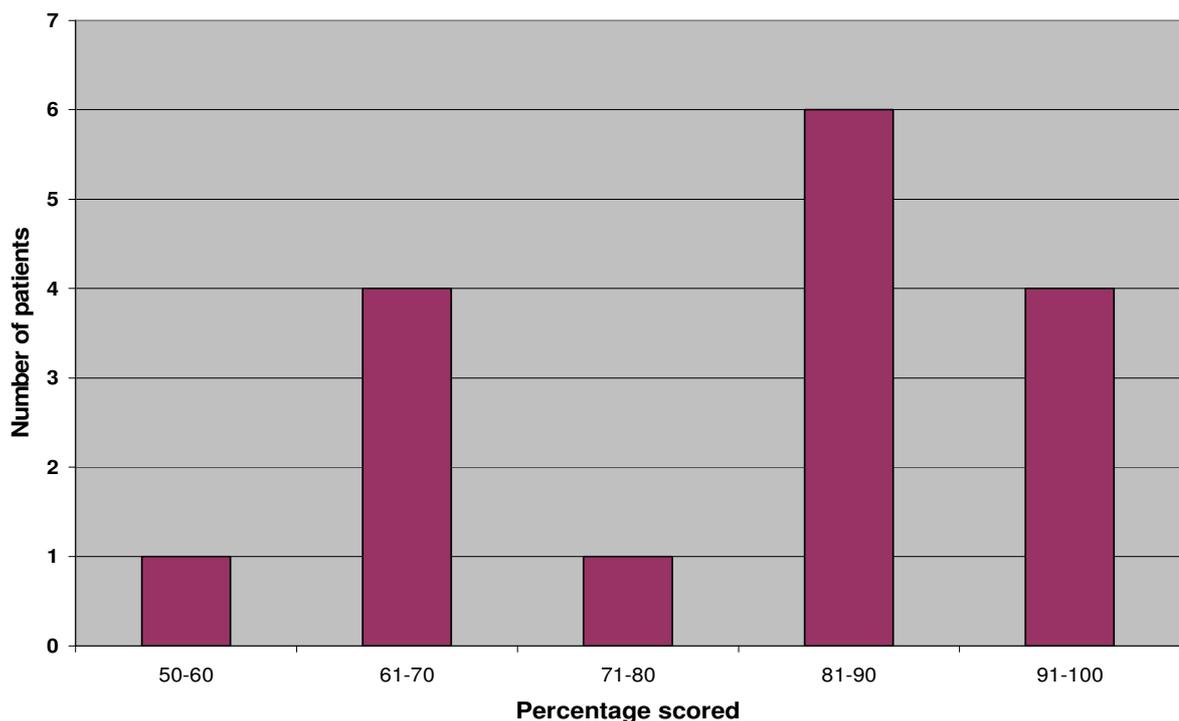


Fig 4.21 Community preparation and work readiness scores

This is the first area to raise some real concerns about the effectiveness of the rehabilitation program as only ten patients (62.5%) scored themselves higher than 80%

(Figure 4.21). Although no patients scored themselves lower than 50%, it is concerning that 31% of the patients had a score below 70%. It seems as if the rehabilitation program needs some changes in this area in order to ensure a higher standard of readiness for community integration and work. Looking closely at the scoring in this category, it was found that the questions on employment were scored the lowest. Seven patients (44%) reported that adaptations are necessary for them to return to work and that at the time of discharge no adaptations were made by their employers, three patients also reported that they had made no plans to return to work at the time of discharge. This is a crucial area and must be addressed to a far greater extent by the rehabilitation program.

As most patients in this study were young adults who had to return to employment, this raised the question whether they would be re-employed after rehabilitation and whether the patients themselves were ready to go back to work.

One of the questions in the category of community preparation asked if the patient had spent some time in an independence ward. At NRH the independence ward is a cubicle in the main ward to which patients are transferred when independent in basic ADL. All patients in the rehabilitation program at NRH spend time in this cubicle before being discharged from hospital. Although it is expected of patients to do all basic ADL themselves with no assistance from the nursing staff, it is still within an accessible area where they have no problems in using, for example, the bathroom facilities.

4.7.3 Discharge Planning

The discharge planning category includes community issues, accommodation and the care package which covers the needs of the patient if they would need a carer and the training of the carer. The questions focus on the patient's preparation for discharge, adaptations to their houses and on knowledge regarding where to find medical assistance in their communities. Contrary to the previous categories, it was found that 75% (twelve) of the patients scored themselves lower than 70% with an alarming 37.5 % (6) scoring below 50% and only 25% (4) above 80% (Figure 4.22). With a mean score of 61 and an even lower median of 56 this was the only NAC score with a mean below 80 (Table 4.2).

Again this indicates an area where the rehabilitation program is lacking and where changes must be made to the program.

The areas in this category which most patients (11 or 86%) scored the lowest were on questions like knowledge on where to find a social worker and nurse in the community and whether they were referred to a social worker in the community. A question that arises from this is the appropriateness of referring a patient with medical insurance to a nurse/social worker. A referral to their general practitioner would be more appropriate in this instance and this could be a reason why so many patients scored very low in this category. As the NAC was not changed at all for use in this study, it should be investigated if all questions are applicable to all South African patients and should be changed if found not appropriate. Unfortunately this issue was not identified during the pilot study. On the other hand should a patient fail to re-enter the labour market they may become disability-grant recipients who are entitled to free public health care and should thus have received above information.

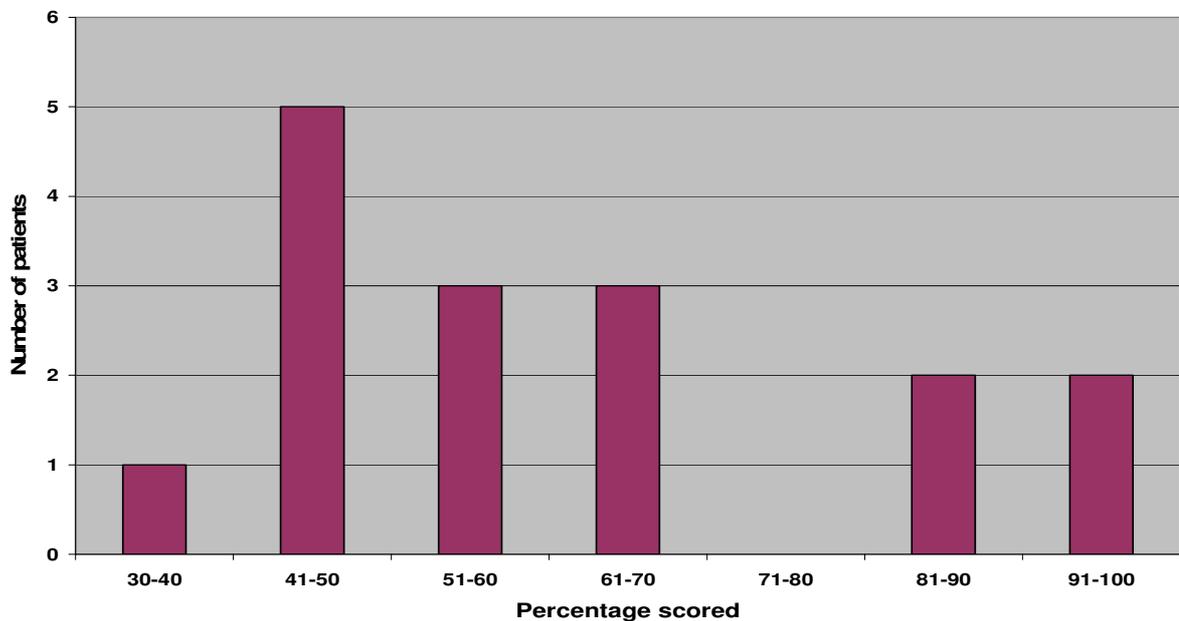


Fig 4.22 Discharge planning scores

Another low score was on the performing of home visits by the occupational therapist to assess homes for accessibility. Six patients (37.5%) were not visited by an occupational therapist at home to assist them with the planning of home adaptations. Both home and work visits to assess for necessary accommodations and accessibility are mentioned as part of the rehabilitation program at NRH. However, from these results it seems as if the program was not always adhered to and some investigation is necessary to find the reason for this.

