

**THE ACTIVITY AND PARTICIPATION PROFILE OF PERSONS WITH
TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLE,
WESTERN CAPE, SOUTH AFRICA: A PROSPECTIVE, DESCRIPTIVE
STUDY**

Mirda Maclachlan



**THE ACTIVITY AND PARTICIPATION PROFILE OF PERSONS WITH
TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLE,
WESTERN CAPE, SOUTH AFRICA: A PROSPECTIVE, DESCRIPTIVE
STUDY**

MIRDA MACLACHLAN

“THESIS PRESENTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE
DEGREE OF MASTER OF PHYSIOTHERAPY IN THE FACULTY OF HEALTH SCIENCES
AT STELLENBOSCH UNIVERSITY.”

Study leaders: Ms Gakeemah Inglis-Jassiem

Associate Prof. Dr Susan Hillier

March 2012

DECLARATION

“By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.”

Signature:

Date:

ABSTRACT

Background

Traumatic spinal cord injury (SCI) remains one of the most serious and devastating injuries often resulting in permanent disability and with life changing implications for the individual and his/her family. Successful reintegration into community life and employment after SCI is considered important goals of rehabilitation as this has been positively associated with quality of life, self esteem and life satisfaction. The International Classification of Functioning, Disability and Health (ICF) allows researchers to identify the impact of environmental factors on functioning and disability. Minimal research, particularly in South Africa, has been done on the impact of the environment on persons living with various health conditions and specifically spinal cord injury.

Objectives

The main purpose of this study was to describe and compare the level of participation of persons with traumatic SCI at two time points (discharge and six months after discharge) from the inpatient rehabilitation setting and to identify the environmental barriers experienced.

Methods

A prospective, descriptive study was conducted using consecutive sampling. All patients with traumatic SCI that were discharged from September 1, 2008 from the Western Cape Rehabilitation Centre (WCRC) who were eligible for this study were included. Two questionnaires (one based on the ICF and one purposely-developed) and the International Standards for the Classification of SCI (ISCSCI) were used. Data were analyzed with the statistical software package STATISTICA.

Results

A person sustaining a traumatic SCI in the Cape Metropolitan area of the Western Cape Province is most likely to be a male, young (20 to 29 years), of the Black or Coloured race and living in the Cape Flats suburbs. More than half of the subjects had a grade eight to ten level of education which together with the lack of employers' responsibilities towards part-time workers might explain the low percentage (11%) of employment at six months after discharge from the WCRC.

Complete paraplegia, occurring mainly in the thoracic cord, was the most common neurological disability found in this study. The most common secondary condition was pain followed by spasticity limiting function. The low incidence of pressure sores and urinary tract infections found in this study contradicts findings of previous studies.

The majority of the subjects were discharged to the same house they were living in at the time of their injury. However, due to various architectural barriers, some of them were not able to function independently in their homes.

Inaccessibility of public transport, the lack of recreational and sport facilities, lack of social support structures in the community and inadequate financial resources were the main environmental barriers experienced by these individuals.

Conclusion

The main finding of this study was the low employment rate and the difficulty experienced with reintegration at community level after SCI. The results of this study confirm the significant contribution of environmental factors in participation, especially those of transport and education in return to work. Fourteen years after the publication of the Integrated National Disability Strategy (INDS) White Paper (1997), legislative strategies to ensure that people with disabilities have equal access to social and economic opportunities remain lacking.

ABSTRAK

Agtergrond

Traumatiese spinaalkoordbesering (SKB) lei dikwels tot permanente verlamming en dit het lewensveranderende implikasies vir die individu en sy/haar familie. Suksesvolle herintegrasie in die gemeenskap en werkverrigting na SKB is belangrike doelstellings vir rehabilitasie omdat dit positief met lewenskwaliteit, selfrespek en lewens-bevrediging geassosieer word. Die Internasionale Klassifisering van Funksionering, Gestremdheid en Gesondheid (IKF) bied aan navorsers die geleentheid om die impak van omgewingsfaktore op funksionering en gestremdheid te identifiseer. Daar is veral in Suid-Afrika beperkte navorsing oor die impak van die omgewing op mense met verskillende gesondheidstoestande, spesifiek SKB.

Doel

Die hoofdoel van hierdie studie was om die vlak van deelname van mense met traumatiese SKB op twee verskillende tye te beskryf en te vergelyk, onmiddellik na hulle uit die rehabilitasiesentrum ontslaan is, en ses maande later. Die studie het ook ten doel gehad om die omgewingsfaktore te identifiseer wat deelname negatief beïnvloed.

Metode

Daar is van 'n beskrywende studie gebruik gemaak. Alle pasiënte met traumatiese SKB wat vanaf 1 September 2008 vanaf die Wes-Kaapse Rehabilitasiesentrum (WKRS) ontslaan is en wat voldoen het aan die insluitingskriteria is ingesluit. Twee vraelyste is gebruik om data in te samel – een is op die IKF gebaseer en een is spesifiek vir die studie ontwikkel. Daar is ook van die Internasionale Standaard vir die Klassifisering van SKB (ISKSKB) gebruik gemaak om data in te samel. Data is met behulp van STATISTICA, 'n statistiese sagteware pakket, geanaliseer.

Resultate

Iemand wat 'n traumatiese SKB in die Kaapse metropolitaanse gebied van die Wes-Kaap provinsie opdoen, is mees waarskynlik 'n jong man (20 tot 29 jaar) van die Swart of Kleurling ras wat woonagtig in die voorstede op die Kaapse Vlakte is. Meer as die helfte van die deelnemers in die studie het slegs 'n opvoedingsvlak van graad agt tot tien. Hierdie aspek, tesame met die gebrek aan werkgewers se verantwoordelikheid teenoor deeltydse werknemers is dalk die rede waarom slegs 11% van die deelnemers ses maande na hulle uit die WKRS ontslaan is, werksaam was.

Volledige paraplegie, hoofsaaklik as gevolg van 'n besering van die torakale spinaalkoord, was die algemeenste neurologiese besering wat in hierdie studie gevind is. Die algemeenste sekondêre komplikasie wat voorgekom het, was pyn gevolg deur spastisiteit. Die lae voorkoms van druksere en urienweginfeksies in dié studie is in teenstelling met bevindings van vorige studies.

Die meeste deelnemers is ontslaan na dieselfde huis waar hulle voor die besering gewoon het, maar as gevolg van verskeie argitektoniese hindernisse, kon sommige van hulle nie onafhanklik binne hulle wonings funksioneer nie.

Die ontoeganklikheid van openbare vervoer, die gebrek aan ontspannings- en sportfasiliteite, die gebrek aan sosiale ondersteuningsnetwerke in die gemeenskap en onvoldoende finansiële hulpbronne was die algemeenste omgewingshindernisse wat deur die deelnemers ondervind is.

Samevatting

Die belangrikste bevinding van dié studie was dat slegs 'n klein persentasie van die deelnemers ses maande na hul ontslaan is, werkzaam was en dat herintegrasie in die gemeenskap na 'n SKB baie moeilik is. Die resultate van die studie bevestig die belangrike rol wat omgewingsfaktore by deelname speel, veral die faktore wat te make het met vervoer en die opvoedingsvlak wanneer daar na 'n werk teruggekeer word. Veertien jaar na die publikasie van die Geïntegreerde Nasionale Gestremdheidstrategie in 1997, is wetgewende strategieë om gelyke toegang tot sosiale en ekonomiese geleenthede vir persone met gestremdhede te verseker, steeds gebrekkig.

ACKNOWLEDGEMENTS

The author would like to thank the following individuals without whose contribution this thesis would not been possible:

The patients and their families, for sharing their experience of living with this serious condition. Meeting and treating persons after SCI has been a privilege and life-changing experience.

Ms Gakeemah Inglis-Jassiem (Stellenbosch University) and Associate Prof. Dr Susan Hillier (South Australia University), my study leaders, for their unstinting guidance, support, encouragement and enthusiasm during this endeavour. I cannot thank you enough.

Prof. Martin Kid for his statistical advice, friendly assistance and patience throughout the process.

Ms Jenny Hendry, for granting me permission to use the WCRC as my research setting and for suggesting and, eventually convincing me, to use the ICF as a measuring tool.

Prof. Jennifer Jelsma and Mr Mansur Cloete for helping me to understand and appreciate the ICF.

Prof. Ed Baalbergen and Dr Rob Campbell for their valuable input on SCI and for sharing my passion for SCI.

Dr Ernst Scriba, Ms Andrea Daniels, Ms Sue Rouillard and Mr Mansur Cloete for their expert advice with the development of the questionnaires.

The secretaries of Wards A, C, E and G and physiotherapists at the Western Cape Rehabilitation Centre for their assistance with identifying subjects for the study.

Ms Vuyiswa Gidigidi for her much appreciated help with the Xhosa translations.

The Harry Crossley Foundation for their financial assistance.

Every individual that crossed my path for their enthusiasm and encouragement. You helped me to persevere through the difficult times.

A very special thanks go to my dear friend, Ms Annette Frieg, who never got tired of my endless questions.

Ms Georgenia Stam for the many hours that she spent on the layout of the document.

CONTENTS

	PAGE
LIST OF ACRONYMS	viii
LIST OF FIGURES	x
LIST OF TABLES	xii
CHAPTER 1: INTRODUCTION	1
CHAPTER 2: LITERATURE REVIEW	4
2.1 THE EPIDEMIOLOGY OF SCI	4
2.1.1 Incidence	4
2.1.2 Prevalence	5
2.1.3 Etiology	6
2.1.4 Age	6
2.1.5 Gender	6
2.1.6 Race	6
2.1.7 Neurological level and extent of injury	7
2.1.8 Occupational status	7
2.2 MECHANISMS OF NEUROLOGICAL DAMAGE	7
2.3 ACUTE MANAGEMENT OF SCI	8
2.4 PREDICTORS OF NEUROLOGICAL RECOVERY AFTER SCI	10
2.4.1 Initial neurological level and extent of injury	10
2.4.2 Patient characteristics and etiology of the injury	11
2.4.3 Surgery	11
2.4.4 Methylprednisolone	12
2.5 REHABILITATION OF SCI	12

2.5.1	Defining rehabilitation	12
2.5.2	Environmental factors and their role in participation after SCI	14
2.5.3	Participation	15
2.5.4	Disability	16
2.5.5	Life satisfaction after SCI	17
2.5.6	Residential reintegration following SCI	17
2.5.7	Community reintegration following SCI	19
2.5.8	Overview of the South African situation on participation following disability	24
2.6	THE INCIDENCE AND PREVALENCE OF SECONDARY CONDITIONS FOLLOWING SCI	25
2.7	CONCLUSION	28
CHAPTER 3: METHODOLOGY		30
3.1	RESEARCH QUESTION	30
3.2	AIM	30
3.3	OBJECTIVES	30
3.4	RESEARCH SETTING	31
3.5	STUDY DESIGN	31
3.6	STUDY POPULATION	32
3.6.1	Sampling and sampling size	33
3.6.2	Inclusion criteria	33
3.6.3	Exclusion criteria	34
3.7	MEASUREMENT	34
3.7.1	Data capturing	34
3.7.2	Measuring instruments	34
3.7.2.1	The ISCSCI	35
3.7.2.2	Questionnaire to establish demographic, medical and socio-economic profile	36

3.7.2.3	The ICF	39
3.7.3	Development of the measuring instruments	43
3.7.3.1	The ISCSCI	43
3.7.3.2	Questionnaire to establish demographic, medical and socio-economic profile	43
3.7.3.3	The ICF	44
3.7.4	Study procedure	45
3.7.4.1	Reliability study	46
3.7.4.2	Pilot study	46
3.7.4.3	Main study	47
3.7.5	Statistical procedure	49
3.8	ETHICAL CONSIDERATIONS	50
CHAPTER 4: RESULTS		51
4.1	THE STUDY POPULATION AND SAMPLE	51
4.2	DEMOGRAPHIC CHARACTERISTICS	51
4.2.1	Age	52
4.2.2	Gender	53
4.2.3	Race	53
4.2.4	Residential address	54
4.3	MEDICAL CHARACTERISTICS	54
4.3.1	Etiology	54
4.3.2	Level and nature of spinal cord involvement	56
4.3.3	Severity of spinal cord involvement	58
4.3.4	Incidence of secondary conditions related to SCI	60
4.4	SOCIO-ECONOMIC CHARACTERISTICS	64
4.4.1	Level of education	65
4.4.2	Level of productive activity	66
4.4.3	Gross monthly income	68

4.4.4	Main source of income	70
4.4.5	Contribution to household income	71
4.5	DESCRIPTION OF THE LIVING ENVIRONMENT AFTER DISCHARGE	71
4.5.1	Type of housing	72
4.5.2	Discharged to original house	72
4.5.3	Same house at six months as discharged to	73
4.5.4	Number of rooms	73
4.5.5	Number of people living in the house	74
4.5.6	Space available inside the house for mobility	74
4.5.7	Type of facility use for washing oneself	74
4.5.8	Location of bathroom	75
4.5.9	Location of toilet	76
4.5.10	Ability to access or use toilet facility	76
4.5.11	Alternative toilet arrangement	77
4.5.12	Access to utilities, communication and personal assistance	77
4.6	ACTIVITY AND PARTICIPATION PROFILE	78
4.6.1	Activity and participation profile for mobility	79
4.6.2	Activity and participation profile for self-care	89
4.6.3	Activity and participation profile for domestic life	93
4.6.4	Activity and participation profile for interpersonal interactions and relationships	97
4.6.5	Activity and participation profile for major life areas and community, social and civic life	100
4.7	ENVIRONMENTAL FACTORS	104
4.7.1	Products and technology	105
4.7.2	Support and relationships	107
4.7.3	Attitudes	108

4.7.4	Services	109
4.8	CONCLUSION	110
CHAPTER 5: DISCUSSION		111
5.1	THE STUDY POPULATION AND SAMPLE	111
5.2	DEMOGRAPHIC CHARACTERISTICS	112
5.2.1	Age	112
5.2.2	Gender	113
5.2.3	Race	114
5.2.4	Residential address	115
5.3	MEDICAL CHARACTERISTICS	115
5.3.1	Etiology	115
5.3.2	Level and nature of spinal cord involvement	117
5.3.3	Severity of spinal cord involvement	119
5.3.4	Incidence of secondary conditions related to SCI	120
5.3.4.1	Secondary complications on admission to the WCRC	120
5.3.4.2	Secondary complications at discharge from the WCRC	121
5.3.4.3	Secondary complications at six months after discharge from the WCRC	123
5.4	SOCIO-ECONOMIC CHARACTERISTICS	125
5.4.1	Level of education	126
5.4.2	Level of productive activity	127
5.4.3	Income	129
5.5	DESCRIPTION OF THE LIVING ENVIRONMENT AFTER DISCHARGE	130
5.6	ACTIVITY AND PARTICIPATION PROFILE	131
5.6.1	Activity and participation profile for mobility	132
5.6.2	Activity and participation profile for self care	137
5.6.3	Activity and participation profile for domestic life	137

5.6.4	Activity and participation profile for interpersonal interactions and relationships	138
5.6.5	Activity and participation profile for major life areas and community, social and civic life	139
5.7	ENVIRONMENTAL FACTORS	140
5.7.1	Products and technology	141
5.7.2	Support and relationships	143
5.7.3	Attitudes	144
5.7.4	Services	145
5.8	ASSUMPTIONS	149
5.9	LIMITATIONS OF THE STUDY	150
	CHAPTER 6: CONCLUSION AND RECOMMENDATIONS	151
6.1	CONCLUSIONS	151
6.1.1	Demographic and socio-economic characteristics	151
6.1.2	Medical characteristics	152
6.1.3	Living environment after discharge	155
6.1.4	Activity and participation	156
6.1.5	Environmental factors identified as barriers	159
6.1.6	The publication of the White Paper on the INDS (1997) and its role in the equalization of opportunities for people with disabilities	162
6.2	RECOMMENDATIONS	163
6.2.1	Recommendations for service planning and delivery	163
6.2.2	Recommendations for further studies	165
	REFERENCES	167

APPENDICES

I	Description of codes attached to ASIA impairment scale (AIS)	183
II	International Classification of Functioning, Disability and Health (ICF)	184
III	Inclusion criteria for admission to the study	188
IV	Standard Neurological Classification of Spinal Cord Injury	189
V	American Spinal Injury Association Impairment Scale (AIS)	190
VI	Statistical results for the inter- and intra-rater reliability study for the International Standards for the Classification of Spinal Cord Injury	191
VII	Questionnaire to establish the demographic, medical and socio-economic profile	195
VIII	Questionnaire to establish the activity and participation profile	205
IX	A detailed description of the activities and participation domains and items included in the questionnaire	209
X	Questionnaire to establish environmental barriers	217
XI	A detailed description of the environmental factors included in the questionnaire	220
XII	Participant information leaflet and consent form: English	227
XIII	Participant information leaflet and consent form: Afrikaans	232
XIV	Participant information leaflet and consent form: isiXhosa	237
XV	Complete results for activity and participation at discharge from the WCRC	242
XVI	Complete results for activity and participation at six months after discharge from the WCRC	245
XVII	Amount and type of assistance utilized at discharge from the WCRC	248
XVIII	Amount and type of assistance utilized at six months after discharge from the WCRC	251
XIX	Complete results for environmental barriers at six months after discharge from the WCRC	254

XX	Letters of permission:	257
	(i) Letter of permission by the Committee for Human Research at the Stellenbosch University to conduct the reliability, pilot and main studies	258
	(ii) Letter to the Institutional Head of the WCRC	259

LIST OF ACRONYMS

AIS	ASIA Impairment Scale
ASCI	Acute Spinal cord Injuries
ASIA	American Spinal Injury Association
CHR	Committee for Human Research
DOH	Department of Health
DOL	Department of Labour
DPSA	Disabled People of South Africa
EPWP	Expanded Public Works Programme
GSH	Grootte Schuur Hospital
ICD-10	International Statistical Classification of Diseases and Related Health Problems Tenth Revision
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairments, Disabilities and Handicaps
IMSOP	International Medical Society of Paraplegia
INDS	Integrated National Disability Strategy
MRC	Medical Research Counsel
NDT	National Department of Transport
NRSCIS	Northwest Regional Spinal Cord Injury System
NSCISC	National Spinal Cord Injury Statistical Centre
SAHRC	South African Human Rights Commission
SCI	Spinal Cord Injury
SEF	Sheltered Employment Factories

SNF	Specialized Nursing Facility
SSA	Statistics South Africa
USCB	United States Census Bureau
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organization

LIST OF FIGURES

	PAGE	
4.1	Number of subjects per age group	52
4.2	Age distribution	52
4.3	Gender distribution	53
4.4	Race distribution	53
4.5	Geographic distribution	54
4.6	Etiology of traumatic spinal cord injury	54
4.7	Breakdown of road traffic accidents statistics	55
4.8	Severity of spinal cord involvement at discharge	59
4.9	Severity of spinal cord involvement at six months	59
4.10	Incidence of secondary complications on admission	60
4.11	Incidence of secondary complications at discharge	61
4.12	Incidence of secondary complications at six months	62
4.13	Level of productive activity at time of injury	66
4.14	Level of productive activity at six months	67
4.15	Gross monthly income at time of injury	68
4.16	Gross monthly income at discharge	69
4.17	Gross monthly income at six months	69
4.18	Main source of income at discharge	70
4.19	Main source of income at six months	71
4.20	Type of housing discharged to	72
4.21	Number of rooms in the house	73
4.22	Number of people living in the house	74

4.23	Facility utilized for washing oneself	75
4.24	Location of bathroom facility	75
4.25	Location of toilet facility	76
4.26	Alternative toilet facility	77

LIST OF TABLES

	PAGE
3.1 Overview of the ICF	40
4.1 Etiology of traumatic SCI by population group	55
4.2 Level and nature of injury at discharge	56
4.3 Level and nature of injury at six months	57
4.4 Neurological deficit related to etiology of SCI at discharge	57
4.5 Incidence of secondary complications by neurological deficit at discharge	63
4.6 Incidence of secondary complications by neurological deficit at six months	64
4.7 Number of subjects in specific educational categories	65
4.8 Number of subjects in specific educational categories by population group	65
4.9 Level of productive activity by population group at the time of the injury	67
4.10 Level of productive activity by population group at six month	68
4.11 Access to utilities, communication and personal assistance	77
4.12 Participation profile for mobility at discharge	79
4.13 Participation profile for mobility at six months	81
4.14 Difference in participation for mobility between discharge and six months after discharge	83
4.15 Activity profile for mobility in relation to amount and type of assistance at discharge and at six months	85
4.16 Participation profile for self care at discharge	89
4.17 Participation profile for self care at six months	90
4.18 Difference between participation profile for self care at discharge and six months after discharge	91

4.19	Activity profile for self care in relation to amount and type of assistance at discharge and at six months	92
4.20	Participation profile for domestic life at discharge	94
4.21	Participation profile for domestic life at six months	95
4.22	Difference between participation profile for domestic life at discharge and six months after discharge	95
4.23	Activity profile for domestic life in relation to amount and type of assistance at discharge and at six months	96
4.24	Participation profile for interpersonal interactions and relationships at discharge	97
4.25	Participation profile for interpersonal interactions and relationships at six months	98
4.26	Difference between participation profile for interpersonal interactions and relationships at discharge and six months	98
4.27	Activity profile for interpersonal interactions and relationships in relation to amount and type of assistance at discharge and at six months	99
4.28	Participation profile for major life areas and community, social and civic life at discharge	100
4.29	Participation profile for major life areas and community, social and civic life at six months	101
4.30	Difference between participation profile for major life areas and community, social and civic life at discharge and at six months	102
4.31	Activity profile for major life areas and community, social and civic life in relation to amount and type of assistance at discharge and at six months	103

4.32	Products and technology identified as barriers	105
4.33	Support and relationships identified as barriers	107
4.34	Attitudes identified as barriers	108
4.35	Services identified as barriers	109

CHAPTER 1: INTRODUCTION

Spinal Cord Injury (SCI) is defined as an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory or autonomic function (Dawodu, 2007). Severe traumatic SCI, although not common, is a serious condition with life changing implications for the individual and his family. It often results in profound and long term disability with major effects on the injured person's functional, medical, financial and psychosocial well-being (Pickett, Campos-Benitez, Keller & Duggal, 2006). Therefore rehabilitation of persons with SCI is essential, to return them to their previous level of function or as close to it as possible. Rehabilitation, according to the World Health Organization (WHO) (1981:9) "... aims not only at training disabled and handicapped persons to adapt to their environment, but also at intervening in their immediate environment and society as a whole in order to facilitate their social integration...". Rehabilitation therefore does not only include inpatient or medical rehabilitation at a rehabilitation centre, but extends to post-discharge from the rehabilitation setting. The Disability Rights Charter of South Africa (Disabled People of South Africa (DPSA), 1993), was written in response to the disabled population of South Africa demands, amongst others, for the right to adequate, accessible and affordable housing, the right to independent community life, sport and recreation as well as the right to employment in the open labour market. Considering the WHO (1981) definition of rehabilitation, the demands from the disabled population according to the Disability Rights Charter of South Africa (DPSA, 1993) and the life-changing implications on the lives of persons with SCI, research in this field, especially in South Africa, is essential to ensure optimal rehabilitation outcomes not only in the clinical setting but also after discharge from the hospital.

The incidence of spinal cord injuries has increased globally over the last three decades. In the United States the incidence has increased from 30 to 40 per million population in 1995 (Go, DeVivo & Richards, 1995) to 30 to 60 per million population per year as reported by Dawodu (2007). No information on the epidemiology of SCI in South Africa could be found in the literature. Thus the incidence of this serious and disabling condition in this country is not known.

The causes of SCI vary from country to country, depending on social and economic factors (Burt, 2004). The main causes of traumatic SCI globally are motor vehicle accidents and falls (Dawodu, 2007; Burt, 2004; Karamehmetoglu, Unal, Karacan, Yilmaz, Togay, Ertiken, Dosoglu, Ziyal, Kasaroglu & Hakan, 1995; Lan, Lai, Chang, Jean & Lien, 1993; Biering-Sorensen *et al.*, 1990). However, a study conducted by Hart and Williams (1994) found that violence (56%) was the most common cause of traumatic SCI in South Africa. Taking into consideration the current political

climate and increasing incidence of violence in South Africa, it is unlikely that the etiology of SCI in South Africa today would be any different from the results recorded by Hart and Williams (1994).

A variety of conceptual models exist to understand and explain disability and functioning i.e. the medical and the social models. The medical model views disability as a direct result of the disease, trauma or other health condition which requires medical care in the form of individual treatment by professionals. Medical care is thus viewed as the main issue. The social model of disability views disability as a socially created problem, which can only be addressed by making the necessary environmental modifications for the full participation of disabled persons in all areas of social life (WHO, 2001). The International Classification of Function, Disability and Health (ICF) (WHO, 2001) is based on an integration of these two opposing models. In order to capture the integration of the various perspectives of functioning a “bio-psychosocial’ approach is used” (WHO, 2001:20). The main aim of this study is to establish the degree to which activity limitations and participation restrictions exist six months after discharge from the WCRC, and to identify the environmental barriers that are associated with these constructs. As the ICF uses the bio-psychosocial approach to explain disability and functioning, it will be used as a measuring tool to address the main aim of this study.

The ICF (WHO, 2001), was developed from, and officially replaced, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). The ICIDH was criticized for not allowing the measurement of environmental and social barriers or facilitators in the process of disablement (Bickenbach, Chatterji, Bradley & Usten, 1999). According to Stucki, Ewert and Cieza (2002), the approval of the ICF by the World Health Assembly in May 2001 is an exciting landmark event for rehabilitation medicine. The purpose of the ICF is to provide a standard language and framework for description of human functioning and disability for common use in everyday work by the multi-professional team (Rentsch, Bucher, Dommen, Wolf, Hefti, Fluri, Wenger, Wälti & Boyer, 2003). It provides a framework to conceptualize disability and to standardize approaches to the collection of data related to disability (Jelsma & Sykes, 2008).

Assessing and understanding the functional ability of patients with SCI after discharge from the rehabilitation setting, as well as the variables that have an impact on functional ability, is important to ensure optimal rehabilitation outcomes. Existing international literature shows clearly that the level of impairment and disability, and thus functional ability, is dynamic rather than static following discharge from hospital (Amsters, Pershouse, Price & Kendall, 2005; Dzidic & Moslavac, 1997; Yarkoney, Roth, Heinemann, Lovell & Wu, 1988). Amsters *et al.* (2005) reported

an increase in functional ability for up to 10 years after discharge from hospital with a subsequent decrease in function after 10 years post discharge. McColl, Charlifue, Glass, Savic and Meehan (2002) identified five ways in which function may change over time including: (1) the effects of living with a SCI for many years, such as shoulder deterioration and chronic bladder infections; (2) secondary complications related to SCI; (3) pathological processes not related to SCI; (4) degenerative changes associated with ageing; and (5) environmental factors such as societal, community and cultural issues.