4.7.4 Psychological issues

In this category patients are questioned on their mood and the sexual counselling they received during their stay at the rehabilitation facility. All patients scored themselves more than 70% and twelve scored themselves more than 80%, indicating that they were satisfied with the counselling and the advice they received and reflecting positively on the effectiveness of the rehabilitation program in this area. (Figure 4.23)

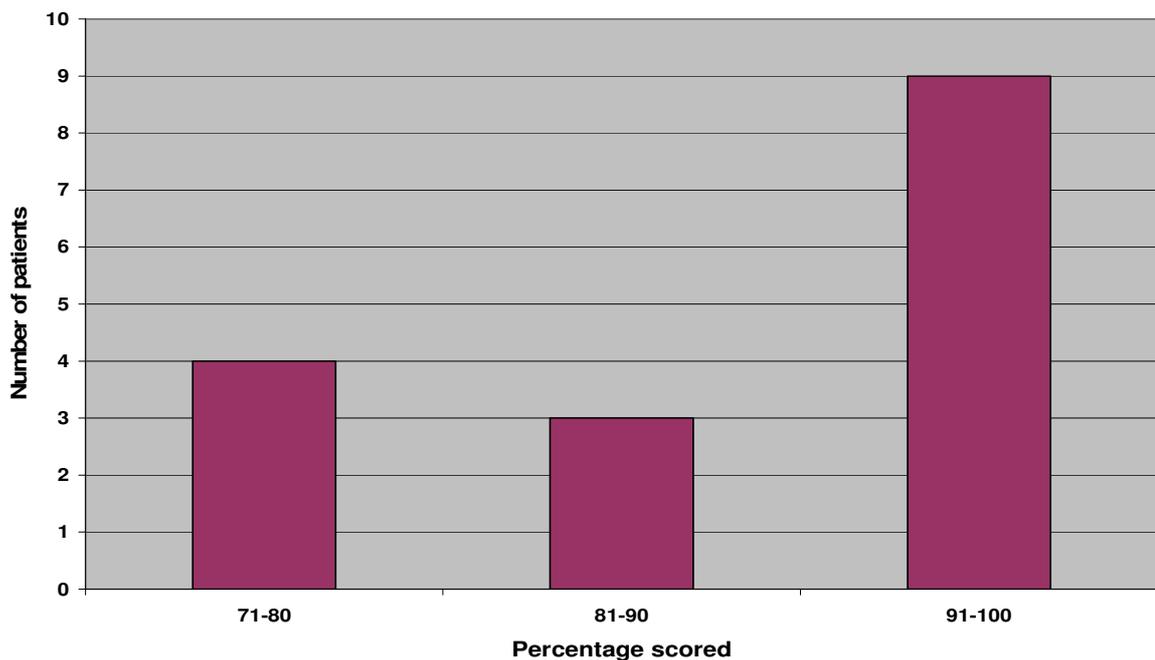


Fig 4.23 Psychological issues scores

4.7.5 Prevention of secondary complications

There are two categories in the NAC that specifically addressed prevention of secondary complications, namely pressure sores and joint stiffness/contractures.

Eleven of the patients had a full score in both these categories, while five patients scored less than the maximum. It is interesting to note that these five patients had neither a full score in the prevention of pressure sores (NAC 2.1-3) nor a full score in the question on standing (NAC 6.3). No score however was below 85%. Prevention of complications was discussed with all patients during the education program that forms part of the rehabilitation program at NRH. The scoring in these categories indicates that the education program was well understood by most of the participants.

4.8 Summary

The effectiveness of the rehabilitation program at NRH with regards to achieving physical independence and preparation for reintegration into the community was measured with 16 participants in this study using two outcome measures and the results as presented in this chapter reveals the following:

The demographic details show sixteen participants who in age and gender compared to findings in the literature reviewed on these aspects and had relatively good socio-economic circumstances when compared to the general population of Gauteng and South Africa. No correlation was found between any demographic detail and FIM or NAC scores. When the LOS were compared to the demographic data there was also no correlation found. The FIM scores showed that a high level of physical independence was achieved by the participants in categories like self-care, mobility and transfers. The NAC scores in these categories also showed that the patients perceived themselves to be physically independent. This gives the impression that the rehabilitation program succeeded in ensuring physical independence of patients.

However, in the categories measuring the patient's preparation to reintegrate into the community, the patients did not score themselves very high. These categories included discharge preparation and community integration. The poor scores definitely gave the

impression that the patients were not adequately prepared during their rehabilitation for discharge and that the rehabilitation program lacked the ability to fully address issues pertaining to successful reintegration into their own communities.

CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

The aim of the study was to determine if the rehabilitation program for patients with complete paraplegia at Netcare Rehabilitation Hospital was effective in terms of physical independence of patients and in terms of preparing the patients for reintegration into the community. From the results it is clear that while patients' needs were met with regards to physical independence they were not totally met with regards to community reintegration.

The study population consisted of a small ($n = 16$), homogenous group which compels one to be careful with generalisation or extrapolation of results in the same setting or to other similar settings or programs. However, the demographic details of study participants were similar to those of participants of similar studies cited in the literature which leads one to assume that although small this was still a representative population and especially since the population represented a relatively scarce condition. Even so the researcher wanted to caution would-be users of these recommendations to carefully consider demographic details and study-setting for similarities and differences before using the recommendations. For instance, the demographic profile - as can be expected of a patient population from a private hospital - points to a relatively advantaged group of urban dwellers, as most were privately funded through medical aids and were living in urban suburbs.

Conclusions will be drawn according to the objectives of the study and recommendations will be made from that.

5.2 Demographic profile of participants

The sixteen study participants had a similar demographic profile to that of participants of studies found in the literature in terms of age, gender, level of lesion and cause of accident. Therefore findings could be compared to those of similar studies which are

reported on in the literature. Furthermore they were urban dwellers and most had occupations that they should be able to go back to once adaptations have been made. The five participants who were dependent on public transport might have difficulties to get to and from work and the current inaccessibility of public transport might even force them to resign. Furthermore the two participants who gave their occupation as mine workers might need to be accommodated in different jobs. Most participants might have benefited from work visits and contact between the rehabilitation team and employers to assist with accommodations and job changes where needed.