Several studies have been conducted internationally on the relationships between functional ability post discharge from the inpatient setting and different variables i.e. (1) demographic- (Amsters *et al.*, 2005; Sipski, Jackson, Gómez-Marín, Estores & Stein, 2004; Putzke, Hicken & Richards, 2002; Greenwald, Seel, Cifu & Shah, 2001; Gerhart, Bergstrom, Charlifue, Menter & Whiteneck, 1993), (2) injury-related- (Dzidic & Moslavac, 1997; Yarkony *et al.*, 1988), (3) environmental variables (Chan & Chan, 2005), (4) level of education (Dvorak, Fisher, Hoekema, Boyd, Noonan, Wing & Kwon, 2005), (5) employment status (Schonherr, Groothof, Mulder & Eisma, 2005) and (6) secondary complications related to SCI (Bloemen-Vrencken, Post, Hendriks, De Reus & De Witte, 2005). There is a paucity of information in South Africa on functional ability after discharge from hospital and the relationship between these variables and function.

Data collected through this study will reveal information on the profile of persons with SCI receiving rehabilitation in the Cape Metropole, which will give insight into resource allocation and motivation thereof, education on prevention of SCI and hopefully set a platform for further research in the field of SCI, not only in the Western Cape, but nationally. Early recognition of variables that have an impact on functional status at discharge and six months after discharge, following inpatient rehabilitation, can contribute to the development and implementation of a cost-effective rehabilitation programme for the successful reintegration of SCI persons into their home environment, community and workplace.

CHAPTER 2: LITERATURE REVIEW

Traumatic SCI has been described as one of the greater calamities that can befall humans (Dijkers, 2005). SCI occurs suddenly, without warning and results in dramatic changes in the lives of individuals, their families and society as a whole (Krause, 1992). It tends to occur to people in their early adulthood when they are developing their careers or starting a family (Lysack, Komanecy, Kabel, Cross & Neufeld, 2007). Severe traumatic spinal cord injury, although not common, is a serious condition often resulting in significant and catastrophic dysfunction and disability (Lim & Tow, 2007). To provide some understanding of this disabling condition, existing literature on the epidemiology and management of SCI will be reviewed in this chapter. Unfortunately there is a paucity of information on SCI in developing countries, including South Africa.

2.1 THE EPIDEMIOLOGY OF SCI

SCI remain one of the most serious and devastating conditions, often resulting in permanent disability and with life-changing results for the individual and his/her family. Due to the severity of SCI, the impact on personal, bio-psychosocial and short- and long-term socio-economic aspects are tremendous (Wyndaele & Wyndaele, 2006). Knowledge of the incidence and prevalence of SCI is important as incidence rates are a reflection of the level of control and the need for improved prevention of SCI, where prevalence rates have an impact on personal and social resources and health care (Wyndaele & Wyndaele, 2006). Understanding the epidemiology of SCI is therefore essential for public resource allocation and primary prevention (van den Berg, Castellote, Mahillo-Fernandez & de Pedro-Cuesta, 2010; Pickett *et al.*, 2006). The incidence, prevalence, etiology and demographic characteristics of SCI internationally will be discussed in this section.

2.1.1 Incidence

In the United States the incidence of SCI has increased from 30 to 40 per million population in 1995 (Go *et al.*, 1995) to 30 to 60 per million population per year as reported by Dawodu (2007). Burt (2004) reported a global SCI incidence rate of 2.5 to 57.8 per million per annum and commented on the wide range of SCI incidence rates that exists. Results of a systematic review on the incidence of traumatic SCI worldwide, conducted by van den Berg *et al.* (2010) also showed a significant variation in SCI incidence, with rates of 12.1 per million in the Netherlands to 57.8 per million in Portugal. In this recent systematic review, the minimum rate is significantly higher than the one which Burt (2004) reported. According to Burt (2004) the variation of the range may be due to the different methods used for data collection and whether pre-hospital mortalities are included in the

study. The incidence rate will also reflect the social and economic factors existing in the population studied. In their systematic review, Wyndaele and Wyndaele (2006) reported incidence rates ranging from 10.4 to 29.7 per million in Europe, 27.1 to 83 per million in North America, 18 to 40.2 per million in Asia and 16.8 per million in Australia. These studies did not include pre-hospital mortalities. With pre-hospital mortalities included, incidence rates are much higher ranging from 52.5 per million in Alberta, Canada to 77 per million in Mississippi, USA. Wyndaele and Wyndaele (2006) could not find any studies on SCI incident rates from South America or Africa. The National Spinal Cord Injury Statistical Centre (NSCISC) (2008) estimated the annual incidence of traumatic spinal cord injury in the United States (excluding pre-hospital mortalities) to be approximately 40 per million population or 12000 new cases each year. According to the systematic review by Wyndaele and Wyndaele (2006), incidence of SCI worldwide lies between 10.4 and 83 per million inhabitants per year.

2.1.2 Prevalence

According to Sekhon and Fehlings (2001:S3), prevalence in acute SCI is defined as “all persons with a SCI in a specified population at a particular point in time”. The lack of a standard definition of prevalence of SCI makes it difficult to evaluate it and therefore not many studies dealing with this subject have been conducted. Wyndaele and Wyndaele (2006) could find only two studies and three reports on the prevalence of SCI since 1995 for their systematic review. Again all these studies were from developed countries and no data could be found for countries in South America and Africa. A SCI prevalence rate of 681 per million inhabitants in 1997 was reported for Australia and 280 per million inhabitants in 1999 for Helsinki, Finland. The Stockholm Spinal Cord Injury Study estimated SCI prevalence to be 223 per million inhabitants in 1996. The National Centre for Injury Prevention and Control estimated a SCI prevalence rate of approximately 700 per million population in the United States in 2001. The NSCISC (2008) database estimated the number of people in the United States, who are living with SCI in June 2005, to be approximately 250 000, with a range of 225 000 to 288 000. This equals a prevalence of about 755 per million population (Wyndaele & Wyndaele, 2006). The NSCISC (2008) reported the number of people who are alive and have SCI in 2009 in the United States as approximately 262 000 persons, with a range of 231 000 to 311 000 persons, which is slightly higher than in 2005. Due to the small number of studies available, Wyndaele and Wyndaele (2006) could not produce a worldwide estimate on SCI prevalence.

2.1.3 Etiology

The causes of SCI vary from country to country depending on social and economic factors. The character of the accidents causing SCI is a reflection of the circumstances in individual countries around the world (Burt, 2004). The main cause of traumatic SCI globally and in economically developed countries is road traffic accidents (van den Berg *et al.*, 2010; Dawodu, 2007; Ho, Wuermsler, Priebe, Chiodo, Scelza & Kirshblum, 2007; Pickett *et al.*, 2006; Burt, 2004; Lan *et al.*, 1993; Biering-Sorensen *et al.*, 1990). Since 2005, road traffic accidents account for 42% of reported SCI cases in the United States, followed by falls, acts of violence and recreational sporting activities (NSCISC, 2008). In Bangladesh and India, falls from a height are the most common cause of injury and in Bangladesh the second largest group were those tripping and falling while carrying a heavy load (Burt, 2004). In Turkey, falls exceeded road traffic accidents as a cause of SCI (Karamehmetoglu *et al.*, 1995). A study conducted by Hart and Williams (1994) found that violence (56%) was the most common cause of traumatic SCI in South Africa, which was a reflection of the political climate and an increasing incidence of violence in the country during that period.

2.1.4 Age

SCI primarily affects young adults. Younger people are more active and therefore more prone to sustain a traumatic SCI. According to the information sheet of the NSCISC (2008), the average age at injury in the United States between 1973 and 1979 was 28.7 years with most of the injuries occurring between 16 and 30 years. The average age has risen to 39.5 years since 2005. Wyndaele and Wyndaele (2006) found in their literature survey that the mean age of patients sustaining their injuries to be 33 years, except for Portugal and Taiwan where the mean was 50 years and 46 years respectively. The percentage of persons older than 60 years at time of injury has increased from 4.7% before 1980 to 11.5% since 2000. A reason for this could be the change in survival rates of older people at the scene of the accident (NSCISC, 2008).

2.1.5 Gender

Since 2000, 77.8% of traumatic SCI in the United States have occurred among males. The percentage of females who sustained a SCI has increased from 18.2% prior to 1980 to 22.2% since 2000 (NSCISC, 2008).

2.1.6 Race

According to the information sheet of the NSCISC (2008), 76.8% of the persons who sustained a SCI in the United States between 1973 and 1979 were Caucasian, 14.2% were African American,

6% were Hispanic and 3% were from other ethnic groups. However among those injured since 2000, 63% were Caucasian, 22.7% were African American, 11,8% Hispanic and 2.4% were from other ethnic groups. Reasons for this change in the racial distribution of SCI in the United States are, according the NSCISC (2008), unknown.

2.1.7 Neurological level and extent of injury

According to a worldwide literature review conducted by Wyndaele and Wyndaele (2006) on the epidemiology of SCI from 1995 until 2000, two-thirds of people with SCI are paraplegic. An equal number of patients with SCI have sustained complete and incomplete lesions. Since 2000, more than 50% of people with SCI in the United States are tetraplegic (NSCISC, 2008). Forty-one percent of people with SCI in the United States have complete lesions (NSCISC, 2008).

2.1.8 Occupational status

More than half (57.4%) of persons with SCI in the United States were employed at the time of their injury (NSCISC, 2008). At 10 years post-injury 32.4% of persons with paraplegia were employed, while 24.2% of persons with tetraplegia were employed during the same year (NSCISC, 2008). No information on occupational status of persons with SCI in other countries could be found.

It is important to note that all of the above statistics provided by the NSCISC are derived from the National Spinal Cord Injury Database. The Database has been in existence since 1973 and in 2007 contained information on 25 415 persons who sustained traumatic SCI.

At present there is very little information available on the epidemiology of SCI in South Africa, as there is no national SCI registry system and no epidemiology study has been conducted nationally on this matter. Therefore the actual extent and impact of this serious and disabling condition in South Africa is not known.

2.2 MECHANISMS OF NEUROLOGICAL DAMAGE

To date the consequences of SCI are permanent. Despite major advances in the medical field over the last century, progress in the treatment of SCI regarding recovery of the spinal cord has been slow. However, a better understanding of the pathophysiology underlying SCI is currently guiding clinical research and treatment strategies (Hurlbert, 2006). Structural damage to the spinal cord is categorized into primary and secondary mechanisms. The primary mechanism involves the initial cell death at the time of the injury due to direct mechanical forces such as shearing, laceration, distraction and compression, which are irreversible. The secondary mechanism of injury encompasses a subsequent cascade of biomechanical and cellular processes, initiated by the primary

process, that may cause ongoing cellular damage or cell death over a period of days to weeks (Hurlbert, 2006; Fehlings & Perrin, 2005). How much the secondary mechanisms contribute to overall neurological deficit, resulting from the primary mechanisms, is not known. However, preservation of only a small amount of functional neural tissue may have a significant impact on the outcome, therefore everything possible must be done to prevent any additional damage to the spinal cord (Hurlbert, 2006).

At the moment the only treatment for the primary injury is prevention of the SCI. Secondary injury is however preventable and may be reversible (Fehlings & Perrin, 2005). Medical treatment of acute SCI is directed at improving the degree of secondary injury that follows the initial injury and is referred to as neuroprotective treatments. Neuroprotective treatments include pharmacological strategies such as the administration of a high-dose of methylprednisolone to complete and incomplete lesions, if given within the first eight hours after injury, as well as early decompression of the spinal cord. Although there is no compelling or reproducible clinical evidence on the advantages of the use of steroids, it has become a common intervention in limiting the secondary injury processes (Lim & Tow, 2007; Hurlbert, 2006). Many new basic science initiatives such as stem cell transplantation, gene therapy, electrical stimulation and support of oxygenation and spinal cord perfusion pressure hold promise for future treatments in SCI, both through neuroprotection and regeneration (Hurlbert, 2006). However, according to this author, the beneficial and/or harmful effects of these treatment options should be documented first before applying them.

2.3 ACUTE MANAGEMENT OF SCI

SCI is described as “an ailment not to be treated” in the Edwin Smith Surgical Papyrus written between 2500 and 3000 B.C. (Eltorai, 2003). Since then and especially over the last 50 years much has changed in spinal cord care relating to survival rate, life expectancy and quality of life. Major advances have been made in the acute care management of traumatic SCI due to the establishment of specialized spinal cord centres. Research over the past 30 to 40 years has focused on the unravelling of the complex pathophysiological processes involved in SCI (Sekhon & Fehlings, 2001). Subsequently, the death rate of individuals with traumatic SCI in America has decreased over the years from an estimated 90% before 1950 (Anson & Shephard, 1996) to only 3% as reported by the NSCISC (2008).

Patients with acute traumatic SCI should be managed at a specialized trauma centre with SCI experience. These centres usually have evidence-based protocols for the management of SCI in place, with well-trained staff specializing in SCI because of a higher volume of fairly low-incidence

injuries (Wuermsler *et al.*, 2007). During the acute stage of traumatic SCI, management consists of two parts i.e. non-operative and operative.

The main goals for the non-operative management of acute SCI are: (1) the preservation of the patient's life and (2) optimizing the potential for neurological recovery (Nockels, 2001). To achieve these goals optimal treatment for life-threatening respiratory and hemodynamic events should be delivered in a manner that will not cause any further instability of the spinal elements resulting in possible deterioration in neurological function. As it is not possible to determine prognosis for neurological recovery during the acute stage, it is essential that these treatment principles are applied to all injured patients (Nockels, 2001). In fact, all patients who have sustained major systemic trauma must be presumed to have a SCI until proven otherwise (Lee & Green, 2002). Improper management of traumatic SCI during the acute stage can further damage the spinal cord with tragic results, considering the impact that SCI has on the individual's physical, psychological and socio-economic well-being (Nockels, 2001). Principles for the operative management of acute traumatic SCI are well-established (Wuermsler *et al.*, 2007). The primary indication for surgical treatment is to stabilize the spine, as an unstable spine has the potential to cause deformity and neurological injury. Secondly, it can relieve neural compression resulting in improving neurological deficit (Licina & Nowitzke, 2005). However there is still much controversy regarding the timing of decompression of the neural elements and whether early decompression actually improves neurological outcome (Fehlings & Perrin, 2005). Early surgical intervention remains a valid and safe practice option, although there is no conclusive evidence showing a benefit over conservative management (Fehlings & Perrin, 2005).

Although the medical management of traumatic SCI takes priority, other important interventions should not be overlooked during the acute stage. Range of movement should be started as soon as there are no medical or orthopaedic contra-indications to doing so. Failing to do this, due to fear of further neurological damage, might result in stiff, painful joints with resulting decrease in function (Wuermsler, Ho, Chiodo, Priebe, Kirshblum & Scelza, 2007). Bowel and bladder management should start as early as possible. Pulmonary complications are the leading cause of mortality during the first year following SCI (Wuermsler *et al.*, 2007). According to these authors, the main reasons for pulmonary dysfunction are difficulty in clearing secretions, due to weak or paralyzed abdominal muscles, and therefore an ineffective cough mechanism, atelectasis and hypoventilation. If required, patients should receive mechanical ventilation, and secretions should be cleared by means of techniques such as manually assisted cough (Wuermsler *et al.*, 2007). Due to the decreased nutritional state of the body and immobilization after SCI, there is a great risk for the development of pressure ulcers. This should be prevented at all costs through regular pressure relief techniques

and optimal nutrition of the body. The presence of pressure sores will result in longer immobilization, and therefore an increased risk for the development of numerous secondary complications causing poor medical and functional outcomes.

2.4 PREDICTORS OF NEUROLOGICAL RECOVERY AFTER SCI

It is important to be able to determine a prognosis for neurological recovery of people who have sustained a SCI to provide accurate information to patients and their families, to guide the patients' rehabilitation and to assess the effectiveness of new treatment methods. Prognosis for neurological recovery is best predicted by the neurologic physical examination of the patient 72 hours after injury rather than earlier (Wuermser *et al.*, 2007). Neurological recovery during the first year after injury will depend largely on the initial neurological level of injury, the initial motor strength and most importantly, whether the injury was classified as a complete or incomplete injury (Wuermser *et al.*, 2007).

2.4.1 Initial neurological level and extent of injury

With complete tetraplegia, the most significant recovery of the upper extremities occurs during the first six months after injury, with the greatest rate of change during the first three months (Wuermser *et al.*, 2005). Although motor recovery can continue after this period, the prognosis for neurological recovery decreases substantially after one year post injury, especially for those patients with no (0/5) initial muscle strength. The stronger the muscles were at the 72 hour neurological examination, the better the chances for improvement in muscle strength during the first year after injury (Wuermser *et al.*, 2007). Presence of sensation at a specific level, and the rate at which a muscle recovers immediately after the injury, improve the chances for motor recovery of those specific muscles (Wuermser *et al.*, 2007). With incomplete tetraplegia the motor recovery of the upper extremities is approximately twice as great compared to complete tetraplegia. There is also a potential for varying degrees of neurological recovery of the lower extremities and even functional ambulation. Patients who have an incomplete sensory lesion, with sparing of pin-prick sensation rather than light-touch sensation alone, have a greater chance for motor recovery (Wuermser *et al.*, 2007). It is also reported that tetraplegic patients with an initial incomplete motor injury, have the best prognosis for neurologic and functional recovery (Wuermser *et al.*, 2007). The most motor recovery occurs during the first six months after injury, and the earlier the motor return, the better the prognosis for further recovery (Wuermser *et al.*, 2007).

The potential for lower extremity recovery in a complete paraplegic patient improves with a lower level of injury initially, as reported by Wuermser *et al.* (2007), where 55% of patients with an initial

neurological level of injury below T12 had some recovery of muscle strength in the lower extremities. It was also reported that patients with incomplete paraplegia have the best prognosis for lower extremity recovery and functional ambulation. Significant return can be expected for up to one year after the injury (Wuermser *et al.*, 2007).

According to a study conducted by Kirshblum, Millis, McKinley and Tulskey (2004), 94,4% of the subjects with a neurological complete SCI at one year, remained the same at the five-year post-injury evaluation. Only 3,5% improved from a American Spinal Injury Association (ASIA) grade A to a ASIA grade B, 1,5% improved from a ASIA A to a C and 1,05% from an ASIA A to a D. In general, patients without sacral sparing at the initial assessment were less likely to improve (Lim & Tow, 2007). (See Appendix I for a description of the ASIA Impairment Scale (AIS) codes).

2.4.2 Patient characteristics and etiology of the injury

Patient characteristics such as age, gender and etiology of the injury may also contribute to the prognosis for neurological recovery after SCI (Lim & Tow, 2007; Wuermser *et al.*, 2007). According to a study conducted by Marino, Ditunno, Donovan and Maynard (1999), SCI as a result of violence (gunshots and stab wounds) were more likely to be complete than those caused by non-violence and, if complete, were more likely to remain complete compared to non-violent injuries. Older people may have a worse outcome regarding neurological recovery for similar injuries than younger patients, maybe due to a decrease in neural plasticity (Wuermser *et al.*, 2007). Research reporting on the effect of gender on neurological recovery is very sparse. Studies conducted by Sipski *et al.* (2004) and Furlan, Krassioukov and Fehlings (2003) showed either no difference or only a slight improvement in neurological recovery for women. However a study conducted by Sipski *et al.* (2004) showed that, on admission, men were more likely to have a complete SCI compared to women who were more likely to have incomplete SCI. Although the etiology of the injury could have contributed to this finding, Sipski *et al.* (2004) stated that the direct effect of gender on severity of injury, and as a result prognosis for neurological recovery, cannot be eliminated. According to Wuermser *et al.* (2007) estrogen may have neuroprotective properties relative to central nervous system disorders, but further research is needed.

2.4.3 Surgery

Whether surgery improves recovery is unclear. As mentioned earlier, surgery for decompression purposes may be more helpful compared to surgery for stabilization. Although studies on the timing of surgery are inconclusive, the indication is that early surgery may not improve neurological outcome (Lim & Tow, 2007).

2.4.4 Methylprednisolone

The administration of methylprednisolone is still practiced in many institutions and has become a common intervention, although the evidence for the effectiveness of methylprednisolone in limiting secondary injury processes is weak and inconclusive (Hurlbert, 2006).

Although certain interventions can minimize the effect of the secondary mechanism of injury, as discussed earlier, the ultimate outcome of SCI depends on the quantity and quality of axons surviving at the level of injury (Nockels, 2001). Quite clearly, the only treatment for a SCI currently is the prevention of the primary injury.

2.5 REHABILITATION OF SCI

2.5.1 Defining rehabilitation

As SCI often results in complete or partial paralysis, rehabilitation of persons with SCI is essential to regain their previous level of function, or as close to it as possible. Understanding the term “rehabilitation” enables the health worker to effectively rehabilitate the individual with disability. Rehabilitation medicine may be defined “as the multi- and interdisciplinary management of a person’s functioning and health” (Stucki *et al.*, 2002:932) and defines itself “with respect to concepts of functioning, disability and health” (Stucki *et al.*, 2002:932). The goals of rehabilitation medicine are to minimize symptoms and disability through the implementation of treatment-, rehabilitative- and preventive strategies (Stucki *et al.*, 2002). Rehabilitation options are to overcome impaired body functions, activity limitations and participation restrictions (Stucki *et al.*, 2002). In this study the focus will be on investigating the participation restrictions and identifying the barriers that prevent the person with SCI from participating at his/her previous levels of functioning.

Past definitions of rehabilitation have been criticized for their narrow perspective, based on the biomedical model which implies that persons with disability should be enabled to fulfil questionable societal norms (Bickenbach *et al.*, 1999). Persons with disability should therefore be enabled to achieve the knowledge and skills needed to achieve optimal physical, psychosocial and social functioning (Stucki, Cieza & Melvin, 2007). What the biomedical model actually means, is that, in order for the individual with the disability to function again in society, the individual should change or empower him/herself to adapt to his/her existing environment. Major conceptual advances in rehabilitation have since occurred. The approach has moved from a predominantly biomedical model to one in which the psychological and socio-cultural aspects of the patients are as important. Furthermore the need for specialized rehabilitation units has been recognized (Wade &

de Jong, 2000) and as more people with SCI survive longer with substantial disability, the demand for rehabilitation services will increase (Wade & de Jong, 2000).

In 1980 the WHO issued a tool for the classification of the consequences of disease, namely The ICIDH. The ICIDH was developed by the WHO and was first published in 1980. The WHO objective for developing a “consequences of disease” classification tool was to find common ground for the results of disease to enable better planning of services and the provision of treatment and rehabilitation (Hurst, 2003). Since 1947, mortality statistics were reported based on the WHO’s International Statistical Classification of Disease and Related Health Problems, Tenth Revision (ICD-10) (Ustun, Chatterji, Bickenbach, Kostanjsek & Scheider, 2003). However, information about non-fatal health outcomes, that is functioning and disability across all aspects of life, was missing (Ustun *et al.*, 2003). The acceptance of the ICIDH in 1980 by the WHO allowed for the capturing of data on the overall health status of living populations. According to Wade and de Jong (2000), the development of this classification model and its worldwide acceptance is arguably the greatest single advance in the field of rehabilitation. Through the ICIDH, the WHO recognized that the biomedical model and the ICD-10 did not address the consequences of chronic diseases. However, the ICIDH was criticized for not recognizing the role of the environment in its model and for its use of negative terminology, mainly supporting a biomedical approach once again, and not acknowledging sufficiently the role of social, cultural, economic and political influences.

In 1993 a revision process was begun to address the WHO’s need for a framework for measuring and reporting health on both individual and population levels. In 2001 the World Health Assembly endorsed the ICF for international use. The ICF is the final result of a long-standing revision process with the input of government and non-government organizations, including groups representing people with disabilities (De Kleijn-de Vrankrijker, 2003). For more background information on the process followed and the role players involved in the birth of the ICF, refer to Appendix II.

An important addition to the ICIDH was the inclusion of environmental factors and personal factors such as contextual factors, thus recognizing the role of the environment in human functioning. The following section expands on the impact of the environment on all components of functioning and disability and the need to recognize the dynamic interaction between health conditions and contextual factors in the understanding and management of people with disabilities.

2.5.2 Environmental factors and their role in participation after SCI

The increase in life-expectancy after SCI, recognized community integration, together with social participation and quality of life, are the ultimate goals of a comprehensive rehabilitation process (Noreau, Fougere, Post & Asano, 2005). Participation is defined as “involvement in life situations” and is a core concept of all major models of disability, including the WHO’s ICF (WHO, 2001). With the development of the ICF (WHO, 2001), the emphasis was shifted from a bio-medical model approach to rehabilitation or the “consequence of impairment and disease” to the bio-psychosocial model or “components of health” approach (Usten *et al.*, 2003).

The ICF is a classification system that allows a detailed description of the person’s experience of disability, including the environmental factors that have an impact on a person’s functioning. The focus of intervention has shifted from the individual to the environment in which the individual functions. Therefore disability is not seen as a direct consequence of the disease or a feature of the individual, but as the outcome of the interaction of the person with the health condition and the environmental factors (Schneidert, Hurst, Miller & Usten, 2003). According to Hurst (2003:574) “the environment is divided into three main areas: those affecting the individual directly i.e. access to the home and technical and personal assistance; factors regarding services and systems; and factors of policy and legislation”. Stiens, Kirshblum, Groah, McKinley and Gittler (2002) divide the environment into sectors i.e. immediate environment (that is directly in contact with the person e.g. wheelchair), the intermediate environment which is the personal living space and workspace; the community environment (the space modified for public use) and the natural environment (the space that has been minimally changed). Environmental factors “make up the physical, social and attitudinal environment in which people live and conduct their lives” (WHO, 2001:16) and the personal factors “are the particular background of an individual’s life and living” (WHO, 2001:17). Although both environmental and personal factors are important in the development of disability, personal factors are not classified in the ICF, because of the large social and cultural variance associated with them (Schneidert *et al.*, 2003).