5.3 Length of stay

The length of stay at Netcare Rehabilitation Hospital is set by the rehabilitation team at twelve weeks (84 days) for a newly injured patient with complete paraplegia. It is expected that the patient should complete the rehabilitation program in this time period and be ready for community reintegration at the end thereof. The mean length of stay for the patients in the study was 95 days (13.5 weeks). Unfortunately neither of the two instruments used in this study was able to give any indication as to why the patients stayed on average longer than the predicted stay to complete their rehabilitation program. All the patients had achieved a high level of physical independence at discharge according to their FIM scores, but not all were ready for reintegration according to their NAC scores. The questions arising from this are two-fold:

- Are the patients not ready for reintegration due to a too short hospital stay?
- Are the issues concerning their readiness for discharge not adequately addressed by the rehabilitation team during their stay in the hospital?

These aspects must be researched further.

5.4 Effectiveness of program in terms of FIM scores

In this study the FIM was used to measure program effectiveness in terms of functional outcome of patients. There was a mean gain in FIM scores of 55. This compared well with findings reported in the literature. Therefore it can be concluded that from an objective point of view the rehabilitation program for patients with complete paraplegia at Netcare Rehabilitation Hospital was effective in terms of addressing patients' physical

needs as all patients in the study had achieved physical independence by the time they were discharged from the hospital.

Even though the results of the FIM were good when compared with the literature, the FIM did show some shortcomings when used to measure functional outcome of complete paraplegics. Firstly, the instrument does not address all the activities necessary for independent functioning in everyday life outside of the hospital e.g. making use of transport, propelling a wheelchair on uneven terrain etc. A huge frustration is the mobility scoring where the patient is scored on propelling a wheelchair independently for 50m on a level surface only. It is well-understood that a person who is paralysed needs wheelchair mobility skills far exceeding that to cope with all surfaces and different terrain when integrated back into the community (Schönherr et al, 1999). On the other hand even a patient who is proficient on all surfaces and terrain cannot score the maximum score since the wheelchair - an assistive device - precludes one from scoring the maximum score. This ceiling effect was also noticeable in areas like bladder and bowel management where patients scored themselves 100% proficient while the use of a device prevents a score of 100% on the FIM even when they can perform the activity completely independently.

Secondly, the FIM showed a lack of sensitivity when compared to the NAC. For instance on bladder and bowel management FIM scores range from 71 to 90% whereas NAC scores ranged from 51 to 100%.

Finally, one must always remember that the FIM is an activity score and does not address participation. Thus high FIM scores are not necessarily equal to successful community integration. This might be one of the reasons why the program under assessment in the current study did so well on physical activities but failed to address community integration equally well. As stated in chapter one the FIM is currently the only outcome measure in use in the rehabilitation program at NRH and according to the FIM the program is performing very well. There is thus a clear need to introduce a participation measure into the program as well.

5.5 Effectiveness of the program in terms of NAC scores

Results from the physical categories of the NAC supported the finding that the rehabilitation program at Netcare Rehabilitation hospital was effective in assisting the patients to achieve physical independence. All patients scored themselves as independent in activities like self-care, bladder and bowel management and wheelchair mobility.

However, in the categories that measured the patients' readiness to be discharge from the hospital, mixed results were obtained. While patients scored their knowledge on their wheelchair and equipment as well as psychological issues high, areas like preparation to go to work and the actual planning of the discharge received a lower mean score from the patients which raises concern. The low scores of more than 50% of the patients in these categories indicate that these aspects were not addressed adequately during the rehabilitation program.

However, it is also necessary to revisit the use of the NAC in a South African private medical care context and investigate if all the questions are applicable to rehabilitation in South Africa. Especially some of the questions in the community integration category which related to referral to a nurse or social worker may need to be changed to fit in with what happens in private health care in South Africa. Questions that are not completely applicable to the patient population may also be a reason for low scores.

As discussed in Chapter 1, the overall aim of the rehabilitation program is to prepare the patient for functional independence in a wheelchair and to successfully integrate back to his/her community. There is no doubt that this research indicated that the patient was functionally independent in physical activities by the time of discharge, on the other hand the findings indicated that the rehabilitation program was not equally effective in the preparation for integration into the community and this must be addressed by the rehabilitation team.

5.6 Comparison of FIM scores to the Clinical Practical Guidelines of the Consortium of Spinal Cord Medicine

The Clinical Practice Guidelines for health-care professionals which outline the expected functional outcome following traumatic spinal cord injury have been used in this study to analyse the outcome of the patients (Consortium for Spinal Cord Medicine 1999).

The FIM motor scores of this study compared well with the expected scores of the guidelines. This once again is an indication of the effectiveness of the rehabilitation program at Netcare Rehabilitation Hospital in terms of physical independence.

5.7 Cost effectiveness

Cost-effectiveness is a crucial part of any treatment in the health-care industry today. For a program to be cost effective it is important that all the objectives of the program are met in the shortest possible time as discussed in Chapter 1. The length of stay (LOS) of the patients in this study is comparing well with similar studies. However the LOS of study participants were longer than what was set by the program, which leads one to question whether the predetermined LOS of twelve weeks is adequate. The patients were all physically independent when they left the hospital. The only other question that arises is what happened to the patients after discharge from hospital. It was unfortunately not the objective of this study to establish if the patients did reintegrate successfully into their communities. Therefore, to determine if this rehabilitation program is justifying the cost thereof, one would have to do a follow-up study to assess the reintegration of the patients.

5.8 Funding for rehabilitation

While completing this study it was observed that a large percentage (nine) of patients admitted to the hospital for rehabilitation did not complete their full rehabilitation program due to financial constraints. The rehabilitation of all of these patients was privately funded by medical aids and their admission for rehabilitation was authorised by the medical aids. Why this authorisation was negated on, and a discharge enforced, prior to the completion of rehabilitation was unfortunately not part of the scope of the current study.

At present there are no rehabilitation protocols for patients with SCI in South Africa which can provide guidelines in terms of LOS. It is therefore the experience of the researcher that the medical insurance companies decide how long they are willing to pay for rehabilitation. Unfortunately medical insurance companies often cut the funding as soon as the patient is able to do the most basic self-care tasks by himself. The rehabilitation providers might actually be in part guilty of the instigation of this practice since we so often also focus only on activity, as the use of the FIM as the only measuring instrument in a program of this nature indicates. This underlines the importance of introducing another outcome measure into the program which measures participation and/or community integration and which is acceptable to medical insurance companies as well as all other stakeholders.

From the results of this study it is noted that a large percentage of patients was not entirely ready for reintegration into the community despite completion of their rehabilitation program. That leads one to be concerned for those individuals who could not complete their program due to financial constraints. The question that arises is: are they even less prepared and how would that impact on future medical costs e.g. infections and pressure sores, to name but two, as well as on their economic self-sufficiency and thus their ability to contribute to a medical aid, amongst other things, in future?

5.9 Recommendations

5.9.1 Measuring instruments

The results of the study had shown the NAC to be a suitable instrument to measure both physical independence and the extent to which patient needs have been met in terms of preparation for participation in social roles. Therefore it is recommended that the NAC is introduced as a measuring instrument into the spinal cord injury rehabilitation program at NRH. Since the data from the NAC on physical abilities were more valuable than that of the FIM, because of the higher sensitivity to changes, lack of a ceiling effect and incorporation of both the use of assistive devices and assistance without penalising the patient, it might even be argued that the NAC can replace the FIM altogether as outcome measurement tool in this setting.