Environmental factors in the ICF focus on two different levels i.e. individual or the immediate environment of the individual, including home, workplace and school, and the societal level which includes formal and informal social structures, services, approaches or systems in the community or society that might have an impact on individuals. The environmental factors are organized into five chapters in the ICF i.e. (1) Products and technology, (2) Natural environment and human-made changes to the environment, (3) Support and relationships, (4) Attitudes, and (5) Services, systems and policies (WHO, 2001). SCI often results in profound and long-term disability with devastating

consequences for the individual, the family and everyone involved with the individual. SCI not only affects the individual's functional life, but also his/her financial and social life with a major impact on his/her medical and psychological well-being. Therefore, the presence or absence of environmental factors such as the amount of support from family members, friends and employers and the availability of services such as wheelchair friendly public transport, will ultimately determine the level of participation after SCI.

2.5.3 Participation

Participation or “involvement” can mean taking part, being included or engaged in an area of life, being accepted or having access to needy resources. Participation is essentially a unique individual response to the integration of environmental, personal and cultural factors with the reality of living with a disability (Carpenter, Forwell, Jongbloed & Backman, 2007). The degree of participation or involvement in life situations is measured by the individual's performance or what an individual does in his or her current environment. Performance can be influenced in a positive or negative way by environmental factors, which are external to the individual. This does not mean that participation is directly equated with performance, as the subjective experience of involvement or “sense of belonging” should be distinguished from the concept of involvement (WHO, 2001). As mentioned earlier, one of the shortcomings of the ICF is the lack of recognition of the impact of the subjective dimension on functioning.

Although functional performance at discharge after in-patient rehabilitation is reduced with greater neurological impairment (Middleton, Truman & Geraghty, 1998), the severity of a SCI is not the best predictor of most long-term outcomes (Whiteneck, Meade, Dijkers, Tate, Bushnik & Forcheimer, 2004). Whiteneck, Tate and Charlifue (1999) found that the neurological level of SCI, age, number of years post injury, gender, race and education explain 29% of the variance in physical independence and mobility after SCI, but only 9% in social integration. In their study on psycho-social adaptation after SCI, Martz, Livneh, Priebe, Wuersmer and Ottomanelli (2005) came to a similar conclusion that injury-related characteristics do not adequately explain psychosocial functioning or life satisfaction. Discharge to, and reintegration into the community are considered positive outcomes of spinal cord injury rehabilitation and according to Anzai, Young, McCallum, Miller and Jongbloed (2006), a range of individual, health-related factors and an array of complex social factors, and not injury severity alone, influence the discharge setting and leave some individuals more vulnerable to long-term institutionalization after SCI. Fortunately with the acceptance of the ICF as a tool to conceptualize disability and the inclusion of environmental

factors, which allow for analysis of their contribution to participation, a shift has taken place in the understanding of long-term social outcomes after SCI (Anzai *et al.*, 2006).

2.5.4 Disability

Historically disability, nationally and internationally, has been regarded as a health and welfare issue, but over the last few decades people with disabilities have been fighting to have disability viewed as a social and human rights issue (Hurst, 2003; Integrated National Disability Strategy (INDS), 1997) and with this shift in the way of thinking, the definitions of disability have changed too. A person with a disability is defined by South African legislation as someone who is “limited in one or more functional activities” (South African Human Rights Commission Report (SAHRC), 2002:10), but “the extent and experience of disability is, to a large extent, determined by how much the person’s environment prevents that individual from taking part in community life on an equal level with others” (SAHRC Report, 2002:10). According to the ICF (WHO, 2001:213), “disability is an umbrella term for impairments, activity limitations and participation restrictions” and “denotes the negative aspects of the interaction between an individual (with a health condition) and that individual’s contextual factors (environmental and personal factors)”. With the recognition of contextual factors as one of the pre-determinants of disability (WHO, 2001), people with disabilities are not regarded as dependent or unable to manage their own lives, but as equal members of society with the same rights and responsibilities as everyone else (Hurst, 2003; INDS, 1997). The result is that all planning and delivery of services, whether by government or private companies, must take into account the needs of people with disabilities. This involves the removal of barriers to equal participation at all levels of society (INDS, 1997). Contextual factors such as the structural environment, discriminatory societal attitudes and unemployment have been identified as some of the barriers that prevent persons with disability in South Africa from achieving their full potential (INDS, 1997).

In a study conducted by Maart, Eide, Jelsma, Loeb and Ka Toni (2007) to identify environmental barriers experienced by persons with disability living within the urban Western Cape region of South Africa, 50% of the participants reported barriers to access to public buildings, which have a negative impact on mobility and social integration. This is of concern, as this study was conducted seven years after the publication of the INDS of South Africa (1997), which recommends (recommendation 5d) that the National Building Regulations be amended to allow barrier-free access and proposes measures to ensure implementation of these regulations (Maart *et al.*, 2007). Furthermore services related to housing, legal services and education were experienced as barriers by a large number of these participants living within the urban Western Cape province of South

Africa. The ability to access services, school or work is largely dependent on the availability and accessibility of transport, which in general presents major challenges to many of the people in South Africa, including people with disabilities (Maart *et al.*, 2007). Assessing the environmental factors, as described within the ICF, “will ensure appropriate policies, systems and services for health care and support, provide measurable indicators for health status and sustainable development and underpin the recognition that disability is a human rights issue” (Hurst, 2003:572).

2.5.5 Life satisfaction after SCI

According to a study conducted by Tonack, Hitzig, Craven, Campbell, Boschen and McGillivray (2008) participation, together with psychological complications and self-perceived health, were the only significant contributors to life satisfaction after SCI and not impairment. Other studies on life satisfaction after SCI conducted by Pierce, Richards, Gordon and Tate (1999) and Richards, Bombardier, Tate, Dijkers, Gordon and Shewchuk (1999) came to a similar conclusion, that participation and environmental access are the strongest predictors of life satisfaction after SCI. A study conducted by Whiteneck *et al.* (2004) supports these findings that life satisfaction is more directly related to participation than to impairments or activity limitations.

According to Noreau and Fougeyrollas (2000:171), for persons living with a disability “... the quality of social participation may be seen as a situational result generated by the interaction between the characteristics of the person and his/her environment” and “... the result is operationalized by the concept of ‘life habits’ which is a key element for measuring the social participation”. ‘Life habits’ are defined by Noreau and Fougeyrollas (2000:171) as “those habits that ensure the survival and development of a person in society throughout his or her life”. They identified three most disrupted life habits, in relation to the long-term consequences of disability following SCI, to be (1) residence maintenance (inside and out), (2) occupational activities (family roles and relations, domestic tasks, employment) and (3) recreational (attending cultural events, sports, fitness, games) activities. For the purpose of this study, the literature review on community reintegration and participation will focus mainly on three major ‘life habits’ identified by Noreau and Fougeyrollas (2000) as most disrupted following SCI, i.e. residential reintegration, employment and recreation.

2.5.6 Residential reintegration following SCI

Reintegration as defined by Stiens *et al.* (2002:S72) “extends beyond the person; it promotes his/her fullest inclusion and participation within the physical and psychosocial environment”.

One of the main areas of the environment includes the individual's personal living space (Stiens *et al.*, 2002) and factors related to access to the home (Hurst, 2003). According to Dijkers (1998), community living describes the situation of an individual who fully participates in all aspects of social life of his or her family, community and society. Residential setting should therefore be considered important, as participation at this level is the first step towards successful social and community reintegration. Unfortunately there is a paucity of information on residential reintegration after SCI nationally and internationally. Although the right to access to adequate housing for everyone is guaranteed in the Constitution of the Republic of South Africa (Bill of Rights: Chapter 2 Act 108 of 1996), the majority of people with disabilities in South Africa survive on a disability grant and have very little hope of accessing independent housing (Integrated National Disability Strategy, 1997). This and the fact that existing dwellings or houses and environments are often inaccessible due to poor design, infrastructure and overcrowding, means that people with disabilities are often forced into institutions against their will (INDS, 1997). A study conducted by Maart *et al.* (2007), on environmental barriers experienced by people living with disabilities in urban and rural areas in South Africa, found that the majority of the Western Cape sample lives in temporary, informal structures that were more susceptible to the climate conditions of the Western Cape with flooding in winter and fires during dry, hot summers.

International research on discharge setting following SCI is mainly conducted on high lesion spinal cord injury. No literature could be found on residential reintegration for all lesions of spinal cord injury. It is therefore unclear whether residential reintegration after spinal cord injury is not a problem in first world countries or that the ability to function at home is more related to impairment than environmental factors. In a study conducted by Whiteneck *et al.* (2004) one environmental factor related to residential reintegration, i.e. "no help at home", was identified by 80% of participants (all levels of spinal cord injury) as an environmental barrier, but that this barrier appears to be more related to impairment, activity limitation and participation restriction than to external factors within the environment. Noreau and Fougere (2000) identified home maintenance as one of three most troublesome life habits following SCI. According to them habits, such as inside and outside maintenance and home upkeep require a critical level of motor capabilities and cannot be achieved without substantial human assistance. For some individuals residential maintenance can be difficult over a long term if resources are not available to carry out activities essential to continuing living in their own home. Although the bio-psychosocial model of disability contradicts this, stating that the disability is not a direct consequence of the impairment or health condition, but the interaction of the person with the health condition and with his immediate environment (Schneider *et al.*, 2003; WHO, 2001), the extent of the injury is directly related to the

amount of assistance needed for functioning. According to the ICF (WHO, 2001) the amount and availability of the assistance can present as a barrier or facilitator to social participation and therefore reintegration.

Participation at different levels of society, including residential, was identified as a significant predictor of, or contributor to, life satisfaction following SCI (Tonack *et al.*, 2008; Pierce *et al.*, 1999; Richards *et al.*, 1999) and that participation is dependent on the presence of barriers and facilitators in the person's immediate environment (WHO, 2001). In a study conducted by Bergmark, Winograd and Koopman (2008) on the relationship between residence location and quality of life amongst persons living with tetraplegia in California and Minnesota, participants consistently reported that residence-specific characteristics such as accessibility, privacy and freedom had major effects on their quality of life. Referring to the findings of the study by Bergmark *et al.* (2008), factors such as poor design of homes resulting in inaccessibility, overcrowding of homes and low incomes which do not allow the freedom of choice regarding residential location, as mentioned in the INDS (1997), could make it almost impossible to have a good quality of life following SCI in South Africa.

2.5.7 Community reintegration following SCI

Rehabilitation aims to enable people with health conditions, experiencing or likely to experience disability, to achieve and maintain optimal functioning in interaction with the environment (Stucki & Melvin, 2007). As the community forms part of the environment, the ultimate goal of rehabilitation is to enable the individual to become reintegrated back into a community. For individuals with SCI, "successful rehabilitation involves maximizing community integration, including: the ability to participate in community life activities, remain active in family and recreational events, and access local activities and resources, including health care follow-up and employment opportunities" (McKinley & Meade, 2004:79). Dijkers (1998:1) defines successful community re-integration "as being part of the mainstream of family and community life, fulfilling normal roles and responsibilities and being an active and contributing member of one's social groups and society as a whole". Through this definition Dijkers (1998) identifies three major areas in the community reintegration process, i.e. independent living, social participation and employment. According to Apple (1998), community reintegration includes physically getting to places that are not adequately accessible, as well as engaging in activities that may be different from those practiced pre-injury, but that nonetheless are fulfilling.

Dijkers (1991:1) defines a community as a "body of individuals organized into a unit, whether designated as a group with common interests, a society, a state, or some other political unit". The

concept of ‘community living’ as described by Townsend and Ryan (1991) is one of participation and contribution in every aspect of community life, including employment and leisure activities, and emphasizes social interaction with others. For the person with the disability, reintegration involves re-establishing previously existing roles and relationships in his/her community (Dijkers, 1998).

Numerous studies came to the conclusion that environmental factors are substantial contributors to life satisfaction (Noreau *et al.*, 2005; McKinley & Meade, 2004; Whiteneck *et al.*, 2004;). Interestingly Whiteneck *et al.* (2004) also found that environmental barriers are more strongly related to life satisfaction than to participation following SCI, and that life satisfaction is more strongly related to participation than to activity limitation or impairment. This potentially indicates that individuals facing barriers may be able to overcome them, but that the experience of encountering barriers may reduce satisfaction. According to McKinley and Meade (2004) community integration emphasizes the ability of individuals with a disability to overcome these barriers and also to have a positive influence on quality of life and therefore life satisfaction.

Previous research has documented that life satisfaction is greater for those who are involved in productive activities such as work, education and recreation (Post, van Dijk, van Asbeck & Schrijvers, 1998) and that reintegration in work, leisure activities and sport following SCI is considered to be an important goal of rehabilitation (Schonherr *et al.*, 2005). Life satisfaction is strongly related to health and well-being (Pentland, Harvery, Smith & Walker, 1999) and better quality of life (Siosteen, Lundqvist, Blomstrand, Sullivan & Sullivan, 1990). It has been demonstrated that involvement in sports after SCI improves rehabilitation outcomes and improves quality of life (Tasiemski, Bergstrom, Savic & Gardner, 2000). Return to work following SCI is regarded as one of the most important outcomes of reintegration into society as it gives people social status and adds meaning to life, as well as ensuring financial independence (Schonherr *et al.*, 2005; Krause, 1992). During a qualitative study conducted by Boschen, Tonack and Gargaro (2003), it was found that the majority of respondents expressed a strong desire to return to a previous or new line of work or to be “productive”. Some of them had managed to find employment, but the barriers related to health and functional ability, physical accessibility, transportation and societal attitudes made it difficult for them to participate in productive activities.

A systematic review of the literature on return to work after SCI, from the years 2000 to 2006, was performed by Lidal, Huynh and Biering-Sorensen (2007). In this review it was found that between 11.5% and 74% of people with SCI are gainfully employed. According to Yasuda, Wehman, Targett, Cifu and West (2002) the variability in employment estimates is dependent upon study

methodology and the different operational definitions of employment being used. Definitions for employment range from income generating, i.e. work for pay or being self-employed to non-income generating, i.e. including homemakers and students. In the review conducted by Lidal *et al.* (2007), the most common barriers to employment were health and physical limitations, lack of work experience, lack of sufficient education or training, physical and architectural barriers, discrimination by employers, loss of benefits, negative societal attitudes and problems with transportation (Boschen *et al.*, 2003; Liese, MacLeod & Drews, 2002). The effect of workplace characteristics and employers who fail to provide accommodation have also been identified as barriers (McMahon, Shaw, West & Waid-Ebbs, 2005). Obstacles or barriers according to numerous studies, as described by Targett, Wehman and Young (2004), are those that prevent persons with spinal cord injury from gaining and maintaining work, and may include difficulties related to social support, transportation, financial security, personal mobility, poor health, lack of suitable jobs, dependence for activities of daily living, accessibility of work environment and availability of assistive devices.

Transportation was identified by subjects with SCI as one of the most important barriers with regard to community participation and in particular return to productive activity (Lin, Hwang, Yu & Chen, 2009; Whiteneck *et al.*, 2004; Yasuda *et al.*, 2002; Conroy & McKenna, 1999; Krause 1992). According to Krause (1992) transportation, including public transport accessibility, should be addressed in order to increase the number of persons who return to work after SCI. Noreau, Dion, Vachon, Gervais and Laramee (1999) found that transportation variables accounted for up to 20% of the variance in productivity among persons with SCI, that the ability to drive a car was the most important transportation variable and that greater independence in transportation was positively correlated with productivity. According to a study conducted by Carpenter *et al.* (2007), amongst persons living with SCI, satisfaction with their main form of transport was clearly enhanced by owning a vehicle.

With their systematic review on return to work following SCI, Lidal *et al.* (2007) confirmed there are ongoing high unemployment rates for individuals with SCI. The most successful return to work rate is seen for persons injured at a younger age, with less severe injuries and with higher functional independence (Lidal *et al.*, 2007). This confirms that environmental barriers play a major role, as identified by numerous studies, in delaying or preventing a return to work, as these barriers will not have the same negative impact on persons with higher functional independence compared to persons who require more assistance for activities of daily living.

Despite the recognition of the major role that environmental factors play in community participation and reintegration, including return to work, very little research, especially in South Africa, has been done on the impact of the environment on persons living with various health conditions and specifically spinal cord injury.

In their systematic review on return to work following spinal cord injury Lidal *et al.* (2007) found that there is a lack of reports, on employment and SCI in developing countries, presented at the WHO, on the World Bank websites and in general a smaller number of studies on SCI, especially follow-up studies. According to Lidal *et al.* (2007), it is understandable considering the high national unemployment rates, poverty and cultural differences in most of these countries. These factors could contribute to the lack of studies on employment in South Africa following disability, and more specifically SCI.

According to the 2001 National Census (Statistics South Africa (SSA), 2005), the current estimated prevalence of disability in South Africa is 5% of the population (or 2 255 982 people with various disabilities), of which 30% had no schooling and only about 19% were in paid employment. The high proportion of disabled people with no schooling could be a reflection of the fact that disabled people are excluded from educational opportunities and the environment in regular schools does not facilitate integration. The low levels of paid employment amongst disabled people could be due to diverse socio-economic and social cultures, particularly their low levels of education, discrimination in the labour market and negative societal attitudes (SSA, 2005). According to the White Paper on the INDS (1997), 99% of disabled people in South Africa are excluded from employment in the open labour market. This high level can be attributed to amongst others, poor skills due to inadequate education, discriminatory attitudes and practices by employers, inaccessible public transport and inaccessible and unsupportive work environments (INDS, 1997).

Another major aspect of community reintegration is participation in recreational activities. As mentioned before, Noreau and Fougeyrollas (2000) identified participation in recreational activities, including sport, as one of the three most disruptive 'life habits' related to the long-term consequences of a SCI. Although physiologically and psychologically beneficial, participation in recreation and sport following SCI are an under-studied aspect of community reintegration (Slater & Meade, 2004).

Reintegration in work, leisure activities and sports following SCI is considered to be an important goal of rehabilitation. For persons living with SCI, return to work is regarded as one of the most important outcomes of reintegration in society. For those people unable to return to work, participation in non-vocational activities must also be considered as a successful rehabilitation

outcome (Schonher *et al.*, 2005). In their study on participation and satisfaction after SCI, Schonherr *et al.* (2005) found that most of the participants were satisfied with their lives, as most of them were able to return to work or to compensate for the time formerly spent on work by being involved with other activities such as sport and leisure. Reduced quality of life was particularly associated with an unsatisfactory vocational and leisure situation. Few studies have investigated the relation between (a) quality of life or (b) community reintegration after SCI and participation in sport and recreational activities. Nemunaitis, Haines, Rizk and Clark (2003) compared individuals with SCI on a wheelchair basket ball team to individuals with SCI who were not part of a team, and came to the conclusion that membership of a wheelchair basket ball team was correlated with improved community integration. Results of a study conducted by McVeigh, Hitzig and Craven (2009) to determine whether community reintegration and/or quality of life among people living with SCI are greater amongst sport participants compared to non-participants showed clearly that participation in sports after SCI was significantly correlated with both increased community reintegration and improved quality of life. They concluded that participation in sport should be promoted as part of the rehabilitation process, as this could contribute to improved rehabilitation outcomes and specifically facilitate community reintegration. According to Schonherr *et al.* (2005) focussing on participation during the rehabilitation period can be difficult as some patients might not be psychologically ready to cope with this aspect.

Physical activity after SCI, both shortly after and long after discharge from inpatient rehabilitation, as well as barriers associated with participation in recreational and sport activities after SCI have been studied. Schonherr *et al.* (2005) and Tasiemski *et al.* (2000) reported a significant decline ($P < 0.001$) in sport and recreational participation after SCI. Van den Berg-Emons, Bussmann, Sluis, Bergen, Van der Woude and Stam (2004) found that a strong decline in physical activity immediately after discharge from inpatient rehabilitation is consistent with the literature. Although it was found that this decline is partly reversed during the first year after discharge, it remained fairly low compared with normative values. This can be attributed to an increase in time spent on self-care and the extra time needed for coping with inconveniences resulting from incontinence and mobility problems (Schonherr *et al.*, 2005). The lack of sporting facilities for the disabled, lack of wheelchair access, a dislike of traditional 'disabled' sport, a lack of opportunities for practising their favourite sport, a fear of further injury and a lack of money and time (Tasiemski *et al.*, 2000) also contribute to lower levels of participation in sport recreation.

Factors identified as barriers to physical activity after SCI, by participants in a study conducted by Levins, Redenbach and Dyck (2004), include (1) 'individual influences', i.e. the issue of self-identity and the struggle to re-establish a new identity consistent with their pre-injury identity, and

(2) ‘societal influences’ which include barriers related to the physical and social environment, of which the most important barriers are inaccessibility of facilities, lack of equipment and negative societal attitudes. Participants reported that the availability of accessible facilities, programmes and equipment in a geographic location are related to the attitudes and priorities of those in that society. According to Levins *et al.* (2004) societal attitudes affect the perception of self. Vissers, Van den Berg-Emons, Sluis, Bergen, Stam and Bussmann (2008) found that problems with self-care and mobility in and around the house were the main barriers to physical activity shortly after discharge from the inpatient setting. More than nine months after discharge, accessibility of public buildings and problems with societal attitudes had the greatest negative impact on the level of everyday physical activity (Vissers *et al.*, 2000). Participants in a very small study, conducted by Njoki, Frantz and Mpofu (2007) on the impact of spinal cord injury on South African youth, expressed their concerns about their personal struggle with their identity as well as society’s struggle to integrate them, which is similar to the findings of Levins *et al.* (2004).

2.5.8 Overview of the South African situation on participation following disability

The Constitution of the Republic of South Africa (1996) Act 108 of 1996 and the Bill of Rights (1996) legislates that disabled people in South Africa should be treated as equal citizens with the same access to social and economic opportunities to improve their quality of life. Gathiram (2008:152) critically reviewed the developmental approach to disability in South Africa since 1994 and came to the conclusion that “... the development of the welfare system in South Africa is firmly rooted in a rights-based approach which aims to achieve social justice for physically disabled people” and that “... South Africa has a facilitative policy and legislative environment and institutional structure to achieve equalization of opportunities and economic empowerment of physically disabled people in South Africa” (153). However, very little has been achieved due to the difficulties of implementing these policies. Twelve years after democracy, the implementation of social assistance programmes has been the most successful. However, social assistance as a tool for development has not been successful, as the disability grant is being used for the survival of the families of the disabled due to poverty or unemployment. Other developmental initiatives, based on a more productive approach to welfare, such as vocational training centres, the Expanded Public Works Programme and the skills development strategy have been slow in meeting these objectives (Gathiram, 2008). Integration of disabled individuals into the workforce has also not been successful. According to Gathiram (2008), it is difficult to achieve goals on social and economic development in a society in which the majority of the population are poor, unemployed and under-developed. Due to the lack of functioning and coordination of the institutional structures and lack of support services to facilitate the goal of holistic service delivery, many people are denied the

promises of the Constitution and the Bill of Rights. If the goals of development are to be achieved, there has to be systematic, integrated and coordinated service delivery, which according to Gathiram (2008), is unlikely at present.

2.6 THE INCIDENCE AND PREVALENCE OF SECONDARY CONDITIONS FOLLOWING SCI

This last section of the literature review delves into the impact of secondary conditions following SCI. The occurrence of these conditions often has a direct impact on the functioning, participation and ultimately the quality of life of persons with long term SCI. According to Potter, Wolfe, Burkell and Hayes (2004), the occurrence of secondary complications is almost like a new set of illnesses that the individual with SCI has to deal with after the initial trauma.

Disabling conditions, including SCI, are long-term, dynamic conditions that can change over time (Pope & Tarlov, 1991). The disabling condition itself is not a static entity, as people with disabling conditions often develop secondary conditions that are related to the primary disabling condition and may be even more debilitating (Pope & Tarlov, 1991). In their landmark report (Disability in America), the Institute of Medicine defined secondary conditions as “pathologies, impairments and functional limitations... that are causally related to a disabling condition...” and that, “by definition, the secondary condition would not occur in the absence of the primary condition” (Pope & Tarlov, 1991:214). The existence of a specific primary condition is a strong risk factor for specific secondary conditions to develop, and due to this causal relationship between the primary and secondary conditions, preventative measures can be introduced to reduce the risk of developing these secondary conditions (Pope & Tarlov, 1991).

Due to the enormous impact that a spinal cord injury has on the functioning of several body systems, i.e. urinary, cutaneous, respiratory, cardiovascular and musculo-skeletal systems, secondary medical conditions are extremely common in patients with SCI. Secondary conditions can occur at any point from time of injury, and given that SCI becomes a chronic condition, the risk of developing secondary conditions are high throughout the lifespan and might even increase over time (Richards, Waites, Chen, Kogos & Schmitt, 2004). However the presence and frequency of these secondary conditions, at specific phases after the onset of the primary injury, has changed over time. According to Chen, Apple, Hudson and Bode (1999) the number of days from injury to rehabilitation has steadily decreased with time, resulting in the development of secondary conditions during the hospital rehabilitation which previously occurred during the acute stage. Chen *et al.*, (1999) found that pressure ulcers were the most common secondary condition to occur during rehabilitation hospitalization and that complete neurologic injuries were at a higher risk of

developing pressure ulcers. This was followed by autonomic dysreflexia and atelectasis and/or pneumonia. The presence of deep vein thrombosis (DVT) and pulmonary embolism during the rehabilitation phase has decreased considerably due to a greater awareness of their potential to develop and improved prophylactic management. Renal complications on the other hand are difficult to determine as very few patients undergo renal testing during rehabilitation hospitalization (Chen *et al.*, 1999).

Cardenas, Hoffman, Kirshblum and McKinley (2004) found in their study on the etiology and incidence of rehospitalisation after traumatic SCI, that the average number of re-hospitalizations in the first year after discharge was significantly higher than during any of the other follow-up years. At year one significant relationships were found between re-hospitalization and (1) functional ability at discharge from rehabilitation and (2) payer source. They found that patients with low functional ability at discharge and patients funded by state or federal programmes were more likely to be re-hospitalized within the first year (Cardenas *et al.*, 2004). Studies have shown that acute rehabilitation lengths of stay (LOS) continue to decrease (NSCISC, 2008). According to Cardenas *et al.* (2004) reduced acute care LOS has led to short-term cost savings, but placed patients at a higher risk of developing secondary conditions, resulting in an increase in cost in the long-term management of SCI. Shorter acute care LOS and earlier discharge has led to an increased potential that patients are being discharged before achieving their highest functional level for mobility and self-care, including bladder management. There is also less time for patient, family and carer education and training (Cardenas *et al.*, 2004). This could explain the high incidence of re-hospitalization for urinary tract infections (UTIs), pressure ulcers and respiratory problems within the first anniversary year, as found by Cardenas *et al.* (2004). Of interest is that patients discharged to a skilled nursing facility (SNF) after acute rehabilitation were at a greater risk of developing secondary conditions that require re-hospitalization than any other discharge residence. Reasons for this could be that patients with decreased functional ability and increased dependence were more likely to be discharged to a SNF, and that bladder management of patients in SNFs is more likely to include indwelling catheters, which are associated with a higher risk of developing UTIs plus renal and urethral calculi (Cardenas *et al.*, 2004).