However, there is a need to complete the NAC during the rehabilitation process as well and not only on discharge. Since the rehabilitation period is set arbitrarily at twelve weeks and the issues that were found lacking in the rehabilitation program according to the NAC focused mainly on community preparation and discharge coordination, areas that are traditionally addressed during the more advanced stages of rehabilitation, the researcher recommends that the NAC is initially completed after the first month of rehabilitation. This information can then be used by the rehabilitation team to set specific patient-centred goals in order to address these issues in the final two months of rehabilitation. A final evaluation can be done on discharge. It is also recommended that all the questions in the NAC are scrutinised for appropriateness and changed if necessary.

5.9.2 Performance measurement of the rehabilitation program

Performance measurement should become an integral part of the rehabilitation program at NRH and must be performed on a regular basis to ensure that the program is effective. Therefore valid, reliable, feasible and responsive performance measurement tools must be identified and implemented as a matter of urgency.

5.9.3 Rehabilitation program for patients with complete paraplegia at NRH

While results from the study showed a successful program in terms of addressing physical independence of patients, it showed a failure to address issues necessary to ensure successful community reintegration. Specific areas of concern that were identified included knowledge on wheelchair and equipment, community preparation with specific emphasis on employment and discharge planning with specific emphasis on community health care resources and accessibility of living spaces.

It is necessary for the program managers and rehabilitation team to look closely at these findings and then incorporate changes into the rehabilitation program that would address these issues. It is, furthermore, important to ensure that these issues are addressed during the 12 weeks of the program as any increase in length of stay will further impact negatively on costs and thus even more patients than is currently the case, might be unable to complete their rehabilitation program due to financial constraints.

One suggestion is the use of the NAC as a tool to determine needs on these aspects during rehabilitation and set goals accordingly as discussed under Section 5.9.1.

A second suggestion is that the rehabilitation program is changed to incorporate an institution based phase as well as a community based phase. The National Rehabilitation Policy of South Africa (Department of Health 2000) advocates for a continuum of care with institution based care where needed, but also with community based care where applicable. The advantages of in-patient rehabilitation after a catastrophic event such as SCI are well-known. However, the advantage of being rehabilitated in one's own environment is also being advocated (Department of Health 2000; Office of the Deputy President 1997). Currently the rehabilitation program has only an institution based component which fails to address community integration issues fully. In addition, funding problems related to costs and LOS were identified.

The researcher suggests a rehabilitation program which combines a shorter in-patient phase to address issues like bladder and bowel management, and basic self-care, with a community based phase that completes above aspects of rehabilitation and also addresses home, community and work integration in the actual environments where this needs to be done. This will decrease LOS and costs while it should improve outcome.

The development of such a program will need careful consideration, planning and research from all stakeholders e.g. the rehabilitation team and management team from NRH, the medical insurance companies and people with SCI. Although the latter will not be the consumers of such a program they can provide valuable input through their experiences and they can even play a role and being employed on a freelance basis as peer instructors etc. in the new program. The funders should be aware that the program continues after discharge and that they are responsible for payment thereof.

5.9.4 Recommendations to other SCI rehabilitation programs

Extrapolation must be done with caution because of the homogeneity of the study population as well as the small size of the population. However the results of the study were so compelling that one wants to urge other settings where SCI rehabilitation is performed to consider using the NAC as an assessment tool and to scrutinise their own programs with regards to their effectiveness in preparing patients for community reintegration and employment.

5.9.5 Recommendation to SASCA

There is a need for community based rehabilitation programs for individuals with spinal cord injuries to complement the institution based rehabilitation. SASCA can play an invaluable role with regards to initiating and developing such CBR programs which would assist the spinal cord injured individual with full community integration and regaining gainful employment.

5.9.6 Recommendations for further studies

- Since the current study had very few participants it can, in a way, be seen as a pilot study which revealed important issues and must now be followed by similar studies, both at NRH as well as on a wider basis throughout South Africa, including patients with all levels of SCI, complete as well as incomplete lesions and all aspects of program effectiveness incorporated.
- A study to assess the outcome of all patients who were unable to complete the rehabilitation program due to financial constraints
- A follow-up study on the potential and real participants of this study, as well as other groupings mentioned under the first recommendation to assess their reintegration into their communities and to justify the cost of the rehabilitation program
- A study into the cost-effectiveness of the rehabilitation program at NRH
- A study on length of stay and community integration outcome of patients with complete paraplegia

- A study on the relationship between admission FIM scores and LOS in a larger population of patients with complete paraplegia
- Develop, implement and assess a rehabilitation program with a shorter in-patient rehabilitation phase which is followed by an out-patient rehabilitation phase.

5.10 Conclusion

This study has shown that the rehabilitation program for patients with complete paraplegia offered at Netcare Rehabilitation Hospital provided patients with the opportunity to reach a level of physical independence with which they are satisfied and which is satisfactory from the viewpoint of the service providers as well. However, the program did not meet the needs of the patients with regards to reintegration into the community.

The need to incorporate the NAC as an assessment measure for the program is strongly supported by the results of the study. Furthermore, it is evident that those issues pertaining to community integration, like accessibility and employment, must be addressed to a greater extent in the rehabilitation program and that the program planners should incorporate changes to that effect.

5.11 Limitations of the study

Some issues regarding the study which impacted negatively on the validity, reliability and usefulness of findings were identified. These include:

- Not scoring the patients with the NAC on admission or at some other point during the rehabilitation process earlier than discharge.
- Not measuring community integration in some other ways as well e.g. how many patients were able to go back into employment, in how many cases did wheelchairs provide the needed mobility in the discharge environment, the impact of transport on integration etc.
- Not determining how many patients were referred to CBR programs or other forms of further rehabilitation or support structures

- In retrospect the researcher feels that she should have included another dimension to the study by incorporating a qualitative component as well and, through the use of focus group discussions or in-depth interviews, determined the opinions of patients on aspects that were only measured through rigid structured questionnaires.
- The intra-rater reliability of the researcher on using the FIM was not established
- The NAC questions were not changed to be more applicable for a South African population after the pilot study was done