Since 1950 the life-expectancy for people with SCI has increased considerably and the mean survival rate after trauma frequently exceeds 30 years. This is mainly due to the improvements in medical, surgical and rehabilitation care of SCI over the years (Bloemen-Vrencken *et al.*, 2005; Noreau, Proulx, Gagnon, Drolet & Laramée, 2000; Charlifue, Weitzenkamp & Whiteneck, 1999; Anson & Shepherd, 1996; Pope & Tarlov, 1991). However, as these individuals live longer, the potential to develop secondary conditions are far greater (Pope & Tarlov, 1991). They are not only

prone to develop secondary conditions related to SCI, but also health conditions typically associated with the aging process (Charlifue *et al.*, 1999). Although life expectancy of people living with SCI has increased, compared with the general population, they are still dying younger because of the development of related secondary medical conditions (NSCISC, 2008).

The incidence of secondary conditions in persons with long-term SCI is extremely high and the occurrence of UTIs and pressure ulcers is remarkably consistent over time (Kroll, Neri & Ho, 2007). A study conducted by Anson & Shepherd (1996) on patients that were discharged between eight weeks and 15 years prior to the examination, showed that only 4.4% of the patients examined at the time were free of secondary conditions, and three or more secondary conditions were present in 58% of the sample. Obesity, pain, spasticity, UTIs and pressure ulcers were the most common secondary conditions present in the study by Anson and Shepherd (1996). According to a study conducted by Cardenas *et al.* (2004) on the etiology and re-hospitalization after traumatic SCI, the leading cause of rehospitalisation for all levels of injury at one, 10, 15 and 20 year time intervals, was diseases of the genitourinary system including UTIs, followed by respiratory and skin problems including pressure ulcers. Respiratory secondary conditions were more likely to develop in patients with tetraplegia, whereas patients with paraplegia were more likely to be re-hospitalized with pressure ulcers. As pressure ulcers were the second most common secondary conditions at most time intervals after discharge (years one, 10, 15 and 20) and the most common at year five, it remains an important secondary condition related to SCI (Cardenas *et al.*, 2004).

It appears that some secondary conditions are inter-related. Pressure ulcers in themselves can cause pain (in incomplete lesions), and increase spasticity and wound infections, resulting in a higher frequency of re-hospitalization (Cardenas *et al.*, 2004). Wound infections and UTIs can increase spasticity, which can increase the risk of developing pressure ulcers. Therefore, Anson and Shepherd (1996) suggested that the relationships amongst the different secondary conditions should be investigated to reduce the potential of developing secondary conditions.

Studies conducted by Noreau *et al.* (2000), Prysak, Andresen and Meyers (2000) and Bloemen-Vrencken *et al.* (2005) investigated the prevalence of secondary conditions in persons with long-standing traumatic SCI. Prysak *et al.* (2000) found in their sample, with a mean injury duration of 17.5 years (range between few months and 54 years), that spasms and/or spasticity were the most common secondary condition (70%) and it had the highest percentage of chronic frequency (94%). Other secondary conditions reported by about half of the group were shoulder pain or other repetitive stress injury (52%), fatigue (51%), UTIs (48%) and chronic pain (45%). Skin and bowel problems were only reported by about one third of the sample. The findings of the study conducted

by Noreau *et al.* (2000) (injury duration range of two to 26 years and Bloemen-Vrencken *et al.* (2005) (injury duration range six months to 62.6 years), were similar to that of Prysak *et al.* (2000) with regard to the prevalence of UTIs (56% and 46%) and pressure sores (28% and 36%). The prevalence of spasticity (40% and 57%) however was significantly lower. The prevalence of bowel problems (61%) as found by Bloemen-Vrencken *et al.* (2005) was significantly higher than that of Prysak *et al.* (2000).

Noreau *et al.* (2000) also investigated the relationships between the prevalence of secondary conditions and the level and completeness of injury, perceived health status, duration of injury and personal income, with interesting results. They found a significant association between the occurrence of secondary conditions, perceived health status and personal income. A higher prevalence of secondary conditions was reported by the individuals who perceived their health status as fair or poor. The study (Noreau *et al.*, 2000) also showed that the individuals with the lowest income showed (1) the highest prevalence of pressure sores and re-hospitalization and (2) that the highest percentage of individuals who perceived their health as fair or poor was found in this income group.

It is problematic to compare the findings of the different studies on the occurrence of secondary conditions among individuals with SCI. Methodologies used, time frames and sample characteristics were different for all the studies. According to Noreau *et al.* (2000) it is also difficult to compare these statistics for people who live in different countries, as prevalence might vary according to the socio-political, economic, sanitary levels and other environmental aspects of the countries. However, the studies all came to the same conclusion that secondary conditions frequently occur in persons with SCI in the period after in-patient rehabilitation and that the occurrence of these problems increases in the long term. As the occurrence of secondary conditions has a profound negative impact on quality of life (Anson & Shephard, 1996) and the development of secondary conditions in the post-acute stage is the leading cause of death in persons with SCI (DeVivo, Krause & Lammertse, 1999), life-long follow-up and medical care of these individuals are essential to address and minimize these problems. Moreover, the first year becomes a crucial period for follow up to monitor these secondary conditions and hopefully initiate preventative strategies as soon as possible.

2.7 CONCLUSION

Due to the disabling nature of SCI and its high personal, bio-psychological and socio-economic impact, information on the epidemiology of SCI is essential for successful outcomes after this devastating condition. However, it is evident in the existing literature that epidemiology factors

such as the severity of a spinal cord injury, age, gender, race or level of education are not the best predictors of most long-term outcomes after SCI.

Preserving life is still the primary aim of the management of traumatic SCI, but equally as important is the quality of life for these individuals. It is clear in the literature that life satisfaction is more strongly related to social participation than to impairment. Literature also acknowledges that activity limitations and environmental factors are substantially contributing to life satisfaction after SCI. Active involvement in productive activities such as work, education and recreation is strongly related to quality of life and life satisfaction. Attaining and maintaining community integration, together with social participation and quality of life are therefore the ultimate goals of the rehabilitation process. There is a need to understand the influence of SCI on the life of the individual better, so that interventions can be proposed to enhance life satisfaction. It is also important to identify environmental facilitators and/or barriers that can influence the successful re-integration of individuals with SCI into their home-, community- and work environment. Despite the recognition of the major role that environmental factors play in community participation and reintegration including return to work, very little research has been done in South Africa on the impact of the environment on persons living with spinal cord injury.

Due to the paucity of information (data/statistics) on the South African SCI population, especially with regard to incidence, prevalence, demographic and injury-related characteristics, as well as the aspects of functioning and participation after SCI, this study aims to shed some light on all of these aspects. The results of this study will create a basis for the successful rehabilitation of persons with SCI in South Africa and for further research on SCI in this country. The study also aims to identify the environmental barriers that may influence outcomes after SCI. A high quality of life after SCI can be achieved, but that would be dependent on several factors. We need to know what these factors are to ensure that persons with SCI in South Africa do not only survive SCI, but that they have a good quality and level of satisfaction with life. This study aims to contribute to “add(ing) life to years” (DeVivo, Richards, Stover & Go, 1991:602) after SCI and not only years to life.

CHAPTER 3: METHODOLOGY

In order to obtain answers to numerous questions regarding the functioning of persons with SCI in South-Africa, and for reasons discussed earlier in the introduction chapter, a study describing the activity and participation profile of persons with SCI was planned. In this chapter methodological issues pertaining to the study are discussed.

3.1 RESEARCH QUESTION

What is the activity and participation profile of adults with traumatic spinal cord injury at discharge and six months after discharge from rehabilitation (the Western Cape Rehabilitation Centre – WCRC)?

3.2 AIM

The primary aim of the study was to establish what the activity and participation profile of persons with traumatic spinal cord injury is, and furthermore to see if it changes after discharge from inpatient rehabilitation.

3.3 OBJECTIVES

The specific objectives of this study were:

- a) To describe the demographic characteristics of the subjects with respect to age, gender, race and residential address.
- b) To describe the medical characteristics of the subjects with respect to etiology, level and nature of spinal cord involvement and severity of neurological deficit at discharge and six months after discharge. The incidence of secondary complications on admission, at discharge and six months after discharge from the WCRC was also sought.
- c) To describe the socio-economic profile of the subjects with respect to level of education, level of productive activity and gross monthly income at the time of the injury, at discharge and six months after discharge from the WCRC.
- d) To describe the living environment to which the subjects were discharged.
- e) To describe the activity and participation profile of the subjects at discharge and six months after discharge from the WCRC.
- f) To compare activity and participation at discharge and six months after discharge from the WCRC.
- g) To identify the environmental factors classified as barriers by the subjects.

3.4 RESEARCH SETTING

The WCRC is located in Mitchell's Plain, Cape Town, South Africa. The Department of Health (DOH) in the Western Cape consolidated the specialized rehabilitation services in the Western Cape Province to make provision for one provincial rehabilitation centre. The amalgamated Conradie Hospital Spinal Cord Injury Unit plus the Conradie and Karl Bremer Comprehensive Rehabilitation Units relocated to new premises on the Lentegour Hospital site in Mitchell's Plain and are now known as the WCRC. The WCRC was officially opened on December 3, 2004 and makes provision for a total user population of 485 950 in the Western Cape Province (WCRC, 2009). According to the official website of the WCRC the primary aim of the rehabilitation services offered by the WCRC is to re-integrate persons with physical disabilities into their communities i.e. home-life or productive activity. Patients are referred from all levels of acute and sub-acute health services (tertiary, secondary, district and primary health care). Clients can also self-refer to the WCRC. The facility is the only one of its kind in the country, which results in numerous referrals from the rest of the country, as well as from neighbouring Namibia and other African countries. The primary target groups referred to the WCRC include persons with spinal cord injury (WCRC, 2009).

The reason for choosing this particular setting for the study was because it is the only government-funded institution in the Western Cape Province for the provision of rehabilitation services, and therefore the institution where the majority of government-subsidized spinal cord injured persons will receive their rehabilitation after their injury. As the primary aim of the rehabilitation services offered by the WCRC is to re-integrate persons with physical disabilities into their communities, home-life and productive activity (WCRC, 2009), the results of this study should be of value in the planning of rehabilitation strategies as implemented by the WCRC. This institution is also a flagship for rehabilitation services in the Western Cape Province and in the country. Information gathered on the impact and effectiveness of the rehabilitation programmes for SCI patients at WCRC will also inform decision making and policy development or review within the DOH.

3.5 STUDY DESIGN

A prospective, descriptive study was the study design of choice. The aim of such a study is to describe a situation in order to gain additional information, which often provides a valuable baseline for further investigations as it defines what actually happens (Drummond, 1996). This was considered to be the most appropriate choice, as information on various aspects of a defined group of persons with spinal cord injury was sought. As there is a paucity of information on the epidemiology of SCI in South-Africa and the degree to which persons with SCI are reintegrated into their home-life, community and work place after discharge from the rehabilitation setting, the results of this study will provide valuable information on the profile of persons with SCI receiving

rehabilitation in the Cape Metropole and more specifically the WCRC. This information can be used for further investigations. Very little is known about the study population, hence it was deemed appropriate to describe the population before being able to formulate hypotheses for further investigations.

Although a prospective study is more costly and time-consuming, a retrospective study was not considered as records may be inaccurate or incomplete. The ICF and the International Standards for the Classification of Spinal Cord Injury (ISCSIC), being two of the measuring instruments for this study, were not included in early assessments of persons with SCI, and due to the fact that the WCRC was formed through the amalgamation of two separate rehabilitation centres, data collected in the past might not have been useful.

Data were gathered at two points in time, i.e. at discharge from the WCRC and at six months after discharge from the WCRC. Despite the disadvantages of longitudinal studies i.e. a possible large fall-out rate and the fact that it is time-consuming, the researcher deemed it important to have a six-month follow-up. At six months after discharge from the WCRC, the SCI injury for the majority of the subjects will have occurred between nine and 12 months earlier. Existing international literature shows clearly that the level of impairment and disability, and thus functional ability, is dynamic rather than static following discharge from hospital (Amsters, Pershouse, Price & Kendall, 2005; Dzidic & Moslavac, 1997; Yarkoney, Roth, Heinemann, Lovell & Wu, 1988). Although significant return can be expected for up to one year after the injury, the most motor recovery occurs during the first six months after injury, and the earlier the return the better the prognosis for further recovery. (Wurmser *et al.*, 2007). The majority of the subjects in this study would be past the period where neurological recovery is likely to occur at the time of their six months follow-up. Amsters *et al.* (2005) however, reported an increase in functional ability for up to 10 years after discharge from hospital. Returning to community life and employment after SCI is considered to be the ultimate goal of rehabilitation, as it brings both economic and intrinsic rewards and is related to greater life satisfaction, higher level of activities and better overall health (Krause 2003). Therefore it was considered essential to investigate the level of functioning, and the variables (excluding neurological recovery) that might have an impact on functioning after discharge from the rehabilitation setting, to ensure optimal rehabilitation outcomes for individuals with SCI.

3.6 STUDY POPULATION

The study population was defined as all adults with traumatic SCI who were discharged to the Cape Metropole after completion of their rehabilitation at the WCRC.

The WCRC has currently a bed capacity of 156, of which 78 are allocated to patients with spinal cord lesions. According to records held by the WCRC, a total of 227 patients with single diagnosis SCI (traumatic and non-traumatic) were admitted to the WCRC during the period April, 1, 2006 and March, 12, 2007. Of the 227 patients, 221 (97%) were from the Western Cape Province, of which the majority (83%) were from the Cape Metropole (Cloete, 2007).

The original protocol of this study indicated that children (aged 12 years and older) would be included in the study; however a change from the protocol was necessary due to ethical considerations regarding consent for participation in the study. As the subjects were interviewed during the two weeks prior to discharge, it was considered impractical to seek consent from legal guardians if they were not present at the time of the interview.

3.6.1 Sampling and sample size

Consecutive sampling was used for this study. All patients with traumatic SCI who were discharged from September 1, 2008 from the WCRC, and were eligible for this study, were included in the study.

A power calculation was done to determine sample size ($\text{Alpha} = 0.05$). It was found that with a population correlation (Rho) of 0.4, significant results would be obtained with a sample size of 50. However, due to the fact that a large number of patients who were discharged did not meet the inclusion criteria and did not return for their follow-up appointment at six months after discharge, the calculated sample size at follow-up could not be met. Due to time-constraints, a cut-off point for data-collection was established for November 30, 2009. The sample size for the study was 47 subjects at discharge and 27 subjects at six months after discharge. As the researcher could not find evidence of other studies with similar objectives that were conducted on persons with spinal cord injuries nationally and internationally, results could still be deemed relevant.

3.6.2 Inclusion criteria

The following criteria were used to include subjects in the study:

- Traumatic SCI.
- Age 18 years and older at time of first interview at discharge from the WCRC.
- Males and females.
- Discharge to the Cape Metropolitan region of the Western Cape Province.
- Able to speak Afrikaans, English or Xhosa.
- Admitted for the first time to WCRC for rehabilitation.

- Informed, written consent was obtained.

Prior to the interview, the researcher gathered information from the subjects' medical records, which was later confirmed with each subject, to ensure that participants met the inclusion criteria (Appendix III). Each subject's contact details were checked to facilitate the six-month follow-up.

3.6.3 Exclusion criteria

The following criteria were used to exclude subjects from the study:

- Impaired cognitive function preventing a client from giving independent and informed written consent, or responding to questionnaires and physical testing.
- Any neurological condition, either at discharge or at six-month follow-up that will prevent the researcher from classifying the subject according to the ISCSCI.

3.7 MEASUREMENT

This section outlines the measuring instruments and the development thereof prior to, and during the pilot study. Methods of data capturing for the main study are given. Aspects regarding reliability, validity and statistical procedures are discussed.

3.7.1 Data capturing

Data were collected during face-to-face interviews with the subjects. Data on the neurological characteristics of the subjects were collected during a physical assessment of each subject. All the data were collected by the researcher. Completed data were captured on a spreadsheet using the Microsoft Excel programme in preparation for analysis.

3.7.2 Measuring instruments

The following measuring instruments were used in this study:

- The ISCSCI
- A purposely-developed questionnaire to gather injury-related, demographic and health information as well as information on assistive devices, socio-economic profile and living environment after discharge.
- The ICF

3.7.2.1 The ISCSCI

The ISCSCI, also known as the ASIA Classification, was used to collect data regarding the neurological level and the degree of impairment of SCI. The ISCSCI consists of two parts i.e. the Standard Neurological Classification of SCI (Appendix IV) to establish the neurological level of the each subject and the AIS (Appendix V) to establish the degree of physical impairment.

Nearly a quarter of a century ago the need for a uniform measure of severity of SCI was identified internationally (Ditunno, Young, Donovan & Creasy, 1994). In response to the need for a uniform measure of impairment and disability for SCI, the ASIA developed and published the first edition of the ISCSCI in 1982 (Maynard, Bracken, Creasy, Ditunno, Donovan, Ducker, Garber *et al.*, 1997). Three revisions (1989, 1992 and 1996) of the ISCSCI by the ASIA Committee followed. In 1992 major revisions were made to the standards to further refine the neurological classification of SCI. The Frankel grading system that formed part of the ISCSCI was refined and called the AIS. The 1992 revision of the ISCSCI was endorsed by the International Medical Society of Paraplegia (IMSOP) (Ditunno *et al.*, 1994). For the purpose of this study the latest version (1996) was used as a measuring instrument.

The precise classification of SCI is essential for determining the severity of the injury, the prognosis, the planning of the rehabilitation and to assess the outcome of the interventions (Cohen, Ditunno, Donovan & Maynard, 1998). It allows for accurate communication between clinicians and for research purposes (Ditunno *et al.*, 1994). The severity of SCI is reflected in the extent of motor and sensory loss (impairment) and the inability to perform activities of daily living (disability or activity limitation) (WHO, 2001; Ditunno *et al.*, 1994). These measurements of disability and impairment serve as the determinants of the clinical outcome in SCI (Ditunno *et al.*, 1994).

Validity of the ISCSCI has been established by a laborious process of discussion and documentation of each measure, and meetings, conferences and the input from national and international societies and organizations (Ditunno *et al.*, 1994). In an effort to increase the reliability of the examination as described in the ISCSCI, a Training Package of four video tapes and a 143-page Reference Manual, completed by members of the 1992 committee, has been available since 1994 (Maynard *et al.*, 1997). The Training Package demonstrates the examination, scoring, scaling and rationale of the measures (Ditunno *et al.*, 1994). Since 1994 much progress has been made in refining the standards of classification of SCI (Maynard *et al.*, 1997).

Inter- and intra-rater reliability study for the ISCSCI

The principal researcher in this study is self-trained in the ISCSCI through extensive reading and studying of the International Standards Booklet for Classification of SCI (1996 Revision) as published by Maynard *et al.* (1997). To assure inter- and intra-tester reliability of the ISCSCI for this study, a seven-day test-retest study was conducted on five subjects prior to the pilot study, comparing the performance of a medical officer trained in the ISCSCI and the principal researcher.

The results obtained from the reliability study to assure inter- and intra-rater reliability for the ISCSCI indicated that for the AIS and completeness of the SCI (C/I) there was 100% conformity between the two raters as well as between the first and second measurements of rater one (i.e. the principal investigator) ($Kappa=1$ for all cases). For all the measurements intra-class correlations (ICC) were found to be greater than 0.95, indicating a high degree of inter- and intra-rater reliability (Appendix VI).

3.7.2.2 Questionnaire to document demographic, medical and socio-economic profile

(Appendix VII)

To facilitate meeting many of the objectives of this study, a purposely-developed questionnaire was utilized to collect data on demographic, injury-related and medical characteristics of the participants, as well as their socio-economic circumstances and living environment on discharge. The final questionnaire comprised of two sections and eleven questions to capture injury-related, demographic and health information, information on assistive devices, the socio-economic profile and discharge living environment. Section One (questions 1-6) was completed at discharge from the WCRC and Section Two (questions 7-11) at six months after discharge from the WCRC. Nominal categorical variables were used throughout the questionnaire except for age which was measured on a continuous scale. Data were obtained from patient records at the WCRC and from each subject by means of a face-to-face interview.

To ensure content validity of the instrument, information from existing literature (Bloemen-Vrencken *et al.*, 2005; Tarrico, Colombo, Adone, Chiesa, Di Carlo, Borsani, Castelnuovo, Ghirardi, Lascioli & Liberati, 1992) was included, as well as from questionnaires used in a related study (Rouillard, 2007) and an expert review. The panel of experts consisted of four physiotherapists and a medical officer. They were identified as experts for their vast experience (more than 15 years) with the rehabilitation of persons with spinal cord injury and their extensive knowledge on the ICF. The completion of the questionnaire by the principal researcher only, attempts to reduce variability in rater responses i.e. inter-tester reliability.

The questionnaire was available in English and a translator was trained to assist with the Xhosa speaking subjects during the interviews. There was no need for an Afrikaans translator, as the researcher is fluent in Afrikaans and could therefore assist the Afrikaans speaking subjects.

The final questionnaire contained the following data:

Question 1 and 11: Injury-related details

- Date of injury
- Date of admission to the WCRC
- Referral hospital
- Time elapsed between injury and admission to the WCRC
- Cause of injury
- Orthopedic lesion and orthopedic surgery
- ISCSCI at discharge and at six months after discharge from the WCRC
- Date of discharge from the WCRC
- Length of stay at the WCRC

Although not specific objectives for this study, the information gathered on the referral hospital, time elapsed between injury and admission to the WCRC and length of stay, can be useful for future studies to explore associations between referral hospitals and the prevalence of secondary complications and between length of stay at the WCRC, neurological level and rehabilitation outcomes. Time which had elapsed between injury and admission to WCRC was added to the questionnaire in order to explore whether participants presenting late for rehabilitation had a higher prevalence of secondary complications on admission to the WCRC.

Question 2: Personal details

Demographic details of participants i.e. age, gender, race and residential address were included in order to characterize the patients with traumatic spinal cord injuries in the study.

Questions 1.9, 3 and 7: Health information

- Health information was included to describe the prevalence of secondary complications, related to the spinal cord injury on admission to the WCRC, at discharge and at six months after discharge from the WCRC. Information regarding the prevalence of secondary complications was included in the questionnaire, as the occurrence of secondary complications related to SCI can influence functional outcomes after spinal cord injury. Furthermore, it has a profound negative impact on quality of life (Anson & Shephard, 1996), and the development of secondary

conditions in the post-acute stage is the leading cause of death in persons with SCI (DeVivo *et al.*, 1999).

- Although not a specific objective of this study, information regarding the prevalence of secondary complications on admission was included in the questionnaire, for future studies to establish the possible association between (1) referral hospital and the presence and/or type of secondary complications and (2) time which had elapsed between injury and admission to the WCRC and presence and/or type of secondary complications.

Question 4 and 8: Assistive devices

- These questions provided information on whether subjects received assistive devices on discharge or after discharge from the WCRC.
- The need for a specific assistive device is an indication of the functional ability of the participant at discharge.
- Information gathered from questions 4 and 8 will also provide information on the type of non-personal assistance needed by the participant and give an indication of the functional ability of the subject.

Question 5 and 9: Socio-economic details

- Information on their level of productive activity and monthly income were collected to describe the socio-economic profile of the sample at injury, at discharge and six months after discharge from the WCRC. Productive activity includes remunerative and non-remunerative employment and education as all of these aspects are addressed in the ICF.
- Information regarding their financial situation (income or not, whether income covers expenses, financial support, reason(s) for not having an income) at discharge from the WCRC was required for comparison at six months after discharge from the WCRC, and to gain a better understanding of the degree of difficulty of economic self-sufficiency as measured by the ICF.
- As the ICF does not allow for additional information on the degree of activity and participation, information collected from questions 5 and 9 would give the researcher more insight into the activity and participation profile of the sample at discharge and six months after discharge from the WCRC.

Question 6 and 10: Details on the living environment after discharge

- Question 6 of the questionnaire was intended to gather information on the type of housing (formal or informal), the availability and use of essential services and wheelchair accessibility,

which would provide additional information on the socio-economic circumstances of the participants as well as their functioning at residential level.

- Question 10 provided information on whether the participant's residential address had changed since discharge from the WCRC and the reasons therefore.

3.7.2.3 The ICF

The ICF (WHO, 2001), was developed from, and officially replaced, the ICIDH (WHO, 1980). The ICF defines health and health-related components of well-being. The health and health-related domains contained in the ICF are described from the perspective of the body, the individual and the society in two basic lists: (1) Body Functions and Structures; and (2) Activities and Participation (see Table 3.1). "Functioning" is a term encompassing all body functions, activities and participation, and "disability" serves as an umbrella term for impairments, activity limitations and participation restrictions. The ICF describes what a person with a specific disease or disorder does (performance) or can do (capacity), but in contrast with the ICIDH, also lists the environmental factors that interact with all of these constructs (WHO, 2001). The ICF forms part of international classifications developed by the WHO to assess various aspects of health. Diseases, disorders and injuries are classified primarily in the ICD-10 and together with the ICF provide a broader and more meaningful picture of the health of people or a population, which can be used for decision-making purposes (WHO, 2001).

As this study focused on the reintegration of persons with disability in all the areas of social life, once rehabilitation has been completed, body structures and function were not assessed. Assessing body functions and structures will provide information only at impairment level and although impairments contribute to the degree of disability, they were not included in this study as the assumption is made that impairments would have been addressed during the more acute stages of rehabilitation.

Table 3.1: An overview of the ICF (WHO, 2001:11) (bold text indicates aspects that were addressed in this study)

	Part 1: Functioning and Disability		Part 2: Contextual Factors	
Components	Body Functions and Structures	Activities and Participation	Environmental Factors	Personal Factors
Domains	Body Functions Body Structures	Life areas (tasks, actions)	External influences on functioning and disability	Internal influences on functioning and disability
Constructs	Change in body functions (physiological) Change in body structures (anatomical)	Capacity Executing tasks in a standard environment Performance Executing tasks in the current environment	Facilitating or hindering impact of features of the physical, social and attitudinal world	Impact of attributes of the person
Positive aspect	Functional and structural integrity	Activities Participation	Facilitators	Not applicable
	Functioning			
Negative aspect	Impairment	Activity limitation Participation restriction	Barriers/hindrances	Not applicable
	Disability			

The following two questionnaires based on the ICF were used to establish the activity and participation profile of the subjects and the environmental barriers:

i) ICF-related questionnaire on activity and participation profile (Appendix VIII)

The Activities and Participation component covers the complete range of domains denoting aspects of functioning from both an individual and a societal perspective. The component can be used to denote activities or participation or both. The domains of this component are qualified by the two qualifiers of performance and capacity (WHO, 2001).