REFERENCES

- American Spinal Injury Association 2002. *Reference manual for International standards for neurological and functional classification of spinal cord injury patients (revised 2002)*. Chicago. American Spinal Cord Injury Association.
- Berkowitz M, O'Leary P, Kruse D, Harvey C 1998. *Spinal Cord Injury: An analysis of medical and social costs*. Demos Medical Publishing Inc. New York.
- Berry C & Kennedy P 2002 'A Psychometric analysis of the Needs Assessment Checklist (NAC)'. *Spinal Cord* 41, 490-501.
- Blackwell T, Krause J, Winkler T & Stiens S 2001 *Spinal Cord Injury Desk Reference: Guidelines for Life care planning and Case management*. Demos Medical Publishing Inc. New York. P133-137.
- Bode R & Heineman 2002. 'Course of functional improvement after stroke, spinal cord injury and traumatic brain injury'. *Arch Phys Med Rehabil*, 83, 100-106.
- Boschen K, Miller W, Noreau L, Wolfe D, McColl M, Ginis K, Prince M, Joe K & Konnyu K 2008. 'Community reintegration following spinal cord injury'. *Spinal Cord Injury Rehabilitation Evidence Version 2.0*. Vancouver.
- Burnett M, Cifu D, Kolakowski-Hayner S & Kreutzer J 2001 'Predicting "Charge Outliers" after spinal cord injury: a multicenter analysis of demographics, injury characteristics, outcomes, and rehabilitation charges'. *Arch Phys Med Rehabil*, Vol 82, 114-119.
- Canadian Paraplegic Association (CPA) 1997. Spinal Cord Injury Workforce Participation National Survey. (online cited on 1 December 2008) www.icord.org/scire.
- Cardenas D, Hoffman J, Kelly E, Mayo M 2004. 'Impact of a urinary tract infection educational program in persons with spinal cord injury'. *J Spinal Cord Med*, 27, 47-54.
- Cardenas D, Hoffman J, Kirshblum, McKinley W 2004. 'Etiology and incidence of rehospitalization after traumatic spinal cord injury: a multicenter analysis'. *Arch Phys Med Rehabil*, 85, 1757-1763.
- Carter GM & Hayden O 2002. *Analysis for the initial implementation of the inpatient rehabilitation facilities prospective payment system*. Santa Monica, Calif: Rand.
- Catz A, Itzkovich M, Steinberg F, Philo O, Ring H, Ronen J, Spasser R, Gepstein R & Tamir A 2001. 'The Catz-Itzkovich SCIM: a revised version of the spinal cord independence measure'. *Disability and Rehabilitation* 23, no6, 263-268.
- Community Based Rehabilitation. 2004. A strategy for rehabilitation and equalization of opportunities of people with disabilities. (www.ilo.org/public/health/english/employment/skill). Cited 28 December 2008.

Cole B, Finch E, Gowland C & Mayo N 1994. *Physical Rehabilitation Outcomes Measures*. Canadian Physiotherapy Association.

Consortium for Spinal Cord Medicine 1999, *Outcomes following traumatic spinal cord injury: Clinical Practice Guidelines for Health Care Professionals*. Paralyzed Veterans of America.

Dawudu S 2008. 'Spinal Cord Injury: Definition, Epidemiology, Pathophysiology'. Viewed on 6 January 2009. www.emedicine.medscape.com.

Department of Health 2000, '*National Rehabilitation Policy. Rehabilitation for all.*' National rehabilitation policy of SA 2000.

Dittmars S & Gresham G 1997, *Functional assessment and outcome measures for the rehabilitation health professional*. Ed Maryland: Aspen productions.

Donnelly C, McColl M, Charlifue S, Glass C, O'Brien P, Savic G 2007. 'Utilization, access and satisfaction with primary care among people with spinal cord injuries: a comparison of three countries. *Spinal Cord*, 45, 25-36.

Donovan W, Carter R, Bedbrook G, Young J, Griffiths E 1984. 'Incidence of medical complications in spinal cord injury: patients in specialised, compared with non-specialised centres'. *Paraplegia*, 22, 282-290.

Duckworth, M 1999, 'Outcome measurement selection and topology', *Physiotherapy*, 85, (1), 21-27.

Eckenrode J, Hamilton S 2000. 'One-to-one support interventions: home visitation and mentoring. In: '*Social support measurement and intervention: a guide for health and social scientists*'. Oxford, Oxford University Press. P246-277.

Eng J and Miller W 2008. 'Rehabilitation: From bedside to community following spinal cord injury (SCI)'. *Spinal Cord Injury Rehabilitation Evidence Version 2.0*. Vancouver. p1.1-1.11.

Exner G, Meinecke FW 1997. 'Trends in the treatment of patients with spinal cord lesions seen within a period of 20 years in German Centres'. *Spinal Cord*, 35,415-419.

Forrest G & Gombas G 1995. 'Wheelchair-accessable housing: Its role in cost containment in spinal cord injury. *Arch Phys Med Rehabil*, 76, 450-452.

Gaffneys Local Government in South Africa. Official yearbook. 2007 – 2008.

- Gore V, 2006, 'The challenge of fatalities and injuries on our country's roads'. *Proceedings of National Assembly*. Viewed on 20 November 2008, http://beta.parliament.gov.za/live/commonrepository/Processed/20080825/51348_1.doc
- Granger C & Hamilton B 1996. 'The Functional Independence Measure'. In: McDowell I, Newell C. *Measuring Health: A guide to rating scales and questionnaires*. 2nd edition. Oxford University Press, 115-121.
- Greenwald B, Seel R, Cifu D & Shah A 2001, 'Gender-related differences in acute rehabilitation lengths of stay, charges and functional outcomes for a matched sample with spinal cord injury: a multicenter investigation'. *Arch Phys Med Rehabil* 82, 1181-1187.
- Griffen K 1995, *Handbook of Subacute Health Care*. Aspen Publishers Inc, Gaithersburg, Maryland, 141-148.
- Hall KM, Cohen ME, Wright J, Call M & Werner P 1999, 'Characteristics of the functional independence measure in traumatic spinal cord injury'. *Arch Phys Med Rehabil*. 80, 1471-1476.
- Hamilton B & Fuhrer M 1987, *Rehabilitation outcomes: analysis and measurement*. Baltimore Books, 137-147.
- Hamilton B, Deutsch A, Russell C, Fiedler R & Granger C, 1999, 'Relation of disability costs to function: spinal cord injury'. *Arch Phys Med Rehabil* 80, 385-391.
- Hart C, 2000, 'Spinal Cord injury statistics at the Natalspruit Hospital Unit over an 11 year period'. *SA Journal of Physiotherapy*. 56(2): 13-15.
- Harvey L 2008, '*Management of Spinal Cord Injury. A guide for physiotherapists.*' Butterworth-Heinemann. Elsevier Limited.
- Heineman A, Hamilton B, Linacre J, Wright B & Granger C. 1995, 'Functional status and therapeutic intensity during inpatient rehabilitation'. *Am J Phys Med Rehabil*, 74, 315-326.
- Hoenig H, Hoff J, McIntyre L & Branch L 2001, 'The self-reported functional measure: Predictive validity for health care utilization in multiple sclerosis and spinal cord injury'. *Arch Phys Med Rehabil* 82, May, 613-618.
- Itzkovich M, Tripolski M, Zeilig G, Ring H, Rosentul N, Ronen J, Spasser R, Gepstein R & Catz A 2002, 'Rasch analysis of the Catz-Itzkovich spinal cord independence measure'. *Spinal Cord* 40, 396-407.
- Jongbloed L, Backman C, Forwell S, Carpenter C 2007. 'Employment after spinal cord injury: The impact of government policies in Canada'. *Work*, 29, 145-154.