The performance qualifier describes what an individual does in his or her current environment. As the current environment includes a societal context, performance can also be understood as “involvement in a life situation” (WHO, 2001:123). The capacity qualifier describes an individual’s ability to execute a task or an action. This construct aims to indicate the highest probable level of functioning that a person may reach in a given domain at a given moment (WHO, 2001:123). Both capacity and performance qualifiers are applicable whether the individual accomplishes the task or action with or without assistive devices and/or personal assistance.

For this study the first performance qualifier (involvement in a life situation with assistive devices and personal assistance) was used. Although the first performance qualifier requires coding that takes into consideration the amount and type of assistance needed, the ICF does not provide a way to document details of assistance used by an individual to achieve a performance rating. The result is that two individuals may have identical performance qualifier ratings for an item, but one may use personal assistance and assistive devices, whereas the other may use neither. Although they appear to have the same performance profiles, in fact their use of services and ongoing support is very different (Reed, Lux, Bufka, Peterson, Threats, Trask, Stark, Jacobson & Hawley, 2005). As the ICF is implemented for clinical purposes, Reed *et al.* (2005) suggest that a simple coding system is added to reflect these individual differences. The following scales were therefore used to code the performance qualifier:

SCALE FOR CODING THE DEGREE OF PERFORMANCE (WHO, 2001)

0: No difficulty	(none, absent)	0 – 4%
1: Mild difficulty	(slight, low)	5 – 24%
2: Moderate difficulty	(medium, fair)	25 – 49%
3: Severe difficulty	(high, extreme)	50 – 95%
4: Complete difficulty	(total)	96 – 100%
8: Not specified		
9: Not applicable		

SCALE FOR CODING THE AMOUNT AND TYPE OF ASSISTANCE NEEDED

- 0: No assistance needed
- 1: Non-personal assistance/ adapted or specially designed tools and/or vehicle
- 2: Personal assistance of one or more person(s)
- 3: Both non-personal and personal assistance
- 4: Impossible even if assistance is provided
- 5: Level of assistance unknown
- 6: Not applicable

For a detailed description of the activities and participation domains as included in the questionnaire, see Appendix IX.

ii) ICF-related questionnaire on environmental factors identified as barriers (Appendix X)

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives (WHO, 2001:171).

First qualifier: Indicates the extent to which an environmental factor is a facilitator or a barrier (WHO, 2001:171).

This questionnaire was included to determine which environmental factors, as described by the ICF, presented barriers to people with SCI. Environmental factors were coded from the perspective of the person whose situation is being described.

Through the pilot study (see page 16) it became clear that (1) the majority of subjects participating in the pilot study did not understand the concept of facilitators versus barriers and (2) due to lack of resources, barriers (environmental factors that make life more difficult due to their absence or presence) were more applicable than facilitators. It was therefore decided to assess only the extent to which an environmental factor posed as a barrier.

It is well acknowledged in the literature that environmental factors have an impact on functioning, however very little research has been done in South Africa to explore the impact of the environment on varying degrees of disability in SCI. The purpose of this questionnaire was thus to identify environmental factors that have a negative impact on the functioning of persons with SCI at different levels of participation after discharge from the rehabilitation setting. For a detailed description of the environmental factors as included in the questionnaire, see Appendix XI.

The following scale was used to code the degree to which environmental factors posed as a barrier (WHO, 2001).

SCALE FOR CODING THE DEGREE TO WHICH ENVIRONMENTAL FACTORS POSE AS BARRIERS

0: NO barrier	(none, absent)	0 - 4%
1: MILD barrier	(slight, low)	5 - 24%
2: MODERATE barrier	(medium fair)	25 - 49%
3: SEVERE barrier	(high, extreme)	50 - 95%
4: COMPLETE barrier	(total)	96 - 100%
8: Barrier, not specified		
9: Not applicable		

3.7.3 Development of the measuring instruments

3.7.3.1 ISCSCI

The measuring instrument that was used in the study to capture information on the neurological aspects necessary to classify the subject's spinal cord lesion, is the official data capturing sheet that is used internationally for the classification of spinal cord injuries, as developed by the American Spinal Injury Association (ASIA). Although copying of the data sheet is permitted, no changes are allowed to be made to the content.

3.7.3.2 Questionnaire to establish demographic, medical and socio-economic profile

The draft questionnaire was developed in English, based on existing literature (Tarrico *et al.*, 1992; Bloemen-Vrencken *et al.*, 2005), a previous study (Rouillard, 2007), and experience gained by the researcher through working with spinal cord injuries for 22 years. Experts with more than 15 years experience in the field of the rehabilitation of spinal cord injuries in South Africa were consulted and invited to comment on the content and the clarity of the questions. They were asked to comment in writing, after which a meeting was arranged to discuss their findings.

Expert review

The following changes, based on expert review, were made to the draft questionnaire:

1. Questions 1.9, 3 and 7

A secondary complication i.e. "bowel problems" was added to the existing list as it is fairly common with spinal cord injuries.

2. "Wheelchair cushion" was added to questions 4.1 and 8.1 on assistive devices.

3. The question "Do you have a bathroom inside or outside?" was added to question 6 as part of the living environment after discharge.

4. Question 6.19 "reason for not receiving caregiver training" was added if the response on question 6.18 was "no".

Pilot study

Once changes were made to the draft questionnaire, it was administered to five English and Afrikaans speaking subjects, eligible for the study and due for discharge during the following two weeks. No Xhosa-speaking subjects were available for the pilot study. Due to time constraints the pilot did not include the six-month follow-up of the five subjects after discharge from the WCRC. Most of the questions in Section 2 of the questionnaire, which was administered at six months after discharge, were exactly the same questions as in Section 1 of the questionnaire, therefore the changes made to Section 1 were also applicable to Section 2 of the questionnaire.

The pilot study was conducted over a period of one week. Subjects were invited to comment on the clarity and suitability of the questions. The researcher found the questionnaire easy to administer and the subjects found the questions clear, easy to understand and applicable.

The following changes were made to the questionnaire after the pilot study was conducted:

1. Questions 4 and 8

“Transfer board, wheelchair table, eating strap, commode seat and bath board” were added to assistive devices.

2. Questions 5.2 and 9.3

The category “paid employment” was specified as “paid employment: permanent”, “paid employment: probation period” and “paid employment: casual”.

3. Question 6.5

A third option “unsure” was added as some of the subjects had not been home since admission to the WCRC.

4. Question 6.11

“Can you use the toilet?” was added to the questionnaire as some of the subjects have a toilet but they cannot use it for various reasons.

5. Question 9.7

The wording “not interested in working” were changed to “have not sought employment”, as the subjects interviewed at six months after discharge experienced the original wording to be offensive.

3.7.3.3 The ICF

Two questionnaires i.e. “Activity and Participation” and “Environmental Factors” were used in the study. Both draft questionnaires were based on the ICF Checklist Version 2.1a, Clinician Form for the ICF (ICF Checklist, 2003).

The draft questionnaires were presented to the same experts, in the field of rehabilitation and the practical implementation of the ICF, as mentioned earlier, for comments.

Expert review

No changes were made to the content of the draft Activities and Participation questionnaire by the experts, but codes awarded to the different activities varied amongst the experts. The researcher therefore adapted the original coding as used with the ICF to suit the needs of the study.

The following changes were made to the scale for coding the amount and type of assistance needed:

1. The two categories “personal assistance of 1 person” and “personal assistance of 2 or more persons” were combined into “personal assistance of 1 or more persons” as the researcher was more interested in whether assistance was needed than the number of persons needed to provide that assistance. Chapter 3 of the Environmental Factors component of the ICF (Appendix XI) investigated whether the available assistance is adequate to allow performance and will therefore provide information on the amount of assistance needed.
2. Two categories were added to the existing scale for coding assistance i.e. “not applicable” and “impossible even if assistance is provided” to provide for activities that are not applicable and activities that cannot or are not performed even if assistance is provided.

No changes were made to the content of the Environmental Factors questionnaire after expert review. As the scale for coding barriers and facilitators are very clear, no changes were made to the original scale as used with the ICF.

Pilot study

Once changes were made to the draft Activities and Participation questionnaire, it was administered to the five subjects in the pilot study. No further changes were made to this questionnaire after conducting the pilot study. The Environmental Factors questionnaire was not piloted as this can only be completed at six months after discharge from the WCRC.

Statistician review

Once the necessary changes were made to the draft questionnaires, statistical advice was sought. No further changes to the questionnaires were necessary as nominal categorical variables were used in the questionnaire, except for the age variable, which was measured on a continuous scale. The results were therefore statistically analyzable.

3.7.4 Study procedure

This study was conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for research.

The study commenced only when permission had been obtained from the Committee for Human Research (CHR) at the Stellenbosch University (Appendix XX-i) and the institutional head of the WCRC (Appendix XX-ii), respectively. Permission for conducting the study at the WCRC were

granted verbally during a meeting with all the heads of departments. Variables were measured on discharge from the WCRC and at six months after discharge.

This study was conducted in three parts i.e. (1) a reliability study of the ISCSCI, (2) a pilot study and (3) the main study.

3.7.4.1 Reliability study

This study was conducted once permission had been obtained from the institutional head of the WCRC. Although reliability had been established for the ISCSCI, it was deemed essential to conduct a reliability study to ensure inter- and intra-tester reliability for the ISCSCI as applied by the researcher. A seven day test-retest was conducted. The researcher and a medical officer, trained in using the ISCSCI, classified five patients with traumatic SCI admitted for rehabilitation to the WCRC. These patients were not included in the main study.

Five subjects were conveniently selected. Permission for the study was obtained from the selected subjects. Each subject was assessed and classified according to the ISCSCI independently by the researcher and the medical officer. The subjects were reclassified by the researcher after seven days.

3.7.4.2 Pilot study

Five patients were invited to participate in the pilot study. The pilot study was conducted after ethical approval from the CHR at the Stellenbosch University and permission from the institutional head of the WCRC had been obtained. The pilot study was conducted over a period of two weeks. Data were collected from five patients at discharge from the WCRC. Due to time constraints the pilot study did not include the six-month follow-up of patients after discharge from the WCRC. As the questionnaires at six months are a repeat of the questionnaires administered at discharge, it was assumed that information obtained from the pilot study would be appropriate for the questionnaires at six months after discharge. The questionnaire on environmental factors was only included at six months after discharge. As this questionnaire contained questions on resources and barriers in the community and workplace, it was impossible for the subjects to provide the necessary information since they had not yet been discharged.

The procedure for conducting the pilot study was as follows:

- Information on the patients that were scheduled for discharge was obtained telephonically from the ward secretaries or sisters of each ward at the WCRC.
- The researcher consulted the patients' medical records to determine whether they met the inclusion criteria for the study. The information gathered from the medical records was confirmed with each patient.

- The first five patients who were eligible for the study were invited to participate in the pilot study.
- Although the subjects for the pilot study were eligible for the main study, they were not included in the main study.
- A specific date, time and place for data collection were scheduled for each subject who agreed to participate in the pilot study. The subject was informed of the appointment and reminded thereof one day prior to the date.
- Written consent was obtained from all the subjects prior to the study (refer to ethical considerations below).
- The testing and interview were conducted in a private setting within the WCRC, where only the subject and the researcher were present (and if necessary a translator).
- The data were collected by means of the self-developed questionnaire and two ICF-related questionnaires on activity and participation and environmental factors, as well as the ISCSCI, to determine neurological deficit. Information was provided verbally by the subjects and the documents were completed by the researcher.
- The necessary changes were made to the draft questionnaires and the final questionnaires printed.

The purpose of the pilot study was to test the clarity and understanding of the self-developed questionnaire and to reveal any problems regarding the practical implementation of the ISCSCI and the two ICF-related questionnaires for the designated population, as well as to establish the approximate time it would take to complete each evaluation.

3.7.4.3 Main study

The main study was conducted over a period of approximately 15 months. Data were collected from a group of patients at discharge and six months after discharge from the WCRC.

The procedure for the main study was as follows:

- On the Tuesday of each week the ward sister or secretary of each ward at the WCRC was requested telephonically by the researcher to provide the information on the patients who were scheduled for discharge during the following two weeks.
- The researcher consulted the patients' medical records to determine whether they met the inclusion criteria for the study. The information gathered from the medical records was confirmed with each patient.
- Once the patient was found eligible to participate in the study, a specific date, time and place for data collection were scheduled for each subject prior to discharge from the WCRC. The subject

was informed thereof by either the researcher or the patient's physiotherapist.

- When needed, the translator was briefed on his/her role and on the content of the questionnaire and the tests that were used for collecting the data.
- The researcher, witness and translator (if applicable) visited each subject at the appropriate time and in a private pre-arranged setting at the WCRC.
- Prior to collecting the data, the objectives of the study, the procedure of the testing as well as their right to anonymity and confidentiality were explained to each subject. The importance of the study, their voluntary participation and their right to withdraw from the study at any time was also explained. Consent forms were available in English, Afrikaans and Xhosa. The subject had adequate time to read the consent form in his/her preferred language and the opportunity to ask questions should they need more information. The researcher read the Afrikaans and English consent forms to subjects who were unable to read. A translator was utilized for Xhosa speaking subjects. The consent form was again explained to the subjects and signed in the presence of a witness. Only subjects who gave informed, written consent were included in the study.
- Immediately after consent had been obtained from the subject, data were collected during the interview with the subject. The interview was conducted in English or Afrikaans depending on the interviewee's choice. Two Xhosa-speaking subjects were interviewed with the assistance of a translator.
- Information necessary to complete Section 1, Question 1 of the questionnaire (Appendix VII) was retrieved from the subject's medical records during the interview and confirmed with the subject. The remaining information was provided verbally by the subject and the documents were completed by the researcher. Information regarding the neurology of each subject was obtained through physical testing. Section 1 of the questionnaire, the ISCSCI and the questionnaire on the activity and participation profile were completed at discharge from the WCRC.
- The subject remained seated and was fully dressed during the face-to-face interview to complete all three questionnaires. All the information was provided verbally by the subject.
- For the classification of the SCI, the subject was requested to undress in a suitable manner and to lie down in a supine position on a plinth. Subjects who were unable to perform this activity were assisted by the researcher. The researcher tested the dermatomes of the subject's body for light touch and pinprick to determine the sensory level and the sensory score. The subject was expected to give verbal feedback during these tests. The motor level and motor score were determined through the testing of five key muscles in the lower limb, and five key muscles in the upper limb on the left and right sides of the body. The grading system according to the

ISCSCI was used to quantify the strength of these muscles.

- Each interview lasted between 45 minutes and one hour.
- If more than one subject were tested on one day, the researcher took a 15-minute break between sessions to exclude researcher fatigue.
- Immediately after the evaluation session, an appointment was made with the subject to return to the WCRC for the follow-up evaluation at six months after discharge from the WCRC. An outpatient card was issued with the follow-up appointment date and time.
- Each subject was reminded telephonically of the follow-up session one week, and again one day, prior to the appointment date. New appointments were made when necessary. It was expected of each subject to arrange his/her own transport for the follow-up session, which might have contributed to the low return-rate at six months.
- The procedure for data collection at six months post discharge was exactly the same as the procedure at discharge from the WCRC. Section 2 of the questionnaire: the ICF-related questionnaire on the activity and participation profile, the ISCSCI, as well as the ICF-related questionnaire on environmental factors were completed.
- After completion of the data-collection, the subjects were thanked for their participation in the study and each subject received the amount of fifty rand as a contribution towards their transport costs.

3.7.5 Statistical procedure

- Complete data were captured on a spreadsheet using the Microsoft Excel (2007) programme in preparation for analysis. Question responses were coded into meaningful variables and analysed with the statistical software package STATISTICA (version 10). The services of a statistician were utilized to assist with the data analysis.
- Summary statistics were reported using means and standard deviations for the scores and frequency tables (and percentages) for the categorical variables. Graphs, pie charts and tables were used to present results. For comparison of average scores between baseline and six months, mixed model repeated measures analysis of variance (ANOVA) was employed. For all statistical comparisons, p-values, rounded to two decimal points, were quoted to indicate level of significance. The value of $p < 0.05$ was interpreted as highly significant.

3.8 ETHICAL CONSIDERATIONS

The CHR at the Stellenbosch University accepted the research protocol for the proposed research (reference number N07/07/155). Permission to conduct the research at the WCRC was granted by the head of the institution.

All the subjects of the pilot, reliability and main studies were informed in detail of the study and its objectives in their preferred language i.e. Afrikaans, English or Xhosa and invited to ask questions regarding the study. Confidentiality was assured and interviews were only conducted once the consent forms had been signed. The consent form was available in English, Afrikaans and Xhosa (Appendixes XII, XIII, XIV). Subjects were allowed to withdraw from the study at any time. Interviews were conducted in private and all the information collected during these interviews was handled in a confidential manner. Subjects' privacy was ensured throughout the study, in that each participant was allocated a code, and the corresponding name was only known to the researcher. Only the principal researcher had access to the data during and after the study was conducted.

The results of the study are available to the subjects on request. A copy of the research report will be handed over to the institutional head of the WCRC and feedback on the study will be provided to the staff at the WCRC by the researcher during an academic presentation.

CHAPTER 4: RESULTS

The findings of the study are reported in this chapter. The information will be presented in three main sections. The first section reflects the demographic, medical and socio-economic characteristics of the subjects and a description of the discharge living environment. The second section reports on the activity and participation profile of the subjects and the amount and type of assistance utilized at discharge, and six months after discharge from the WCRC, as well as comparisons made at the different points in time. The difference between the level of participation at discharge and six months after discharge are statistically analyzed. The third section reports on the environmental factors identified as barriers by the subjects.

4.1 THE STUDY POPULATION AND SAMPLE

The study population was defined as all adults with traumatic SCI who were discharged to the Cape Metropole after completion of their rehabilitation at the WCRC. Persons who were discharged between and including September 1, 2008 and June 5, 2009 and who were eligible for the study were included in the sample. Data-collection was terminated at the end of November 2009 due to time-constraints and difficulties in locating/contacting subjects (n=11) with repeated attempts. Some subjects (n=5) who were contacted and agreed to return at six months could not attend their follow-up appointments due to financial or transport difficulties. Four of the subjects were living outside the borders of the Cape Metropole at the time of their six-month follow-up appointment. The sample size for the study therefore reached a total of 47 subjects at discharge and 27 subjects at the six month follow-up date.

SECTION ONE

Findings on the demographic-, medical- and socio-economic characteristics and the living environment after discharge will be reported on in this section. The information was gathered on admission to, discharge from and/or six months after discharge from the WCRC. The sample size for this section equals 47 subjects on admission and discharge and 27 subjects at the six month follow-up date.

4.2 DEMOGRAPHIC CHARACTERISTICS

Demographic information on the sample such as age, gender, race and residential address will now be described in more detail. The percentages do not necessarily equal 100% because of rounding.

4.2.1 Age

The number of subjects per age group is summarized in Figure 4.1.

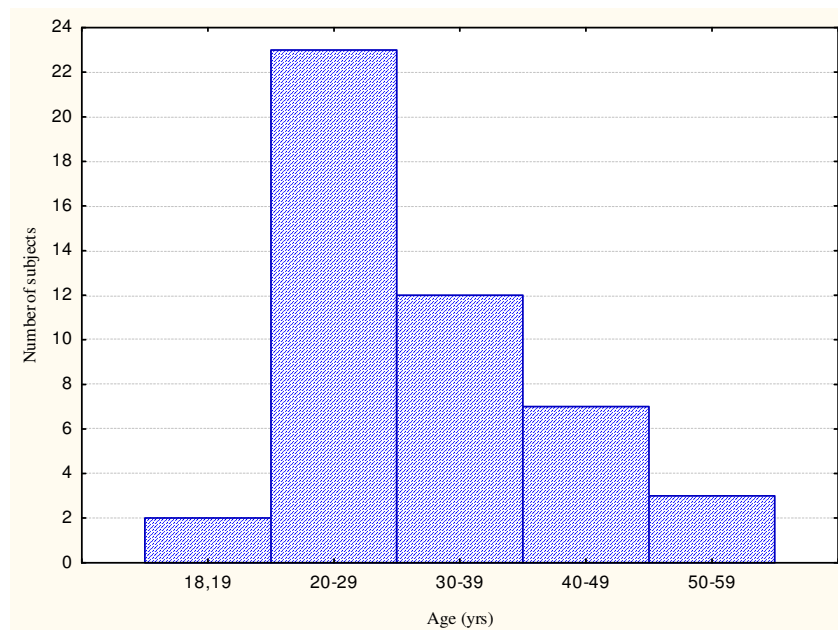


Figure 4.1: Number of subjects per age group

Most of the subjects were in the age category 20 to 29 years (49% or 23/47) followed by the age category 30 to 39 years (26% or 12/47). The other 25% of the subjects (12/47) were divided amongst the remaining age groups (Figure 4.1).

The mean age of the subjects was 31.7 years (SD=9.6). The range and median age can be seen in Figure 4.2.

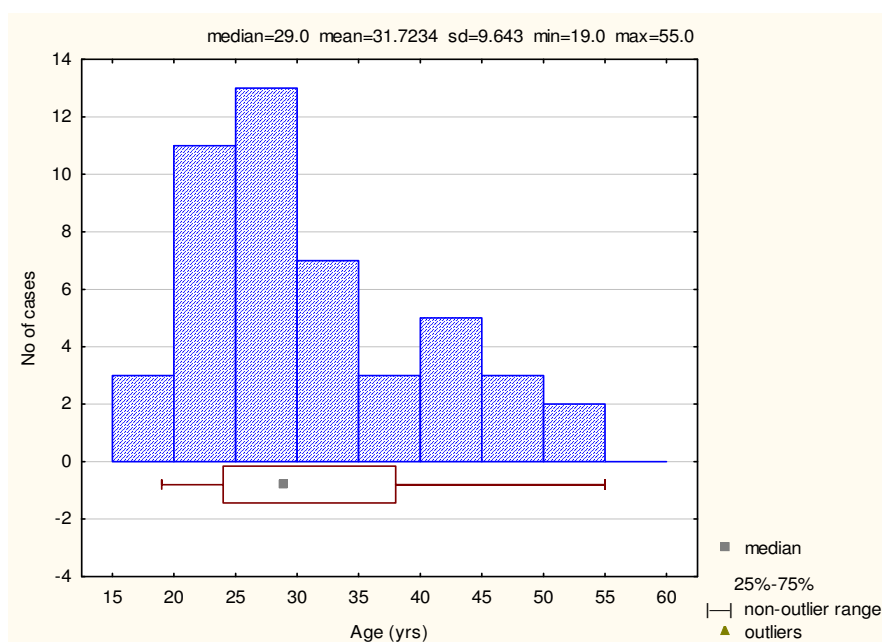


Figure 4.2: Age distribution

The ages of the subjects were nearly equally distributed with a mean of 32 years and a median of 29 years. This indicates that there were no outliers to skew the results and confirms the unimodal distribution of age and the high percentage (75%) of subjects in the 20 to 39 year age group (Figure 4.2).

4.2.2 Gender

Figure 4.3 shows the gender distribution of the study sample, clearly illustrating a much higher proportion of men (91%) to women (9%) who suffered traumatic SCI.

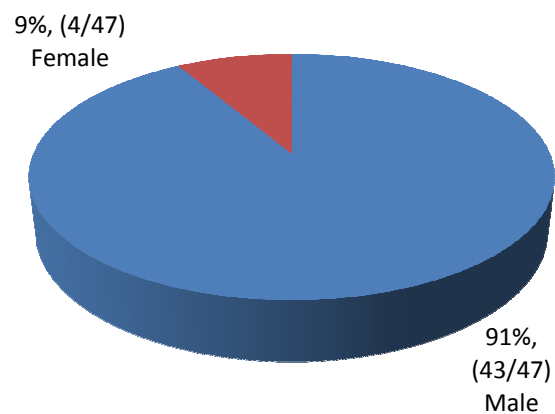


Figure 4.3: Gender distribution

4.2.3 Race

Figure 4.4 shows the race distribution of the study sample, illustrating the majority of the subjects to be from the Coloured and Black racial groups.

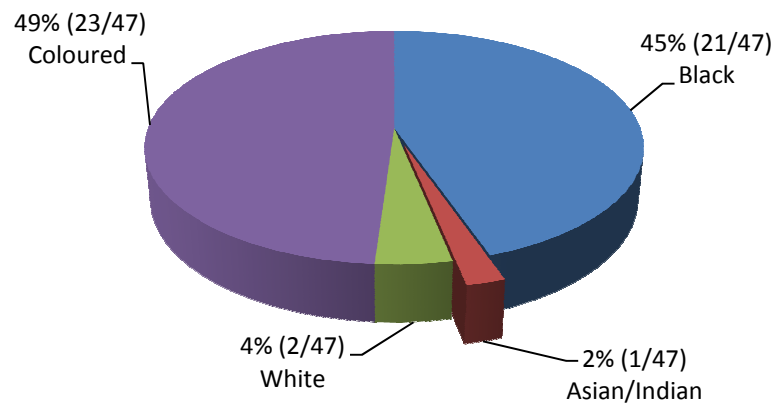


Figure 4.4 Race distribution

4.2.4 Residential address

Figure 4.5 shows the geographic distribution of the subjects.

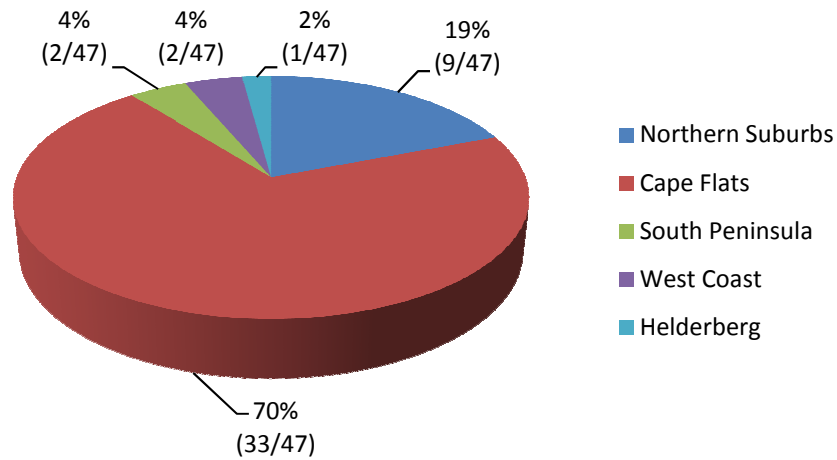


Figure 4.5: Geographic distribution

It is clear that the majority of the subjects (70% or 33/47) live in the Cape Flats suburbs of the Cape Metropole (Figure 4.5).

4.3 MEDICAL CHARACTERISTICS

Medical information related to the SCI such as etiology, level and nature of spinal cord involvement, severity of neurological deficit and secondary complications will now be described in more detail. Information was gathered on admission to the Acute Spinal Cord Injury Unit (ASCI) at Groote Schuur Hospital (GSH), at discharge and six months after discharge from the WCRC. The percentages do not necessarily equal 100%, because of rounding.

4.3.1 Etiology

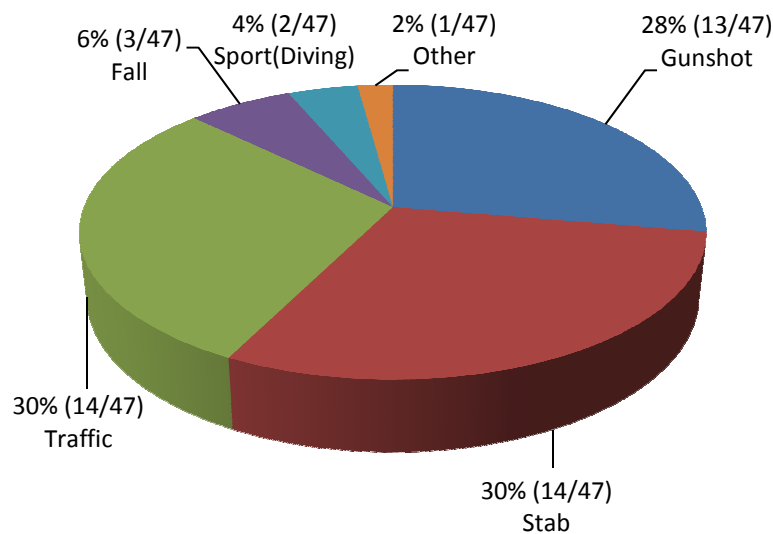


Figure 4.6: Etiology of traumatic spinal cord injury

It was found that violence was the leading cause of acute traumatic SCI accounting for 58% (27/47) of all the subjects, followed by road traffic accidents (30% or 14/47). All the injuries caused by violence were penetrating in nature, including gunshots (28% or 13/47) and stabbing (30% or 14/47) (Figure 4.6). Road traffic accidents included those caused by motor vehicles, bicycles, motorbikes and pedestrians (Figure 4.7). In the minority were falls (6% or 3/47), sports injuries (4% or 2/47) and other (2% or 1/47) (Figure 4.6).

The nature of each of the causes of road traffic accidents is illustrated in Figure 4.7. The percentages do not equal 30% because of rounding.

Figure 4.7: Breakdown of road traffic accident statistics

Nineteen percent (9/47) of the subjects were involved in a motor vehicle accident, 6% (3/47) were as pedestrians involved in a road traffic accident and 2% (1/47) were in motorbike and motorcycle accidents respectively (Figure 4.7).

Table 4.1 displays the etiology of the spinal cord injury by racial group.

Table 4.1: Etiology of traumatic SCI by population group ($n = 47$)

	Black	Coloured	White	Asian/Indian	Total
Stab	6 (13%)	8 (17%)	0 (0%)	0 (0%)	14 (30%)
Traffic	6 (13%)	7 (15%)	1 (2%)	0 (0%)	14 (30%)
Gunshot	7 (15%)	5 (11%)	0 (0%)	1 (2%)	13 (28%)
Falls	1 (2%)	2 (4%)	0 (0%)	0 (0%)	3 (6%)
Sport	0 (0%)	1 (2%)	1 (2%)	0 (0%)	2 (4%)
Other	1 (2%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)
Total	21 (45%)	23 (49%)	2 (4%)	1 (2%)	47 (100%)

The majority of the subjects of the black (62% or 13/21) and coloured (57% or 13/23) racial groups were injured through acts of violence, which include gunshot and stab injuries followed by road traffic accidents. The etiology of spinal cord injury was very similar for the black and coloured racial groups (Table 4.1).

4.3.2 Level and nature of spinal cord involvement

The ASIA classification for SCI (Ditunno *et al.*, 1994) was used to determine the level of spinal cord involvement. The groups used to describe the level of injury are a reflection of the functional ability at those specific levels of injury. Information on the level and nature of spinal cord involvement at discharge and six months after discharge from the WCRC is displayed in Tables 4.2 and 4.3 respectively. Table 4.4 shows the relationship between the etiology of the SCI and the resulting functional impairment or neurological deficit at discharge.

Table 4.2: Level and nature of injury at discharge

Level of injury	<i>n</i> = 47	Complete (<i>n</i> = 21)	Incomplete (<i>n</i> = 26)
C1–C5 (tetraplegic)	15 (32%)	4 (9%)	11 (23%)
C6–C8 (tetraplegic)	2 (4%)	1 (2%)	1 (2%)
T1–T6 (paraplegic)	11 (23%)	7 (15%)	4 (9%)
T7–T12 (paraplegic)	15 (32%)	8 (17%)	7 (15%)
Lumbar (paraplegic)	4 (9%)	1 (2%)	3 (6%)
Sacral (paraplegic)	0 (0%)	0 (0%)	0 (0%)
Total	47 (100%)	21 (45%)	26 (55%)

The majority of the subjects (64% or 30/47) were paraplegic and the remaining 17 subjects (36%) were tetraplegic. Amongst the tetraplegic subjects, the C1–C5 level was the most common (88% or 15/17) and levels T7–T12 were most common in the paraplegic group (50% or 15/30). The thoracic cord was the most common site of injury accounting for 55% (26/47) of the cases. Incomplete paralysis was the most common neurological disability accounting for 26 subjects (55%) and was more frequent in the C1–C5 group (42% or 11/26). Complete paralysis was more frequent in the T1–T6 (33% or 7/21) and T7–T12 (38% or 8/21) paraplegic groups (Table 4.2).

Table 4.3: Level and nature of injury at six months

Level of injury	<i>n</i> = 27	Complete (<i>n</i> = 12)	Incomplete (<i>n</i> = 15)
C1–C5 (tetraplegic)	9 (33%)	1 (4%)	8 (30%)
C6–C8 (tetraplegic)	1 (4%)	1 (4%)	0 (0%)
T1–T6 (paraplegic)	7 (26%)	5 (19%)	2 (7%)
T7–T12 (paraplegic)	6 (22%)	4 (15%)	2 (7%)
Lumbar (paraplegic)	4 (15%)	1 (4%)	3 (11%)
Sacral (paraplegic)	0 (0%)	0 (0%)	0 (0%)
Total	27 (100%)	12 (44%)	15 (56%)

The majority of the subjects (63% or 17/27) were paraplegic. Regarding the tetraplegic subjects, the most common level was C1–C5 (90% or 9/10), and in those who were paraplegic T1–T6 (41% or 7/17) followed by T7–T12 (35% or 6/17). The thoracic cord was the most common site of injury accounting for 48% (13/27) of the cases. The C6–C8 group accounted for the lowest number of subjects (2% or 1/47) followed by the lumbar group with four subjects (9%). Incomplete paralysis was the most common neurological disability accounting for 15 subjects (55%). Of the 27 subjects, two (7%) had motor complete tetraplegia, 8 (30%) incomplete tetraplegia, 10 (37%) complete paraplegia and the remaining 7 (26%) incomplete paraplegia (Table 4.3).

Table 4.4: Neurological deficit related to etiology of SCI at discharge (*n* = 47)

Etiology	Complete paraplegia	Incomplete paraplegia	Complete tetraplegia	Incomplete tetraplegia
Gunshot	5 (11%)	5 (11%)	1 (2%)	2 (4%)
Stab	3 (6%)	6 (13%)	0 (0%)	5 (11%)
Traffic	6 (13%)	2 (4%)	3 (6%)	3 (6%)
Sport	0 (0%)	0 (0%)	1 (2%)	1 (2%)
Fall	1 (2%)	0 (0%)	0 (0%)	2 (4%)
Other	1 (2%)	0 (0%)	0 (0%)	0 (0%)
Total	16 (34%)	13 (28%)	5 (11%)	13 (28%)

Of the 47 subjects, 29 (62%) were paraplegic and 18 (38%) were tetraplegic. In the paraplegic group there were slightly more complete paralysees (55% or 16/29) than incomplete paralysees (45% or 13/29). However, in the tetraplegic group the majority of the subjects had incomplete paralysis (72% or 13/18) compared to five subjects (28%) with complete paralysis.

Gunshot injuries (34% or 10/29), stab injuries (31% or 9/29) and traffic accidents (28% or 8/29) were the most common causes of paraplegia (29 subjects). However, the relationship between the cause of injury and the nature of the injury in the paraplegic group was different. Road traffic accidents resulted in more complete paralysis (75% or 6/8 subjects), stab injuries in more incomplete paralysis (67% or 6/9 subjects) and with gunshot injuries the distribution was equal for the resultant complete and incomplete paralysis.

The most common cause of injury in the tetraplegic group was road traffic accidents (33% or 6/18), followed by stab injuries (28% or 5/18). Complete paralysis was mainly caused by road traffic accidents in the tetraplegic group (17% or 3/18). The main cause of injury in the incomplete tetraplegic group was stab injuries (38% or 5/13), followed by traffic accidents (23% or 3/13), falls and gunshot injuries (15% or 2/13 each) and sport injuries (8% or 1/13). As expected, the two diving (sport) injuries both resulted in tetraplegia. Two of the falls resulted in tetraplegia and one in paraplegia.

Of the 27 subjects who sustained SCI through violent acts (stab- and gunshot injuries), 67% (18/27) had incomplete paralysis. Traffic accidents resulted in more complete paralysis (64% or 9/14) compared to incomplete paralysis (36% or 5/14) (Table 4.4).

4.3.3 Severity of spinal cord involvement

Information on the severity of spinal cord involvement at discharge and six months after discharge from the WCRC, according to the AIS (Ditunno *et al.*, 1994) is illustrated in Figure 4.8. and 4.9 respectively. For a description of the codes attached to the AIS, see Appendix I.

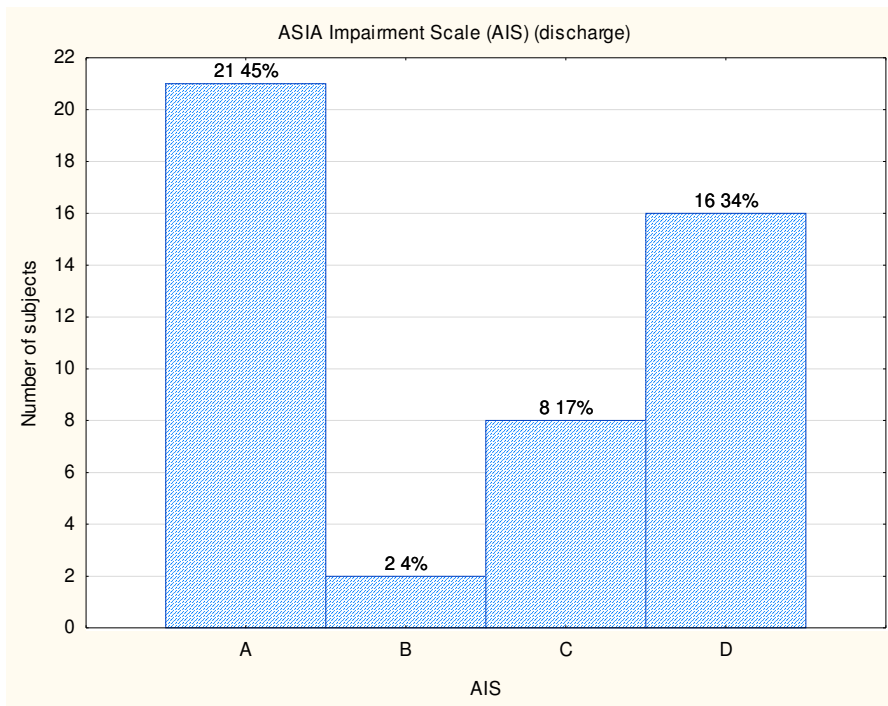


Figure 4.8: Severity of spinal cord involvement at discharge

The majority of the subjects (45%) were classified as an ASIA A. This represents the 21 subjects with complete paralysis. The subjects with incomplete paralysis are divided amongst the ASIA B group (4%), the ASIA C group (17%) and the majority in the ASIA D group (34%). Therefore, the majority of the subjects with incomplete paralysis had preservation of motor function below the motor level (51%), although 17% of the subjects did not have adequate motor function for functional walking. The remaining 34% of the subjects who had motor preservation could potentially walk functionally (Figure 4.8).

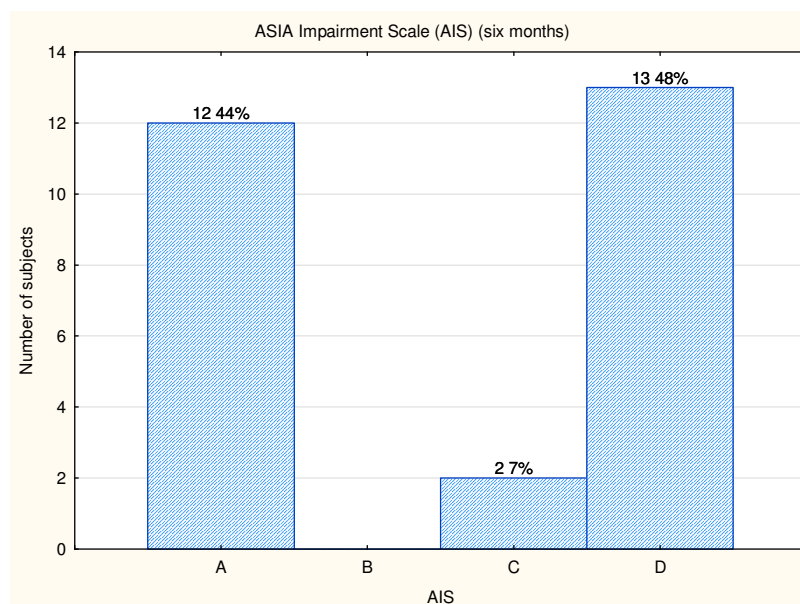


Figure 4.9: Severity of spinal cord involvement at six months

The majority of the subjects (48%) were classified as an ASIA D. The 15 subjects with incomplete paralysis were divided amongst the ASIA D group (48%), the ASIA C group (7%). Therefore, the majority of the subjects with incomplete paralysis had adequate preservation of motor function below the motor level (48% or ASIA D) for functional walking. The remaining 12 subjects (44%) with complete paralysis were represented in the ASIA A group (Figure 4.9).

4.3.4 Incidence of secondary conditions related to SCI

The secondary complications of SCI present on admission to, at discharge from, and six months after discharge from the WCRC are illustrated in Figures 4.10, 4.11 and 4.12 respectively. The sample size on admission and at discharge equals 47 and at six months after discharge 27. The number of subjects does not equal 47 at discharge and 27 at six months, and percentages do not equal 100%, because subjects were not limited to one condition.

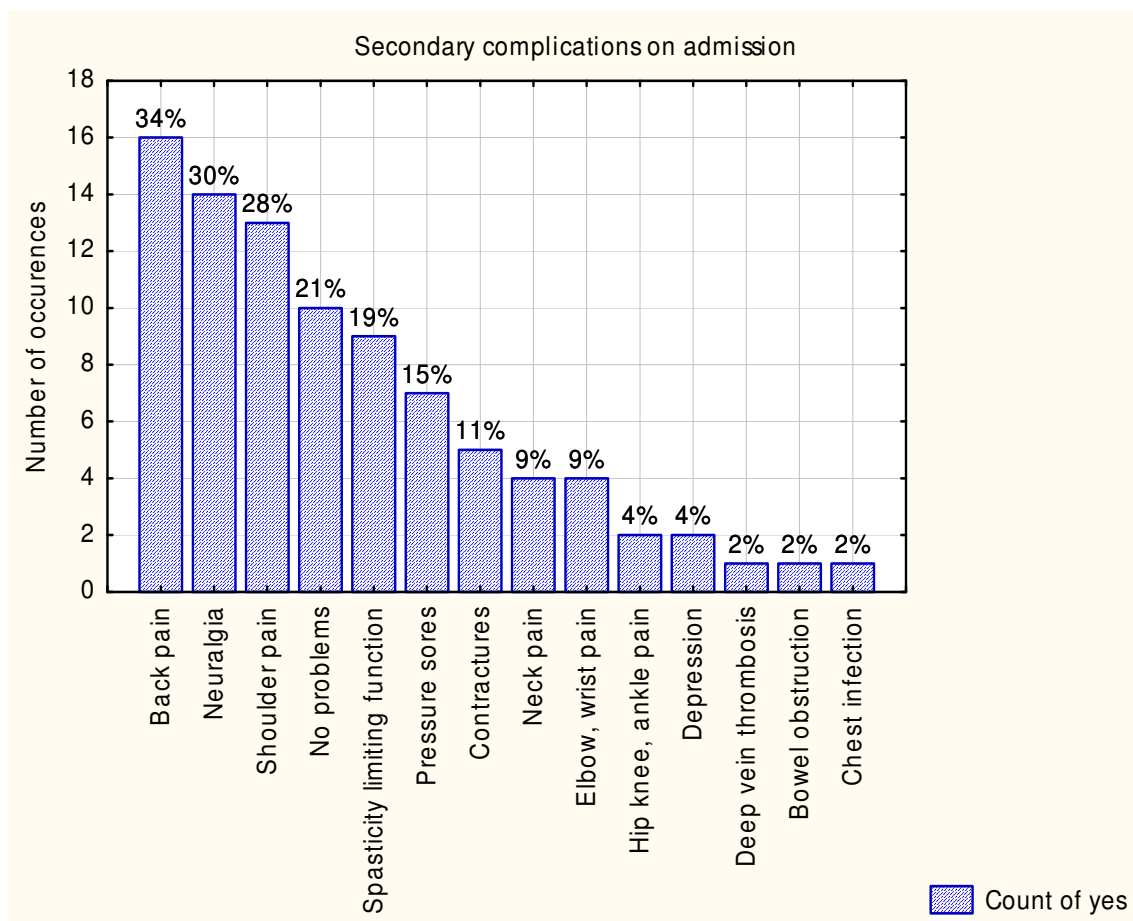


Figure 4.10: Incidence of secondary complications on admission

Back pain, neuralgia and shoulder pain were the most common secondary complications present on admission accounting for 34% (16/47), 30% (14/47) and 28% (13/47) of the subjects respectively.

Of the 47 subjects 10 (21%) did not experience any problems with secondary complications (Figure 4.10).

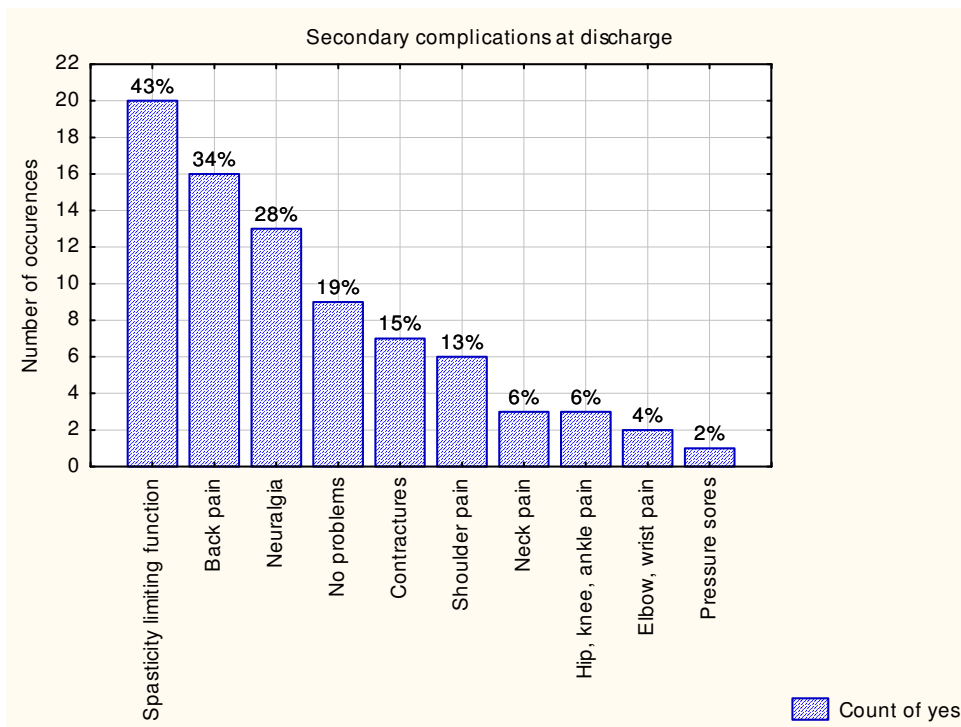


Figure 4.11: Incidence of secondary complications at discharge

Spasticity limiting function (43% or 20/47) was the most common secondary complication reported by the subjects at discharge. Other fairly common secondary complications identified by the subjects were back pain (34% or 16/47) and neuralgia (28% or 13/47). Nine of the 47 subjects (19%) did not experience any problems regarding secondary complications (Figure 4.11).

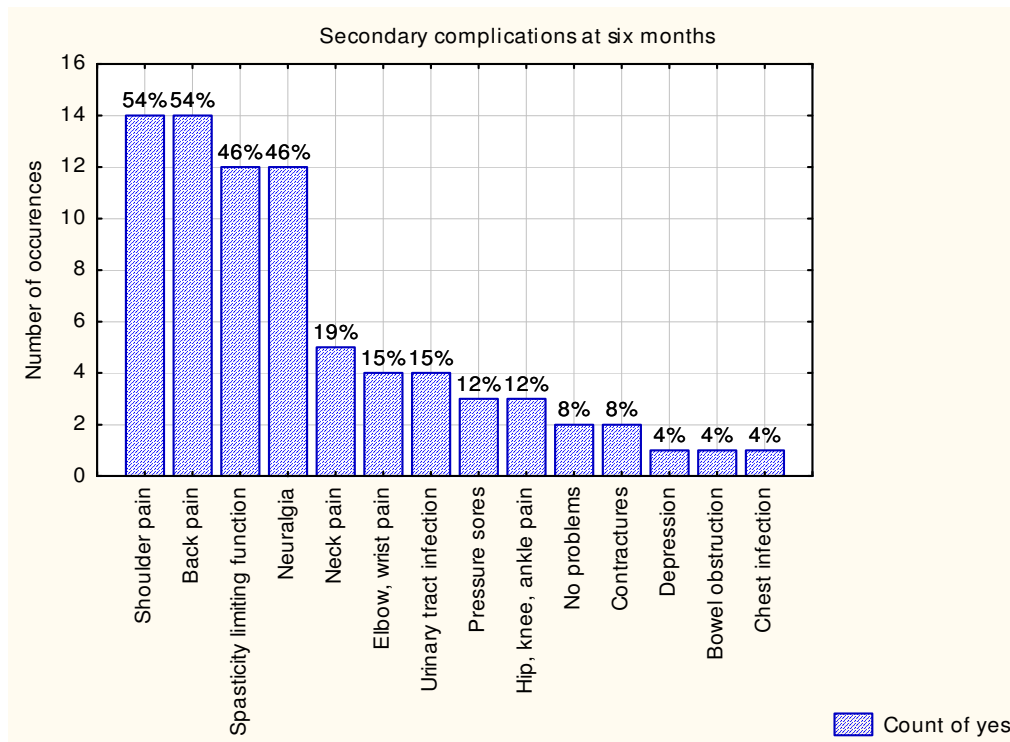


Figure 4.12: Incidence of secondary complications at six months

Shoulder pain and back pain (54% or 14/27 each) were the most common secondary complications reported by the subjects at six months. The second most common secondary complications present were spasticity limiting function and neuralgia at 46% (12/27) each. Only two subjects (8%) had not experienced any secondary complications since their discharge from the WCRC (Figure 4.12).

The differential incidence of secondary complication amongst tetraplegic and paraplegic patients at discharge and six months after discharge from the WCRC are displayed in Tables 4.5 and 4.6 respectively.

Table 4.5: Incidence of secondary complications by neurological deficit at discharge

Condition	Tetraplegic	Paraplegic	Total
Spasticity limiting function	9 (19%)	11 (23%)	20 (43%)
Back pain	7 (15%)	9 (19%)	16 (34%)
Neuralgia	6 (13%)	7 (15%)	13 (28%)
No problems	1 (2%)	8 (17%)	9 (19%)
Contractures	5 (11%)	2 (4%)	7 (15%)
Shoulder pain	2 (4%)	4 (9%)	6 (13%)
Neck pain	2 (4%)	1 (2%)	3 (6%)
Hip, knee, ankle pain	3 (6%)	0 (0%)	3 (6%)
Elbow, wrist pain	1 (2%)	1 (2%)	2 (4%)
Pressure sores	0 (0%)	1 (2%)	1 (2%)

The majority of secondary complications reported by the tetraplegic group were spasticity limiting function (19%), back pain (15%), neuralgia (13%) and contractures (11%).

In the paraplegic group, spasticity limiting function (23%), back pain (19%) and neuralgia (15%) were the most common secondary complications. Eight of the paraplegic subjects did not experience any problems with secondary complications.

Table 4.6: Incidence of secondary complications by neurological deficit at six months

Condition	Tetraplegic	Paraplegic	Total
Back pain	7 (26%)	9 (33%)	16 (59%)
Shoulder pain	8 (30%)	6 (22%)	14 (52%)
Spasticity limiting function	6 (22%)	6 (22%)	12 (44%)
Neuralgia	5 (19%)	7 (26%)	12 (44%)
Neck pain	3 (11%)	2 (7%)	5 (19%)
Elbow, wrist pain	3 (11%)	1 (4%)	4 (15%)
Urinary tract infection	2 (7%)	2 (7%)	4 (15%)
Pressure sores	0 (0%)	3 (11%)	3 (11%)
Hip, knee, ankle pain	2 (7%)	1 (4%)	3 (11%)
Contractures	1 (4%)	1 (4%)	2 (7%)
No problems	0 (0%)	2 (7%)	2 (7%)
Pneumonia or chest infection	0 (0%)	1 (4%)	1 (4%)
Bowel obstruction	0 (0%)	1 (4%)	1 (4%)
Depression	1 (4%)	0 (0%)	1 (4%)

The secondary complications reported most frequently by the tetraplegic group were shoulder pain (30%), back pain (26%), spasticity limiting function (22%) and neuralgia (19%). None of the tetraplegic group had pressure sores, bowel obstruction or chest infection. All the tetraplegic subjects reported having some secondary complications present during the six months after discharge from the WCRC. In the paraplegic group back pain (33%), neuralgia (26%) and shoulder pain and spasticity limiting function (22%) were the most common secondary complications. Three paraplegic subjects (11%) had problems with pressure sores. Only two of the paraplegic subjects had no secondary complications.