- Jutai J, Teasell R 2003. 'The necessity and limitations of evidence-based practice in stroke rehabilitation'. *Top Stroke Rehabil* 2003;10:71-78.
- Karamehmetoglu SS, Karacan I, Elbasi N, Demirel G, Koyuncu H & Dösoglu M 1997, 'The functional independence measure in spinal cord injured patients: comparison of questioning with observational rating'. *Spinal Cord* 35, 22-25.
- Kendall N 1997, 'Development outcome assessments: a step-by-step approach'. *NZ Journal of Physiotherapy*. Dec, 11-17.
- Kennedy P & Hamilton L 1999, 'The needs assessment checklist: a clinical approach to measuring outcome'. *Spinal Cord* 37, 136-139.
- Kennedy P, Evans M, Berry C & Mullin J 2003, 'Comparative analysis of goal achievement during rehabilitation for older and younger adults with spinal cord injury'. *Spinal Cord* 41, 44-52.
- Kilkens O, Post M, van der Woude L, Dallmeijer A & van den Heuvel W 2002, 'The wheelchair circuit: Reliability of a test to assess mobility in persons with spinal cord injuries'. *Arch Phys Med Rehabil* 83, 1783-1788.
- Kirby R, Swuste J, Dupuis D, MacLeod D & Monroe 2002, 'The wheelchair skills test: A pilot study of a new outcome measure'. *Arch Phys Med Rehabil* 83, 10-18.
- Landrum P K, Schmidt N D & McLean A 1995, *Outcome-Oriented Rehabilitation*. Aspen Publishers Inc. Gaithersburg, Maryland.
- Life Rehabilitation. Viewed on 12 December 2008 on www.lifehealthcare.co.za
- Martin LL & Kettner PM, 1996, *Measuring the performance of human service programs*. 1st ed. Thousand Oaks: SAGE Publications
- Masedo AI, Hanley M, Jensen MP, Ehde D & Cardenas DD 2005, 'Reliability and validity of a self-report FIM™ (FIM-SR) in persons with amputation or spinal cord injury and chronic pain'. *Am J Phys Med Rehabil* 84, 167-176.
- Mawson S 1995, 'What is the SF-36 and can it measure the outcome of physiotherapy?' *Physiotherapy*, 81, (4), 208-212.
- McClain C, Howell C, Lagadien F, Pretorius L, Rantho M & Thompson P 1997. Integrated National Disability Strategy. *White paper on an integrated national disability strategy*. Office of the deputy president T M Mbeki.
- McKinley W, Santos K, Meade M & Brooke K 2007, 'Incidence and outcomes of spinal cord injury clinical syndromes'. *Journal of Spinal Cord Medicine* Vol 30 No 3 215-224.
- Mount Sinia Medical Centre ©2008. Viewed on 12 December 2008, www.mssm.edu/rehab/spinal.

National Spinal Cord Injury Statistical Center (NSCISC) 2004. *Annual Statistical Report for the Model Spinal Cord Injury Care Systems*.

Netcare Rehabilitation Hospital. Viewed on 12 December 2008, www.netcare.co.za

Office of the Deputy President, 1997. 'Integrated National Disability Strategy'.

Ottenbacher KJ, Mann WC, Granger CV, Tomita M, Hurren D & Charvat B 1994, 'Interrater agreement of the stability of functional assessment in the community based elderly'. *Arch Phys Med Rehabil*. 1299-1301

Rick Hanson Man-In-Motion Foundation (RHMIMF) 2004. *Ipsos Reid SCI Community Survey*. Rick Hanson SCI Network.

Roth E, Davidoff G, Houghton J & Ardner M, 1990, 'Functional assessment in spinal cord injury: a comparison of the modified Barthel Index and the adapted functional independence measure'. *Clinical Rehabilitation*. 4, 277-285.

Salter K, Jutai J, Foley N, Teasel R 2005. *Evidence-Based review of stroke rehabilitation: Outcome Measures in Stroke Rehabilitation*. (8th ed) Viewed on 17 December 2008, www.ebrsr.com/index_modules_sub4.html.

Schönherr M, Groothoff J, Mulder G & Eisma W 1999, 'Functional outcome of patients with spinal cord injury: rehabilitation outcome study'. *Clinical Rehabilitation* 13, 457-463.

Slade M 1994, 'Needs assessment. Involvement of staff and users will help to meet needs'. *British Journal of Psychiatry*. 165: 293-296.

Smith M 2002. Efficacy of specialist versus non-specialist management of spinal cord injury within the UK. *Spinal Cord*, 40, 10-16.

Southern African Spinal Cord Association (SASCA). 2000 *Resources*. Viewed on 12 December 2008, www.sasca.org.za.

Spaulding Rehabilitation Hospital, Massachusetts. Viewed on 12 December 2008, www.spauldingrehab.org.

Technical assistance guidelines on the employment of people with disabilities (Dept of Labour). Viewed on 20 December 2008, www.labourguide.co.za.

Tooth L, Ottenbacher K, Smith P, Illig S, Linn R and Granger C 2004, 'Satisfaction with medical rehabilitation after spinal cord injury'. *Spine* Vol 29 No 2, 211-219.

University of Virginia. Health System. Physical Medicine and Rehabilitation viewed on 19 November 2008, www.healthsystem.virginia.edu/uvahealth/adult_pmr/spcrd.cfm

Wade DT. *Measurement in neurological rehabilitation*. Oxford: Oxford University Press 1992

Wade D 2004, 'Assessment, measurement and data collection tools'. *Clin Rehabil* 18, 233-237.

Waters R, Yakura J, Adkins R, Sie I 1992. 'Recovery following complete paraplegia'. *Arch Phys Med Rehabil* 73, 784-789.

Webster G & Kennedy P 2007, 'Addressing children's needs and evaluating rehabilitation outcome after spinal cord injury: The child's needs assessment checklist and goal planning program'. *Journal of spinal cord medicine* 30, 140-145.

Wehman P, Wilson K, Targett P, West M, Bricout J, McKinley W 1999. 'Removing transportation barriers for persons with spinal cord injuries: An ongoing challenge to community reintegration'. *Journal of Vocational Rehabilitation*, 13, 21-30.

Western Cape Health Plan: Comprehensive service plan for the implementation of healthcare 2010, May 2007. Viewed on 28 December 2008, www.capegateway.gov.za.

Whiteneck GG 1992, *Graig Handicap Assessment and reporting Technique* 3425 S Clarkson Street Englewood Colorado: The Graig Hospital department

Wolfe D, Mehta S, Hsieh J 2008, 'Rehabilitation Practice and associated outcomes following spinal cord injury.' *Spinal Cord Injury Rehabilitation Evidence Version 2.0*. Vancouver. p 3.1-3.65

World Health Organization, 2000, *International Classification of function, disability and health*. Geneva: WHO.

www.gautrain.co.za Viewed on 28 December 2008.

Wyndaele M, Wyndaele J-J 2006, 'Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey?' *Spinal Cord* 44, 503-508.

APPENDIX A

Consent letter addressed to manager of Netcare Rehabilitation Hospital

13 August 2003

The Manager
Netcare Rehabilitation Hospital
P O Box 150
Auckland Park
2006

Dear Mrs Gnäde

RESEARCH STUDY AT NETCARE REHABILITATION HOSPITAL

I would like to ask the permission of the hospital management to conduct a research study in the hospital. The research is for the purposes of a M Sc degree in Rehabilitation.

The proposed study is to evaluate the efficacy of the rehabilitation programme for complete paraplegics in terms of their functional outcomes as well as their needs. The study will use the FIM score as it is being used at the moment with all patients in the hospital and compare the scores with the scores of a Needs Assessment Checklist which will be completed by all complete paraplegics with levels between T1 and T12 at intervals during their rehabilitation.

The results of such a study will be of extreme value to the planning and development of the rehabilitation program for patients with spinal injuries at Netcare Rehabilitation Hospital.

2.1. All participants in the study will be adequately informed and written consent will be obtained from each one. The information obtained would be used confidentially.