4.4 SOCIO-ECONOMIC CHARACTERISTICS

Information on the socio-economic characteristics of the subjects such as level of education, level of productive activity, gross monthly income, main source of income and contribution to household income will now be described in more detail. Information was gathered at the time of the injury, at discharge and six months after discharge from the WCRC. Percentages do not necessarily equal 100% because of rounding.

4.4.1 Level of education

Table 4.7 displays an overall summary of the level of education of the subjects within specific educational categories.

Table 4.7: Number of subjects in specific educational categories

Level of Education	<i>n</i> (<i>n</i> = 47)	Percentage (%)
Pre-primary/no formal education	1	2
Grade 1 – 3	0	0
Grade 4 – 7	7	15
Grade 8 – 10	27	58
Grade 11 - 12	8	17
Tertiary education: diploma	3	6
Tertiary education: degree	1	2

The findings of this study show that the majority of the subjects (58% or 27/44) have a grade eight to ten level of education. This is followed by a grade 11 to 12 education of 17% (8/47). The two extreme categories i.e. pre-primary/no formal education and tertiary education are in the minority where 8% (4/47) of the subjects have some form of tertiary education and 2% (1/47) no formal or pre-primary education (Table 4.7).

Table 4.8 displays an overall summary of the level of education of the subjects within specific educational categories by population group.

Table 4.8 Number of subjects in specific educational categories by population group (*n* = 47)

Level of education	Black	Coloured	White	Asian/Indian	Total
Pre-primary/no formal education	0 (0%)	1 (2%)	0 (0%)	0 (0%)	1 (2%)
Grade 1-3	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Grade 4-7	4 (9%)	3 (6%)	0 (0%)	0 (0%)	7 (15%)
Grade 8-10	10 (21%)	16 (34%)	0 (0%)	1 (2%)	27 (57%)
Grade 11-12	5 (11%)	3 (6%)	0 90%)	0 (0%)	8 (17%)
Tertiary education (diploma, certificate, degree)	2 (4%)	0 (0%)	2 (4%)	0 (0%)	4 (9%)

The majority of the Black (48% or 10/21) and Coloured (70% or 16/23) subjects have a grade eight to ten level of education (Table 4.8).

4.4.2 Level of productive activity

Information on the level of productivity of the subjects at the time of injury and six months after discharge from the WCRC is illustrated in Figures 4.13. and 4.14 respectively. The level of productive activity by the racial group at the time of the injury and at six months after discharge is displayed in Tables 4.9 and 4.10.

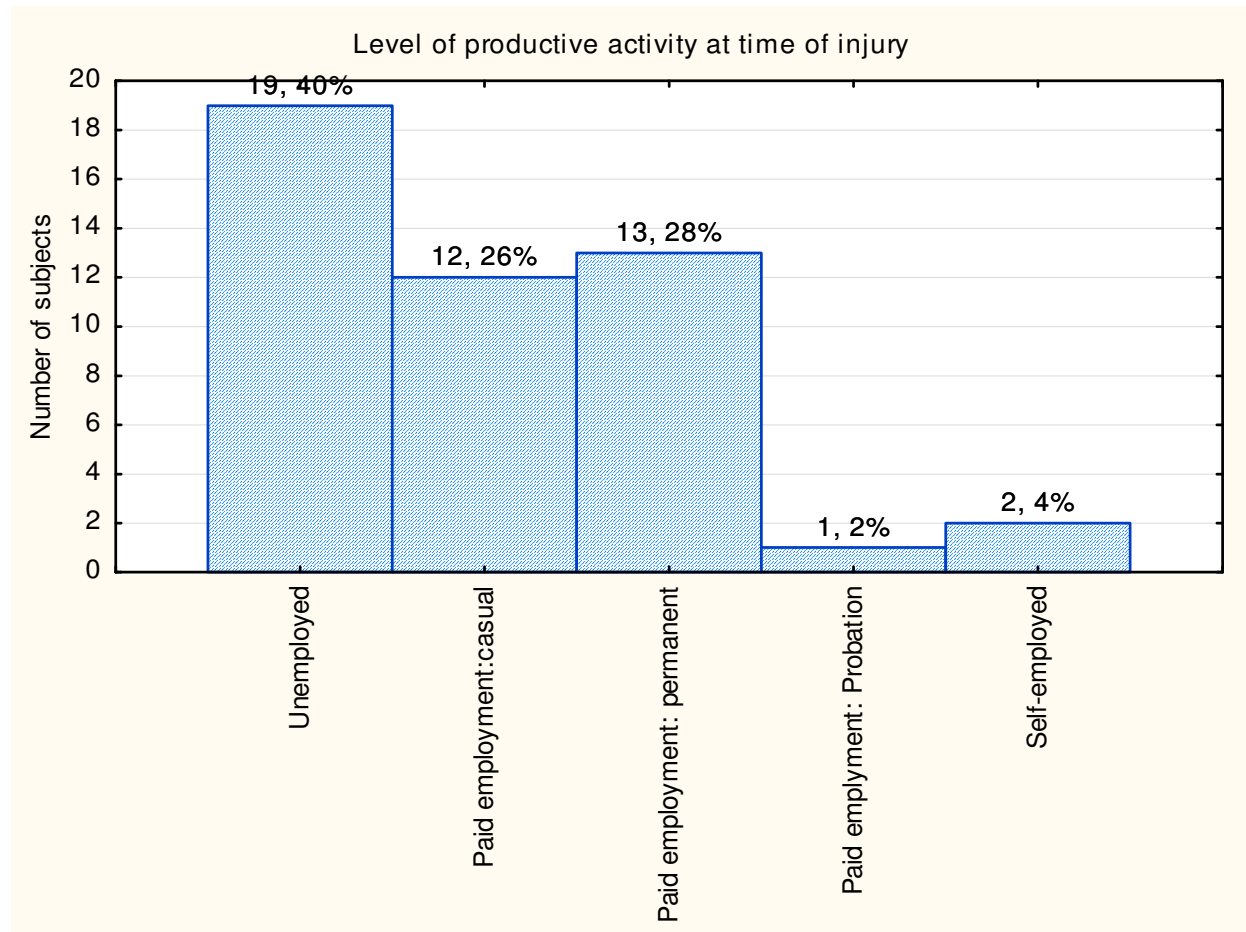


Figure 4.13: Level of productive activity at time of injury

Nineteen subjects (40%) were unemployed at the time of injury. The majority of the subjects (60% or 28/47) were in paid employment, but only 13 (28%) in a permanent capacity. The remaining 15 subjects (32%), although in paid employment, did not have a fixed monthly income.

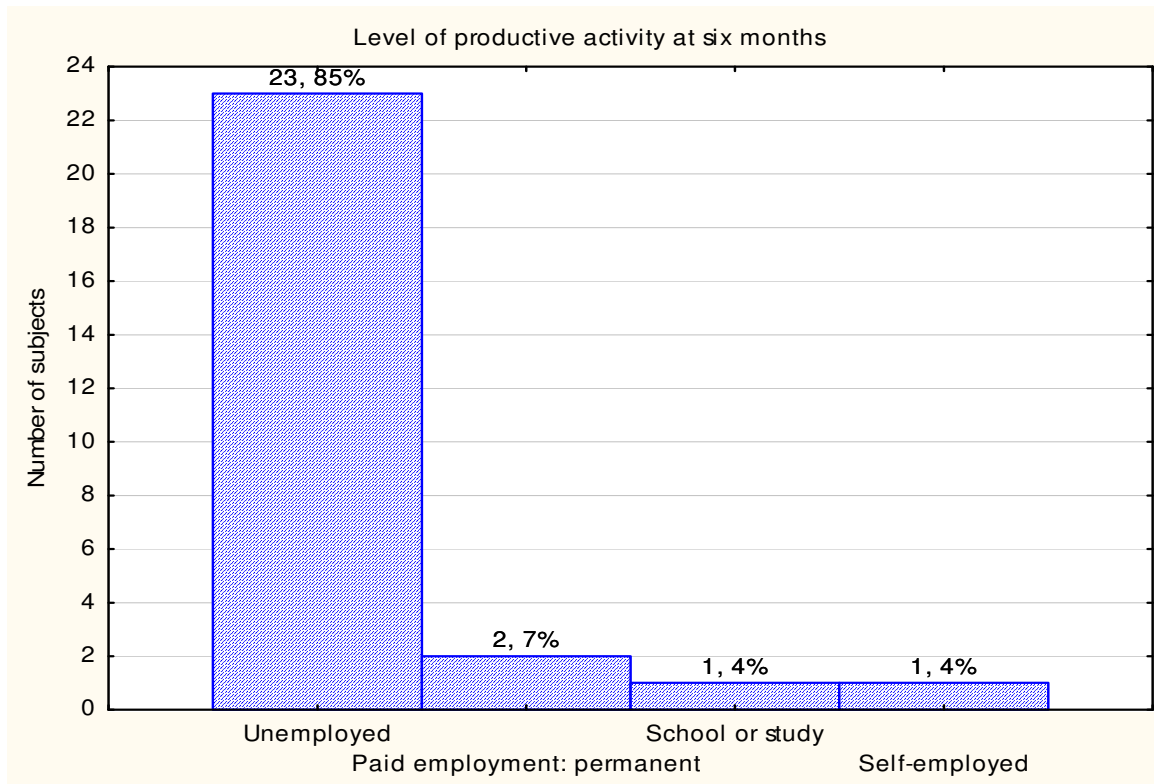
At the time of discharge none of the 47 subjects were productively active. The 28 subjects (60%) who were employed at the time of injury could not return to their previous employment due to their disability, or were still in the process of recovery (Figure 4.13).

Table 4.9: Level of productive activity by population group at the time of the injury (n=47)

	Unemployed	Paid employment: Permanent	Paid employment: Probation	Paid employment: Casual	Self-employed	Total
Black	9 (19%)	8 (17%)	0 (0%)	3 (6%)	1 (2%)	21 (45%)
Coloured	8 (17%)	5 (11%)	1 (2%)	9 (19%)	0 (0%)	23 (49%)
White	1 (2%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)	2 (4%)
Asian	1 (2%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1 (2%)

Of all the subjects, nine Black subjects (19%) and eight Coloured subjects (17%) were unemployed. As only eight Black (17%) and five Coloured subjects (11%) were permanently employed, the majority of Black and Coloured subjects (70.5% or 31/44) either had no income or no fixed monthly income (Table 4.9).

At the time of discharge all 47 subjects were unemployed.

**Figure 4.14: Level of productive activity at six months**

The majority of the subjects (85% or 23/27) were unemployed at six months after discharge. Only two of the subjects, (7%) were permanently employed, one (4%) was studying and one (4%) was self-employed (Figure 4.14).

Table 4.10: Level of productive activity by population group at six month (n=27)

	Unemployed	Paid employment: Permanent	Paid employment: Probation	Paid employment: Casual	Self-employed	School/study	Total
Black	11 (41%)	1 (4%)	0 (0%)	0 (0%)	0 (0%)	1 (4%)	13(48%)
Coloured	10 (37%)	0 (0%)	0 (0%)	0 (0%)	1 (4%)	0 (0%)	11(41%)
White	1 (4%)	1 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	2(7%)
Asian	1 (4%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1(4%)

Of the 27 subjects, only one Black (4%) and one White subject (4%) were permanently employed at six months after discharge. The majority of Black and Coloured subjects (92% or 21/24) were unemployed at the same point in time (Table 4.10).

4.4.3 Gross monthly income

A summary of the gross monthly income of the subjects at the time of injury, at discharge and six months after discharge from the WCRC is displayed in Figure 4.15, 4.16 and 4.17 respectively.

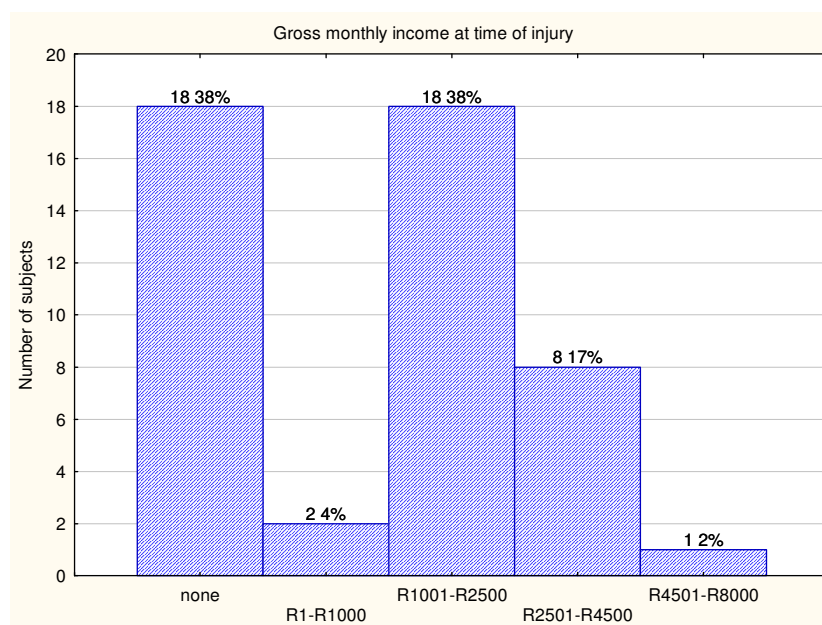


Figure 4.15: Gross monthly income at time of injury

Eighteen subjects (38%) had no income at the time of injury, with another eighteen subjects (38%) earning a gross income of between R1001 and R2500. Only one subjects (2%) earned more than R4500 while eight subjects (17%) earned between R2501 and R4500 (Figure 4.15).

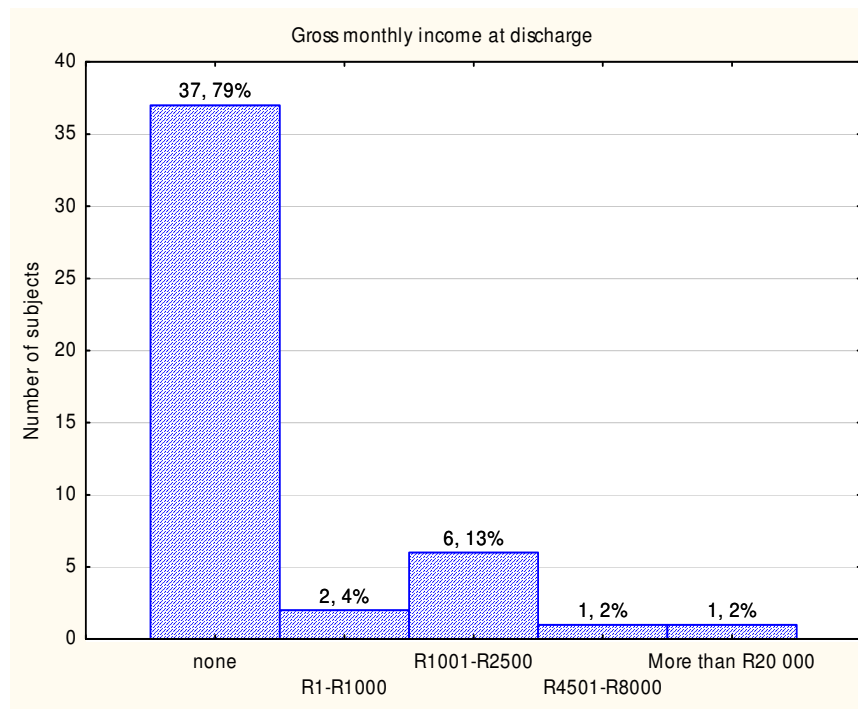


Figure 4.16: Gross monthly income at discharge

In contrast to the pre-injury figures, the majority of the subjects (79% or 37/47) did not have any income at discharge with only six subjects (13%) earning between R1001 and R2500 (Figure 4.16).

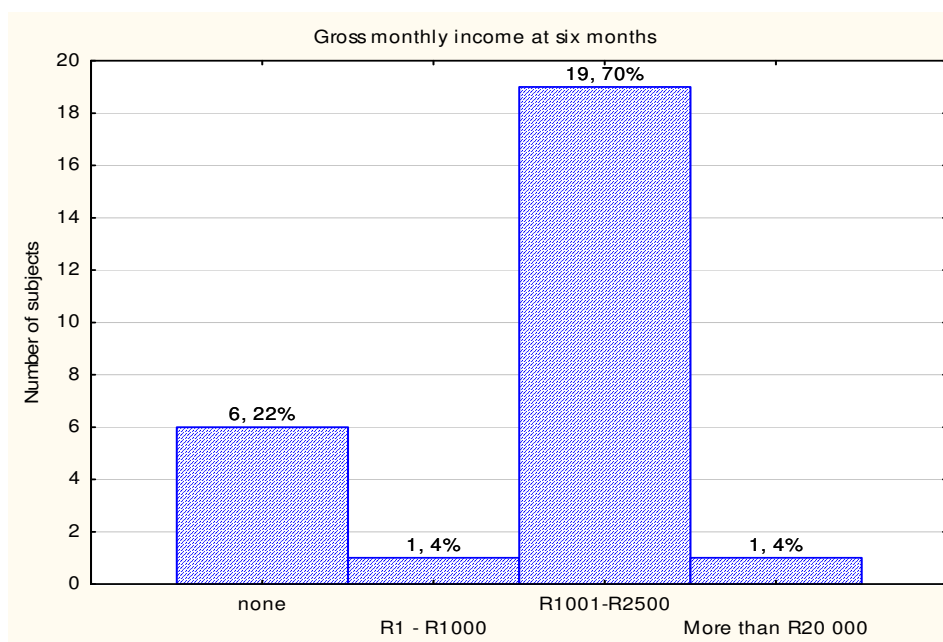


Figure 4.17: Gross monthly income at six months

The majority of the subjects (70% or 19/27) had a gross income of between R1001 and R2500. Six of the subjects (22%) had no income, one (4%) had an income of R1 to R1000 and one subject (4%) an income of more than R20 000. Only eight subjects reported their income sufficient to cover their expenses at six months after discharge (Figure 4.17).

4.4.4 Main source of income

Information on the main source of income of the subjects at discharge and six months after discharge from the WCRC is illustrated in Figures 4.18 and 4.19 respectively.

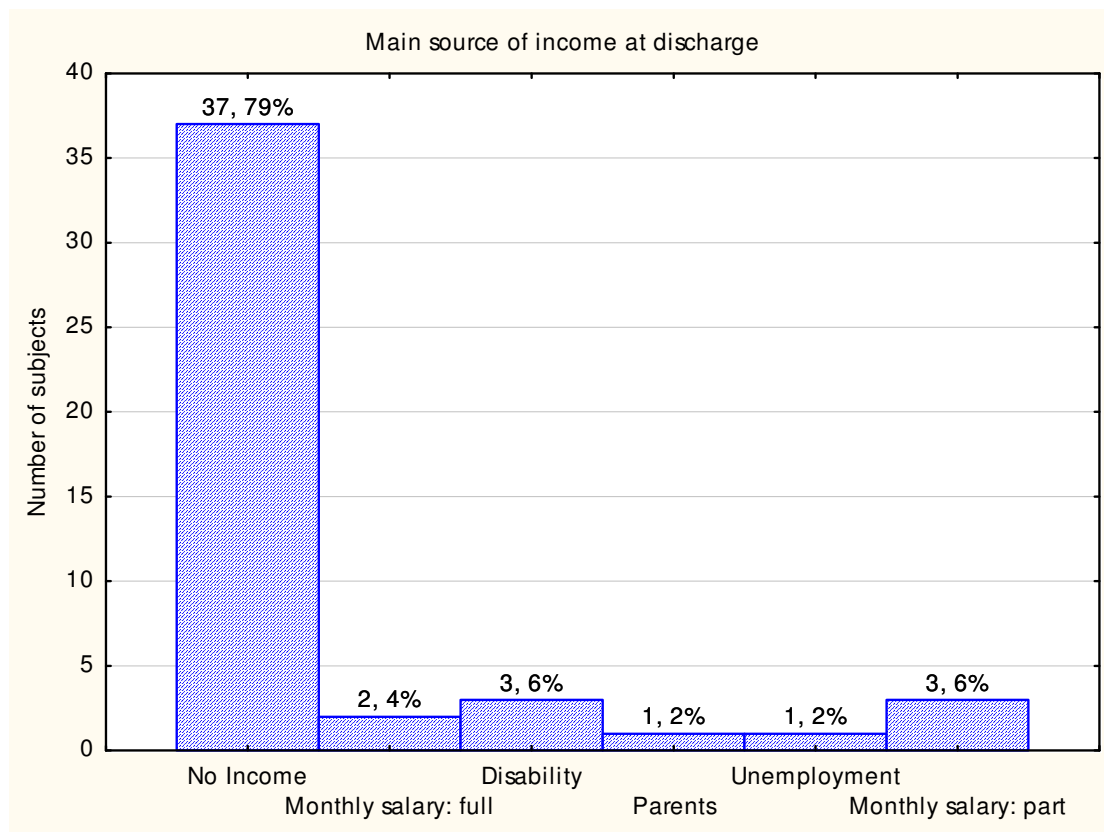


Figure 4.18: Main source of income at discharge

Of the small number of subjects who still had an income at discharge, only four percent of the subjects (2/47) received their monthly salary in full, while six percent of the subjects (3/47) received only part of their salary. Three of the subjects (6%) received a disability grant from the government and one of the subjects (2%) had unemployment benefits. Only three of the 10 subjects (30%) who had an income at discharge indicated that they could still cover their expenses (Figure 4.18).

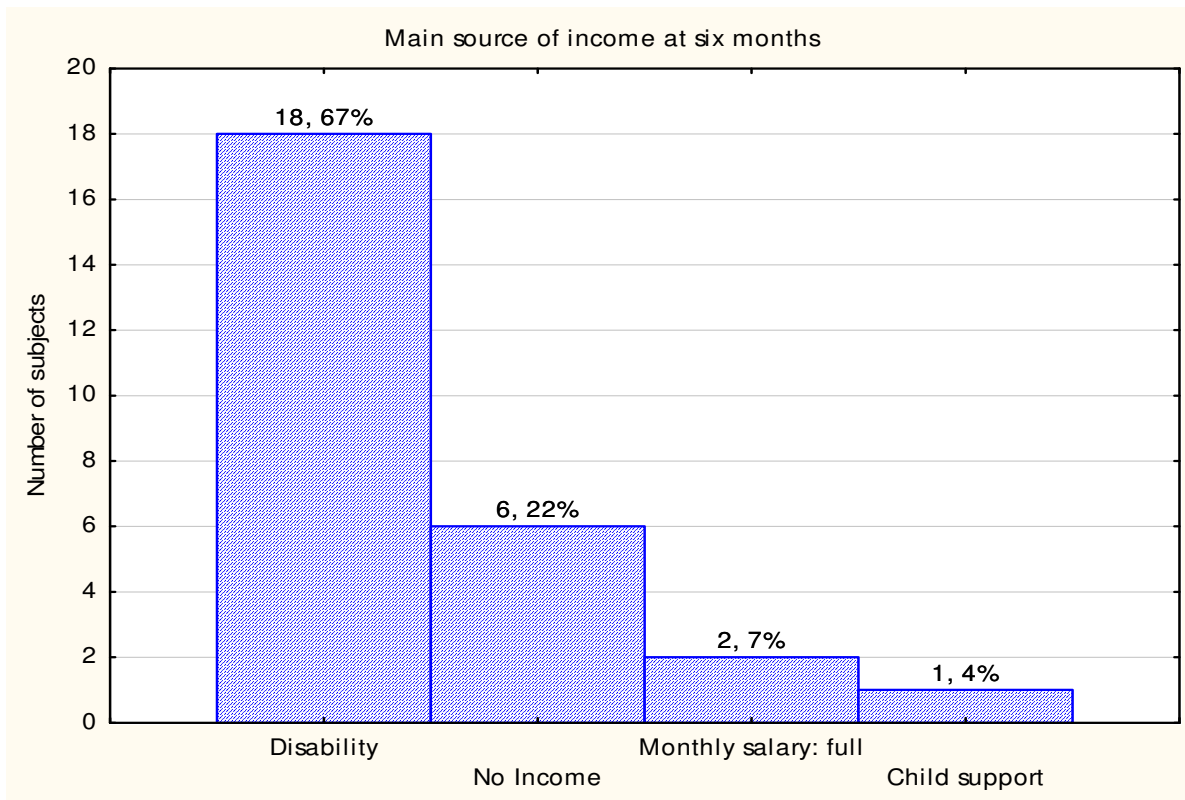


Figure 4.19: Main source of income at six months

The main source of income for the majority of the subjects (67% or 18/27) was a disability grant from the state. Two subjects (7%) received a full monthly salary, one received a child support grant from the state and six subjects (22%) had no income (Figure 4.19).

4.4.5 Contribution to household income

For 43 of the 47 subjects (91%), their income was the only source of income in the household at discharge from the WCRC. Only four subjects received financial support from others. At six months after discharge from the WCRC, fifteen subjects (56%) shared the financial responsibilities with others in the household, while 12 subjects (44%) did not receive any financial assistance from household members.

4.5 DESCRIPTION OF THE LIVING ENVIRONMENT AFTER DISCHARGE

Information on the living environment of the subjects after discharge with regard to type and size of the house (number of rooms), persons in the house (number of residents), available space in the house, washing and toilet arrangements and availability or access to essential utilities and services such as electricity, running water, telephone and personal assistance will now be described in detail. Percentages do not necessarily equal 100% because of rounding.

4.5.1 Type of housing

The type of housing the subjects were discharged to is illustrated in Figure 4.20.