2.2. It is proposed that the study, once finalised, would be published in appropriate journals.

Your thoughtful consideration in this matter will be appreciated.

Thank You

Rita Henn

APPENDIX B

Consent letter addressed to Dr in Charge of patients

13 August 2003

Dr M Mochan
Netcare Rehabilitation Hospital
P O Box 150
Auckland Park
2006

Dear Dr Mochan

RESEARCH STUDY AT NETCARE REHABILITATION HOSPITAL

I would like to ask the permission to conduct a research study on some of your patients in the hospital. The research is for the purposes of a M Sc degree in Rehabilitation.

The proposed study is to evaluate the efficacy of the rehabilitation programme for complete paraplegics in terms of their functional outcomes as well as their needs. The study will use the FIM score as it is being used at the moment with all patients in the hospital and compare the scores with the scores of a Needs Assessment Checklist which will be completed by all complete paraplegics with levels between T1 and T12 at intervals during their rehabilitation.

The results of such a study will be of extreme value to the planning and development of the rehabilitation program for patients with spinal injuries at Netcare Rehabilitation Hospital.

All participants in the study will be adequately informed and written consent will be obtained from each one. The information obtained would be used confidentially

It is proposed that the study, once finalised, would be published in appropriate journals
Your thoughtful consideration in this matter will be appreciated.

Thank You

Rita Henn

APPENDIX C

INFORMATION AND INFORMED CONSENT DOCUMENT

TITLE OF RESEARCH PROJECT:

Evaluation of the rehabilitation program for complete paraplegics at a private rehabilitation centre.

RESEARCHER: Rita Henn

DECLARATION BY OR ON BEHALF OF THE PARTICIPANT

I, /*the participant was invited to participate in the abovementioned research project which is being undertaken by the Centre of Care and Rehabilitation of the disabled, Faculty of Health Sciences, Stellenbosch University.

The following aspects have been explained to me/*the participant

AIM OF STUDY: The aim of the study is to measure if the needs of the paraplegics have been met during their rehabilitation and to determine if the program is effective.

PROCEDURES: Each participant will be measured with the FIM™ instrument and he/she will have to complete the Needs Assessment Checklist during regular intervals during the rehabilitation.

CONFIDENTIALITY: the data collected is and will stay confidential and no data will be used in such a way that could lead to identification of any of the participants.

VOLUNTARY PARTICIPATION: participation is voluntary and each participant has the right to refuse or to discontinue participation in the study at any time. Participation will not result in any costs to the participants.

The information above was explained to me/*the participant

by _____

in English/*Afrikaans/*Other _____ an I/*the participant is in command of this language/*it was satisfactorily translated to me/*him/*her by

I/*the participant was given the opportunity to ask questions and all these questions were answered satisfactorily.

No pressure was exerted on me/*participant to consent to participation and I/*the participant understands that I/*the participant may withdraw at any stage without any penalisation.

Participation in this study will not result in any additional costs to myself/*the participant.

I hereby consent voluntarily to participate in the abovementioned study/*the participant consent to participate voluntarily in the study.

Signed/confirmed at

_____ on _____ 200__

Signature of participant

Signature of witness

STATEMENT BY OR ON BEHALF OF INVESTIGATOR:

I, Rita Henn, declare that

- I explained the information in this document to _____
- He/she was encouraged to ask questions.
- This conversation was conducted in English/*Afrikaans and no translator was used/*this conversation was translated in _____ by _____ (translator).

Signed _____ on _____ 200__

Signature of investigator

Signature of witness

DECLARATION BY TRANSLATOR

I, _____, confirm that I

- translated the contents of this document from English into _____ to the participant
- explained the contents of this document to the participant
- also translated the questions posed by the participant as well as answers given by Rita Henn and
- conveyed a factually correct version of what was related to me.

Signed at _____ on _____ 200_____

Signature of translator

Signature of witness

**APPENDIX D
FUNCTIONAL INDEPENDENCE MEASURE**

FUNCTIONAL INDEPENDENCE MEASURE

Patient information				
First name	<input type="text"/>			
Surname	<input type="text"/>			
Address	<input type="text"/>			
	<input type="text"/>			
	<input type="text"/>			
Country	<input type="text"/>			
Age	<input type="text"/>			
Gender	Male	<input type="checkbox"/>	Female	<input type="checkbox"/>
Marital status	Single	<input type="checkbox"/>	Married	<input type="checkbox"/>
	Widowed	<input type="checkbox"/>	Separated	<input type="checkbox"/>
	Divorced	<input type="checkbox"/>		
Educational level	Primary education		Grade	<input type="text"/>
	Secondary education		Grade	<input type="text"/>
	Tertiary education	<input type="text"/>		
Employment	<input type="text"/>			
Living setting	Rural	<input type="checkbox"/>	Urban	<input type="checkbox"/>
	Other	<input type="text"/>		
Transport	Private	<input type="checkbox"/>	Public	<input type="checkbox"/>

Funder information

Funder name

Membership no

Case information

Admission date

Discharge date

Referring hospital

Medical information

Level of injury

ASIA Impairment Scale

Date of onset

Cause of injury

Scale

Independent	
7	Complete Independence (Timely, safely)
6	Modified independence (Device)
Modified dependence	
5	Supervision (Subject = 100%+)
4	Minimal assistance (Subject = 75%+)
3	Moderate independence (Subject = 50%+)
Complete dependence	
2	Maximal assistance (Subject = 25%+)
1	Total assistance (Subject = less than 25%)

**FUNCTIONAL INDEPENDENCE MEASURE
SCORE SHEET**

SELF-CARE

Admission Discharge

Eating

Grooming

Bathing

Dressing-Upper

Dressing-lower

Toileting

SPHINCTER CONTROL

Bladder

Bowel

TRANSFERS

Bed, Chair, Wheelchair

Toilet

Tub, shower

LOCOMOTION

Walk, Wheelchair

Stairs

Total

APPENDIX E

NEEDS ASSESSMENT CHECKLIST

In order for this form to be scored up correctly, please ensure that all sections are fully completed.

PATIENT NAME: _____

Date of injury: _____

Date of admission: _____

Age: _____

Gender: _____

Date checklist completed: _____

This checklist highlights some of the main areas of need that the patient now have as a consequence of his/her recent condition. It rates his/her involvement and awareness on a number of aspects of his/her rehabilitation on a scale according to the degree of physical/verbal independence he/she has achieved in carrying out each activity, as follows:

- 0 = patient completely DEPENDENT on staff/carers; knows nothing about x/ has never attempted to do x/ never does x**
- 1 = patient mostly DEPENDENT on staff/carers; knows a little about x/ has perhaps attempted to do x once/ sometimes does x**
- 2 = patient moderately INDEPENDENT; knows a fair bit about x/ may just need more practice at x/ usually does x**
- 3 = patient completely INDEPENDENT; has complete knowledge of x/ can do x successfully/ always does x**
- N/A= NOT APPLICABLE. This section should only be ticked when the activity is not applicable to the patient.**

1. ACTIVITIES OF DAILY LIVING

1.1. Food Management

	0	1	2	3	N/A
Can you (or do you instruct others to)* use feeding utensils?					
Can you (or do you instruct others to)* carry a plate of food on a tray?					
Can you (or do you instruct others to)* pick up a glass/cup?					
Can you (or do you instruct others to)* get a drink?					
Have you been involved in preparing a meal?					

1.2. Dressing

	0	1	2	3	N/A
Do you know how to dress your upper body?					
Do you do it (or do you instruct others to do it)*?					
Do you know how to undress your upper body?					
Do you do it (or do you instruct others to do it)*?					
Do you know how to dress your lower body?					
Do you do it (or do you instruct others to do it)*?					
Do you know how to undress your lower body?					
Do you do it (or do you instruct others to do it)*?					
Can you (or do you instruct others to)* put on shoes/tie laces?					
Can you (or do you instruct others to)* use fasteners (zips, buttons)					

- Please ensure to delete as applicable

1.3. Facial Hygiene

	0	1	2	3	N/A
Can you (or do you instruct others to)* wash your face?					
Can you (or do you instruct others to)* shave/put make-up on?					
Can you (or do you instruct others to)* comb/style your hair?					
Can you (or do you instruct others to)* wash your hair?					
Can you (or do you instruct others to)* brush your teeth?					

1.4. Personal Hygiene

	0	1	2	3	N/A
Do you know how to wash your upper body?					
Do you do it (or do you instruct others to)*?					
Do you know how to wash your lower body?					
Do you do it (or do you instruct others to)*?					
Do you know how to dry your upper body?					
Do you do it (or do you instruct others to)*?					
Do you know how to dry your lower body?					
Do you do it (or do you instruct others to)*?					

2. SKIN MANAGEMENT

2.1. Skin checks

	0	1	2	3	N/A
Do you know how to check your skin with a mirror?					
Do you know what to look for, and where to look?					
Do you carry out this skin checking as instructed?					

- Please ensure to delete as applicable

2.2. Preventing pressure sores	0	1	2	3	N/A
Do you know how to relieve pressure by leaning, lifting etc?					
Do you know how often and for how long to carry out pressure relief?					
Can you (or do you instruct others to)* change your position in bed?					
Can you (or do you instruct others to)* position your pillows correctly in bed?					

2.3. Preventing skin insults	0	1	2	3	N/A
Are you aware of the danger of zips, seams, calipers, etc?					
Are you aware of the danger of hot objects (coffee, hot water bottles, the sun)					
Can you (or do you instruct others to)* avoid scrapes/bumps when transferring?					
Do you (or do you instruct others to)* regularly check for ingrowing toenails?					

3. BLADDER MANAGEMENT

3.1. Bladder care	0	1	2	3	N/A
Suprapubic/Urethral catheter: do you know how to empty the legbag?					
Suprapubic/Urethral catheter: do you know how to change the catheter?					
Sheath drainage: do you know how to apply the sheath?					
Are you independent in performing self-intermittent catheterisation?					
Can you use pads?					
Can you tap and express?					

*** Please ensure to delete as applicable**

3.2. Bladder related problems

	0	1	2	3	N/A
Do you know how to recognise that you are not passing urine?					
Would you know how to sort out this problem?					
Do you know the amount of fluid per day you should drink?					
Can you recognise the early signs of bladder infection?					

4. BOWEL MANAGEMENT

	0	1	2	3	N/A
Do you know the dose and type of aperients you use?					
Do you know the dose and type of suppositories you use?					
Do you know how to insert the suppositories?					
Do you know how to do a digital check?					
Do you know how to cleanse yourself after using the toilet?					
Can you deal with a bed evacuation?					
Do you have access/transfer to a toilet at home?					

5. MOBILITY**5.1. Transfers and Wheelchair skills**

	0	1	2	3	N/A
Do you know how to transfer to/from a bed?					
Do you know how to transfer to/from a toilet?					
Do you know how to transfer to/from a shower chair?					
Do you know how to transfer to/from a bath?					
Do you know how to transfer to/from a car?					
Do you know how to transfer to/from the floor?					
Do you know how to transfer to/from a standing frame?					

Do you know how to maintain a range of movement in your joints by stretching?					
Do you know how to go up and down kerbs in your wheelchair?					
Can you go up/down stairs on your bottom and in your wheelchair?					
Do you know how to get your wheelchair in/out of a car?					

6. WHEELCHAIR AND EQUIPMENT

6.1. Wheelchair

	0	1	2	3	N/A
Do you know your wheelchair make and model?					
Do you know how to contact your wheelchair providers?					
Do you understand how to maintain your wheelchair?					

6.2. Cushion

	0	1	2	3	N/A
Do you know your cushion type?					
Can you recognise for signs of wear and tear on your cushion?					
Do you know how and where to replace your cushion?					

6.3. Standing

Do you know the reason for standing?					
Do you know how often and for how long to use your standing frame/device?					

7. COMMUNITY PREPARATION

7.1. Social activity (Please tick applicable boxes for each question)

Have you been out of the hospital?

Never	0	Once or twice?	1	3 or 4 times?	2	5 or more times?	3
-------	---	----------------	---	---------------	---	------------------	---

Have you been to:

A shopping centre	1
Town	1
A Pub/hotel	1
A Restaurant	1
A friends house	1

7.2. Employment

0 1 2 3 N/A

Have you contacted your employer?					
Have you made plans to return to work?					
If you are returning to work, are adaptations to the workplace required?					
Have the adaptations been planned?					

7.3. Community Preparation

Yes No N/A

Have you spent time in the Independence ward?	3	0	3
Have you attended all the patient teaching sessions?			
Has your family attended a family meeting?			

7.4. Driving and related issues

Yes No N/A

Do you wish to drive?	3	0	3
Have you arranged a driving assessment through the driving school?			
Have you applied for a parking disc?			

8. DISCHARGE COORDINATION

8.1. Community issues

Yes (3) No (0) N/A (3)

	Yes (3)	No (0)	N/A (3)
Do you know who your Social Worker in the community is?			
Have you been referred to him/her?			
Has he/she made contact with you?			
Has a date for a discharge planning meeting been arranged?			
Have you been given a provisional discharge date?			

8.2. Accommodation

Yes (3) No (0) N/A (3)

	Yes (3)	No (0)	N/A (3)
Has the Occupational Therapist visited and assessed your home?			
Do you need rehousing?			
Are adaptations needed in your home?			
Will you be funding the adaptations yourself?			
Has a building date been set?			
Do you need an interim placement?			
If yes, have arrangements been made to visit suitable placements?			
Is long-term residential placement needed?			

8.3. Care Package

Yes (3) NO (0) N/A (3)

	Yes (3)	NO (0)	N/A (3)
Have you identified your care requirements?			
Have arrangements been made to train people who will be giving you care?			
Do you know how to contact your district nurse?			
Do you know where your nearest clinic is?			

9. PSYCHOLOGICAL ISSUES

9.1. Mood

Key

Not at this time	3
Sometimes	2
Most of the time	1
Always	0

	0	1	2	3	N/A
Do you feel sad?					
Are you distressed?					
Are you frightened by the future?					
Do you feel panicky?					
Do you wake in the early hours of the morning and have difficulty getting back to sleep?					
Do you have a poor appetite?					
Do you feel excessively tired?					
Are you worried about the future?					

9.2. Sexual issues

Yes (3) No (0) N/A(3)

Have you been informed of any changes in sexual function?			
Have you received fertility advice?			
Have you had as much information as you want about sexual issues?			