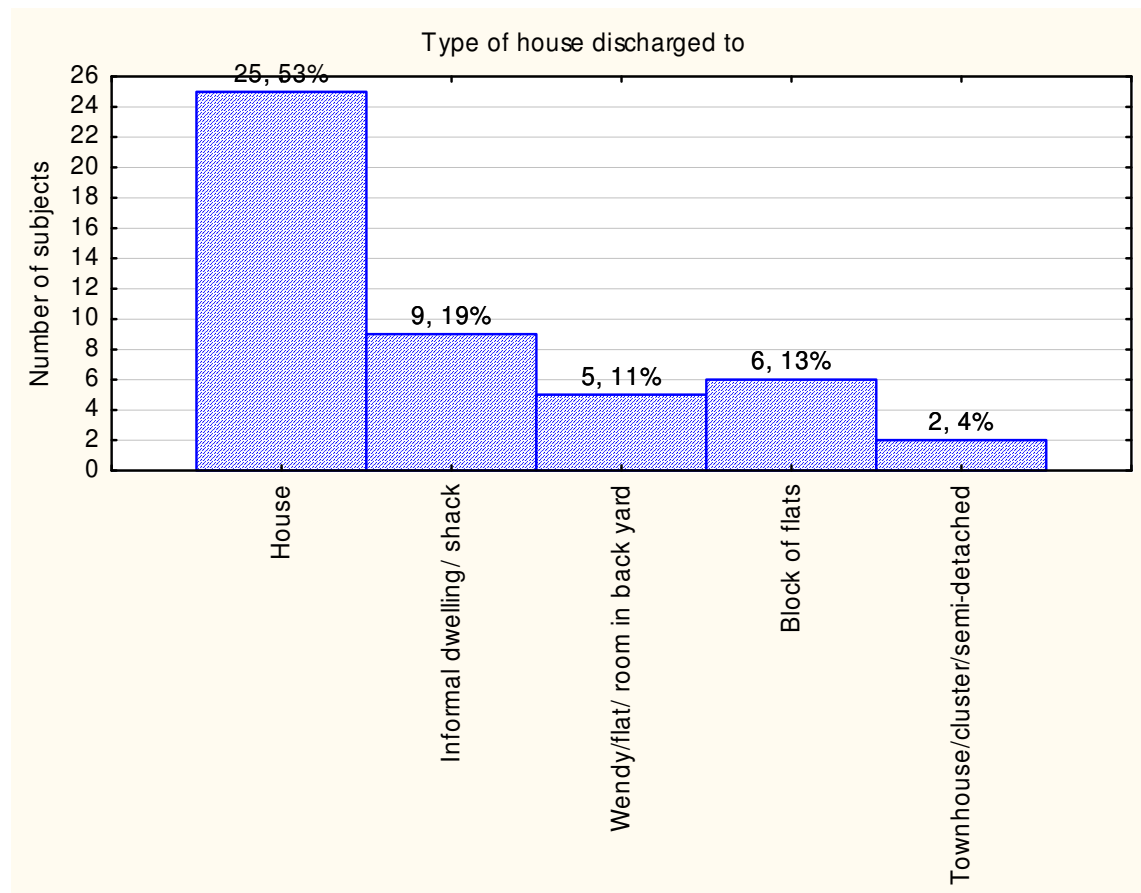


Figure 4.20: Type of housing discharged to

The majority of the subjects (53%) were discharged to a brick house. An informal dwelling or shack (19%) was the second most common housing environment the subjects were discharge to (Figure 4.20).

4.5.2 Discharged to original house

The subjects were asked if they were being discharged to the same house as they were living in at the time of injury. The majority of the subjects (79% or 37/47) responded positively. Reasons for not returning to the same house were that the house was unsuitable or inaccessible (13% or 6/47), not safe due to violence (4% or 2/47), was destroyed in a fire (2% or 1/47) and that no caregiver was available (2% or 1/47).

4.5.3 Same house at six months as discharged to

The subjects were asked if they were still living in the same house at six months as the one to which they were discharged. The majority of the subjects (89%) responded positively. Only one subject (4%) reported unsuitability of the house for wheelchair use as the reason for moving to another house. The remaining subjects were living with their children immediately after discharge or were currently living with them.

4.5.4 Number of rooms

A summary of the number of rooms per house is illustrated in Figure 4.21. The number of rooms in the house was defined as: all rooms except bathrooms, garages or sheds, unless there is someone living in them.

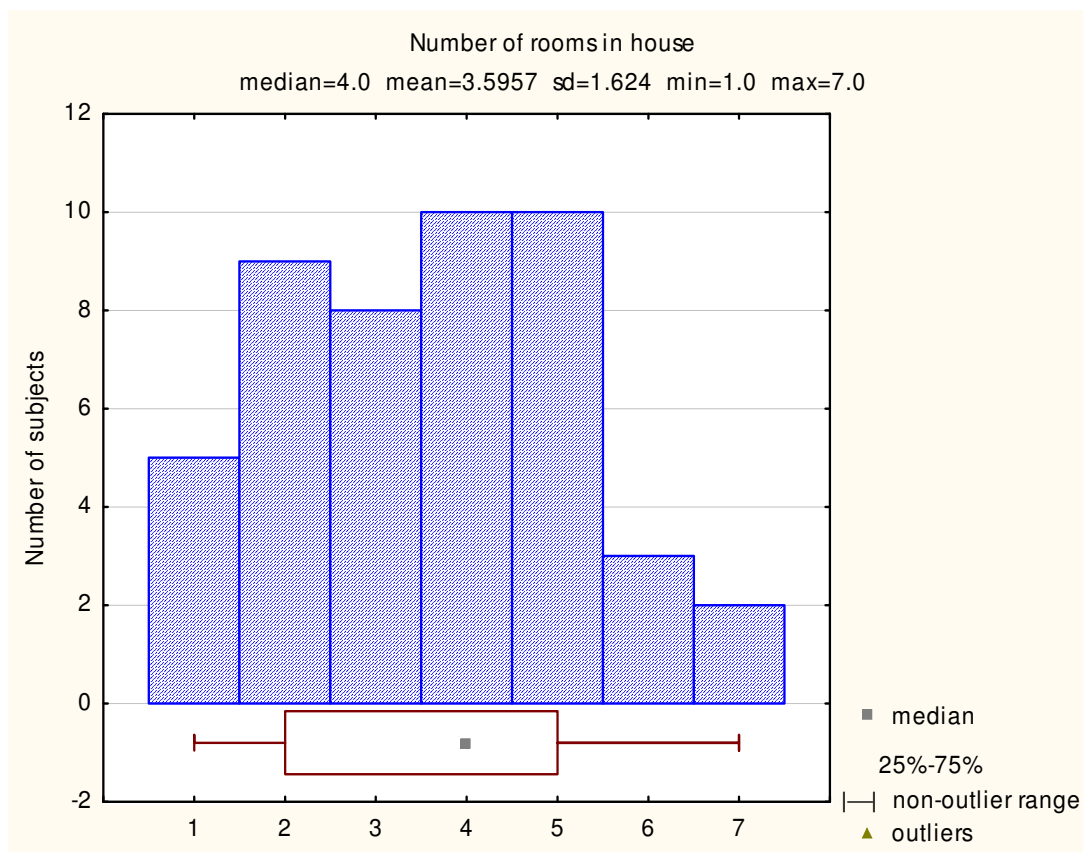


Figure 4.21 Number of rooms in the house

The number of rooms in the house range from one to seven with a median of four rooms. The mean equals 3.6 (SD 1.6), which indicates that there were no outliers present regarding number of rooms per house. The majority of subjects (79% or 37/47) reported to have between two (25% quartile) and five (75% quartile) rooms per house. Four and five were the most common numbers of rooms reported by 10 subjects (21%) each (Figure 4.21).

4.5.5 Number of people living in the house

A summary of the number of people living in the house is illustrated in Figure 4.22. The subjects were included in the number of people in the house.

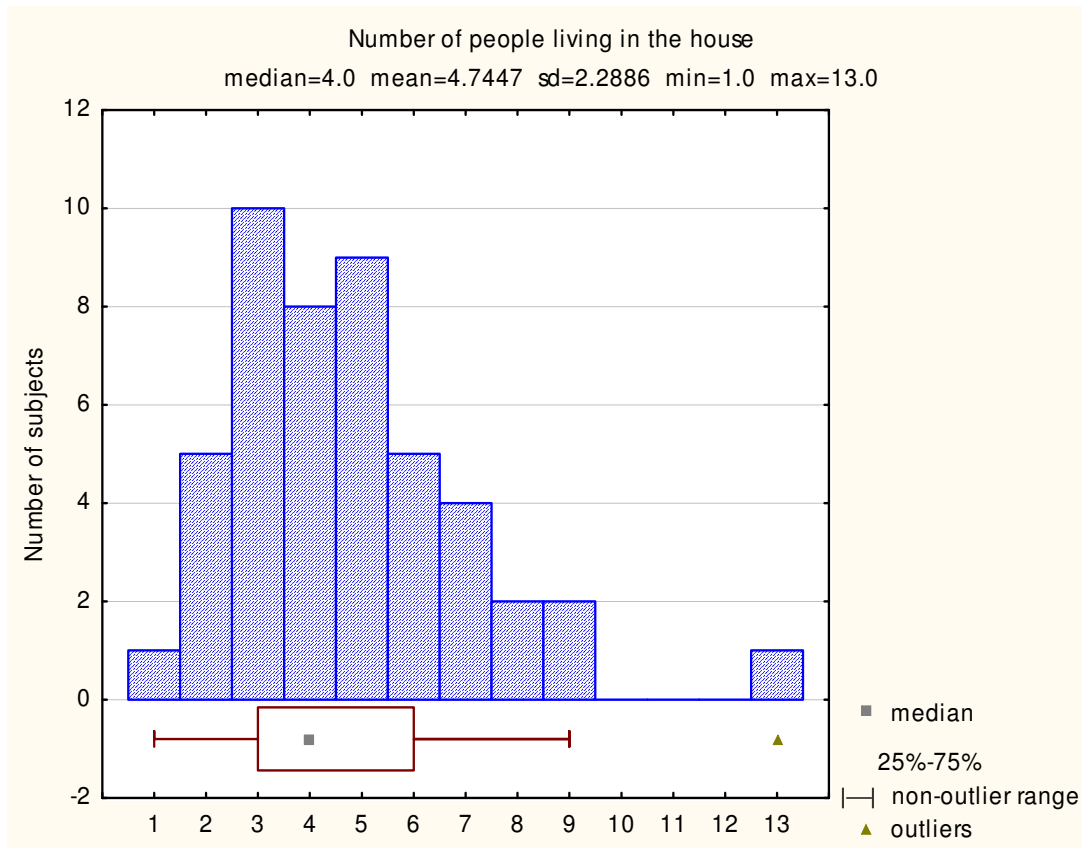


Figure 4.22: Number of people living in the house

The number of people living in the house ranged from one to 13, with a non-outlier range of one to nine rooms. The only outlier present was 13. The median number of people was 4 per house. The majority of subjects (68% or 32/47) reported to have between three (25% quartile) and six (75% quartile) people living in the house (Figure 4.22).

4.5.6 Space available inside the house for mobility

Subjects were asked if they had adequate space inside their houses for mobility purposes. Mobility was defined as any form of moving around such as walking, crawling and wheelchair propulsion. The majority of the subjects (81% or 38/47) responded positively.

4.5.7 Type of facility used for washing oneself

The type of facility that the subjects use to wash themselves is illustrated in Figure 4.23.

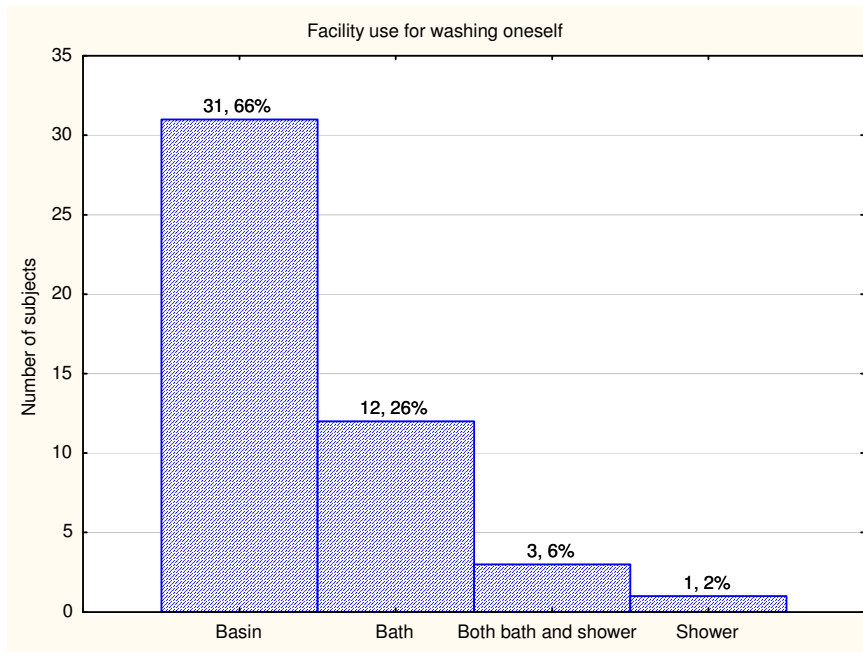


Figure 4.23: Facility used for washing oneself

It is clear that the majority of the subjects (66% or 31/47) used a basin to wash themselves, while twelve subjects (26%) used a bath for washing (Figure 4.23).

4.5.8 Location of bathroom

The location of the bathroom in relation to the house is illustrated in Figure 4.24. The options were inside or outside the house, and neither, if they did not have access to a bathroom facility.

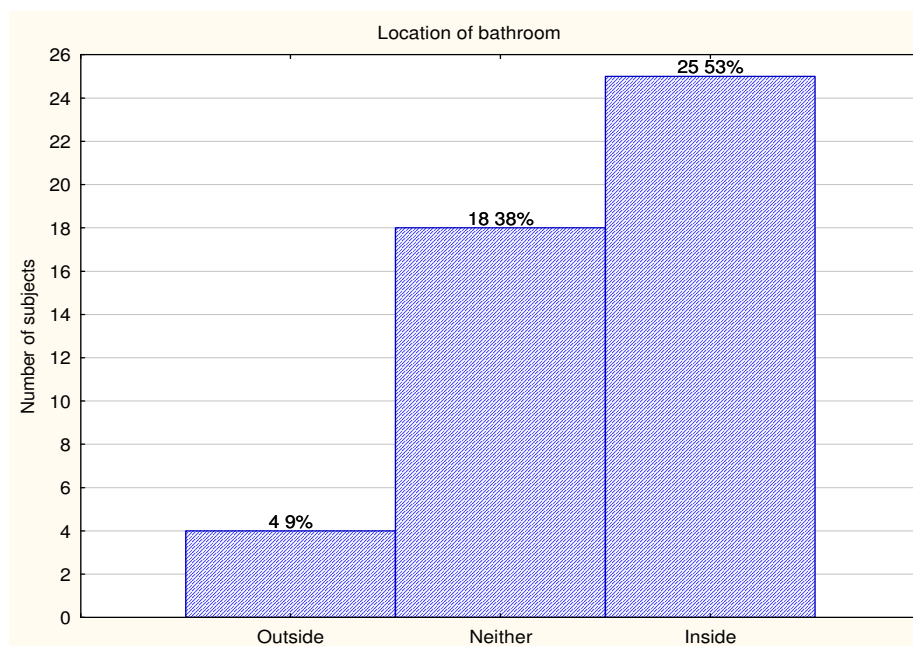


Figure 4.24: Location of bathroom facility

The majority of the subjects (53% or 25/47 subjects) had bathrooms inside their houses. Eighteen subjects (38%) reported to have no access to a bathroom facility (Figure 4.24).

4.5.9 Location of toilet

The location of the toilet in relation to the house is illustrated in Figure 4.25. The options were inside and outside and neither, if they didn't have access to any toilet facility.

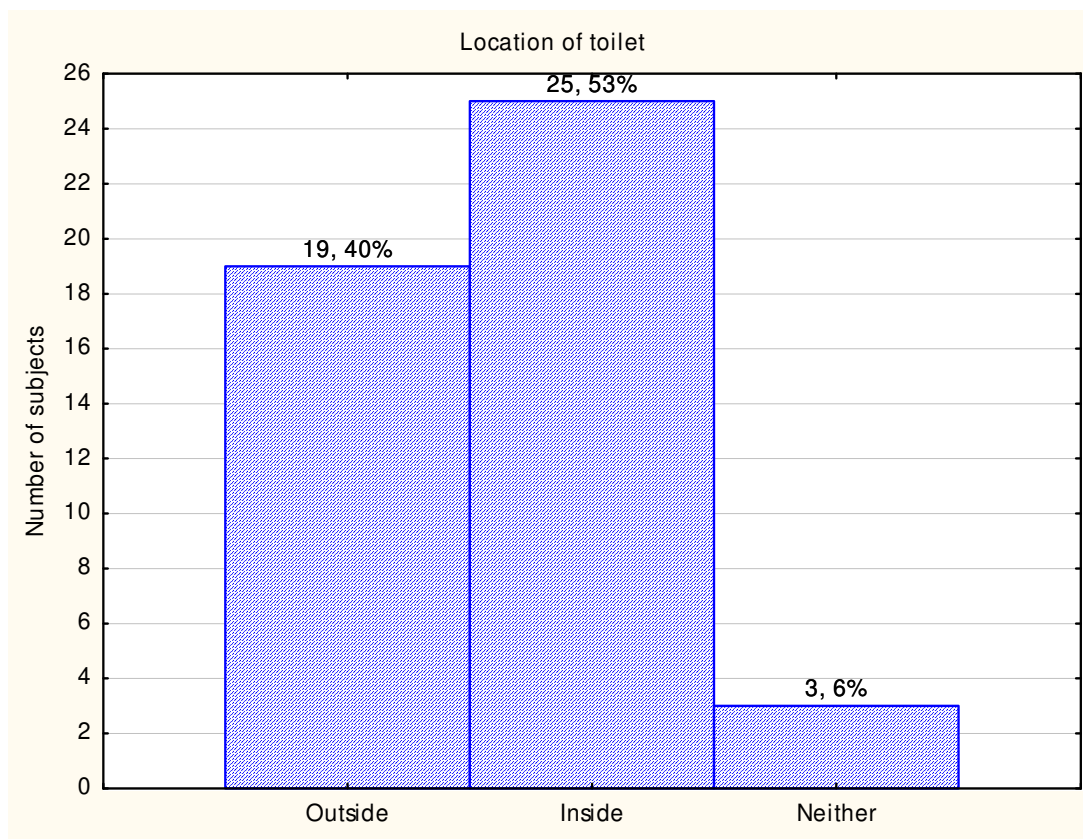


Figure 4.25: Location of toilet facility

Again the majority of the subjects (53% or 25/47 subjects) reported having a toilet inside their houses while 19 subjects (40%) have a toilet outside the house (Figure 4.25).

4.5.10 Ability to access or use toilet facility

Subjects were asked if they could use their toilet facility with or without assistance.

The majority of the subjects (68% or 32/47 subjects) were able to use their toilet facility on discharge. The remaining 15 subjects (32%) were not able to use their toilets with or without assistance.

4.5.11 Alternative toileting arrangement

Subjects were asked to indicate the exact nature of the toilet facility they used, if they had toilet facilities, but were unable to use them, or if they had no toilet facility. The findings are illustrated in Figure 4.26.

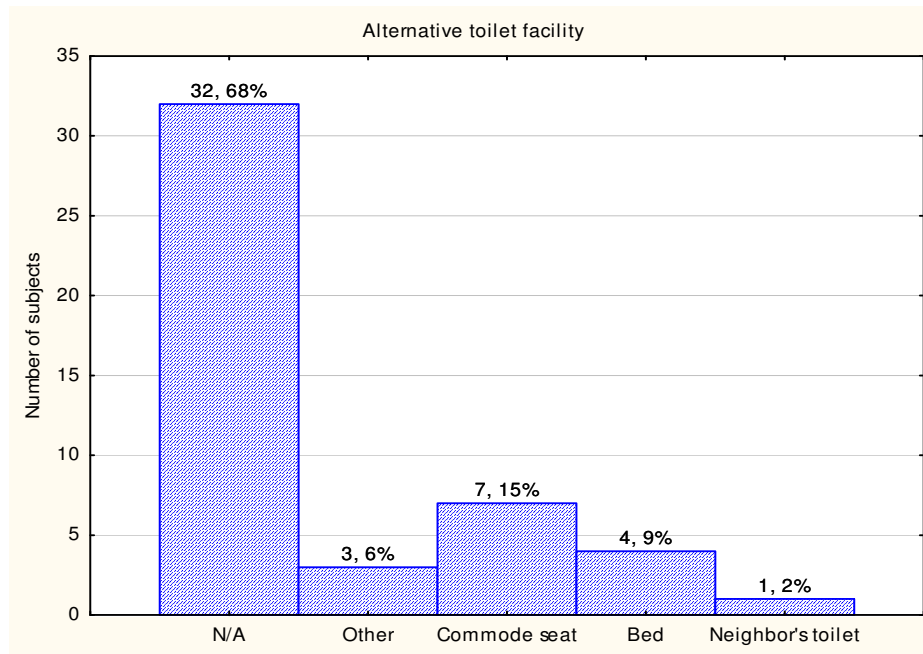


Figure 4.26: Alternative toilet facility

Of the 15 subjects who did not have a toilet facility or could not use it, seven subjects (15%) were using a commode seat, four subjects (9%) used their beds, one subject (2%) used the neighbour's toilet and three subjects (6%) reported making other arrangements (Figure 4.26).

4.5.12 Access to utilities, communication and personal assistance

Subjects were asked if they had access to essential services such as electricity, running water, telephones and personal assistance. A summary of the findings is displayed in Table 4.11.

Table 4.11: Access to utilities, communication and personal assistance

Service	Yes		No	
	<i>N (n=47)</i>	Percentage (%)	<i>N (n=47)</i>	Percentage (%)
Electricity	45	96	2	4
Running water	47	100	0	0
Telephone	47	100	0	0
Personal assistance	40	85	7	15

All 47 subjects (100%) had access to running water and a telephone. Electricity was available to 45 subjects (96%) and personal assistance to 40 subjects (85%) (Table 4.11).

SECTION TWO

This section reports on the activity and participation profile of the sample for each domain or life situation at discharge, and six months after discharge from the WCRC, as well as comparisons made between activity and participation at the different points in time. For all statistical comparisons, p-values were rounded to two decimal points. The value of $p < 0.05$ was interpreted as highly significant, and $p < 0.10$ as worth noting (especially, because of the small sample size).

4.6 ACTIVITY AND PARTICIPATION PROFILE

A summary of the ability of the subjects to participate in different life situations at discharge, and six months after discharge from the WCRC, as well as comparisons made between activity and participation at these points in time, is displayed in Tables 4.12 to 4.31. The different domains of the activity and participation component addressed in this study i.e. mobility, self care, domestic life, interpersonal interactions and relationships, major life areas and community, social and civic life will be displayed separately.

The domains of the participation component are described by the performance qualifier. The performance qualifier describes what the individual with SCI does in his or her current environment and whether it can be performed with or without personal assistance and/or assistive devices. For the purpose of this study, the performance qualifier is: “used with personal assistance and/or assistive devices” i.e. the first qualifier according to the ICF (WHO, 2001).

The domains of the activity component are described by the capacity qualifier. The capacity qualifier describes what the individual with SCI does in a standard environment, with or without personal assistance and/or assistive devices. For the purpose of this study the capacity qualifier is: “used without any assistance” i.e. the second qualifier according to the ICF (WHO, 2001). The activity profile is described in terms of the amount and type of assistance utilized to perform the activities in each domain.

Codes from zero (no difficulty) to four (complete difficulty) were attached to the degree of difficulty it took to participate (WHO, 2001). A code of four was also awarded if the activity was applicable for the subject, but at the time of data collection the subject had not performed the activity. If the activity was not applicable for the subject, a code of nine was awarded. However, for analysis purposes, codes one (mild difficulty), two (moderate difficulty) and three (severe difficulty) will be combined into one category i.e. some difficulty. The adaptation of the original

scale does not affect the results. Complete data for activity and participation at discharge, and six months after discharge, and the amount and type of assistance utilized at discharge and six months after discharge from the WCRC can be seen in Appendixes XV, XVI, XVII & XVIII respectively.

The information for this section was gathered at discharge and at six months after discharge from the WCRC. Although the sample size for discharge and six months after discharge was 47 and 27 respectively, the number of subjects for each activity does not necessarily equal this number, as only subjects for which the activities were applicable and/or those who were able to perform these activities were considered for analysis. The number of subjects for each activity is displayed in the relevant tables.

4.6.1 Activity and participation profile for mobility

A summary of the subjects' capacity and performance levels for mobility at discharge and six months after discharge is displayed in Tables 4.12 to 4.15. The percentages do not always equal 100% because of rounding.

Table 4.12: Participation profile for mobility at discharge (n=47)

Mobility					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d4100	Changing basic body position: Lying down	45 (96%)	2 (4%)	0 (0%)	0 (0%)
d4101	Changing basic body position: Squatting	3 (6%)	14 (30%)	30 (64%)	0 (0%)
d4102	Changing basic body position: Kneeling	3 (6%)	13 (28%)	31 (66%)	0 (0%)
d4103	Changing basic body position: Sitting	45 (96%)	2 (4%)	0 (0%)	0 (0%)
d4104	Changing basic body position: Standing	14 (30%)	7 (15%)	26 (55%)	0 (0%)
d4105	Changing basic body position: Bending	35 (74%)	4 (9%)	8 (17%)	0 (0%)
d4153	Maintaining a body position: Sitting	44 (94%)	3 (6%)	0 (0%)	0 (0%)
d4154	Maintaining a body position: Standing	12 (26%)	9 (19%)	26 (55%)	0 (0%)
d4200	Transferring oneself while sitting	37 (79%)	10 (21%)	0 (0%)	0 (0%)

ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d430	Lifting and carrying objects	33 (70%)	14 (30%)	0 (0%)	0 (0%)
d440	Unilateral fine hand use	34 (72%)	6 (13%)	7 (15%)	0 (0%)
d445	Unilateral hand and arm use	35 (74%)	9 (19%)	3 (6%)	0 (0%)
d4500	Walking short distances	10 (21%)	10 (21%)	27 (57%)	0 (0%)
d4501	Walking long distances	5 (11%)	4 (9%)	38 (81%)	0 (0%)
d4502	Walking on different surfaces	7 (15%)	6 (13%)	34 (72%)	0 (0%)
d4503	Walking around obstacles	8 (17%)	6 (13%)	33 (70%)	0 (0%)
d4600	Moving around within the home	34 (72%)	10 (21%)	3 (6%)	0 (0%)
d4601	Moving around buildings other than home	16 (34%)	6 (13%)	25 (53%)	0 (0%)
d4602	Moving around outside the home and other buildings	24 (51%)	20 (43%)	3 (6%)	0 (0%)
d465	Moving around using equipment	21 (45%)	16 (34%)	0 (0%)	10 (21%)
d4701	Moving around using private motorized transportation	24 (51%)	19 (40%)	4 (9%)	0 (0%)
d4702	Moving around using public motorized transportation	3 (6%)	7 (15%)	33 (70%)	4 (9%)
d475	Driving	0 (0%)	1 (2%)	16 (34%)	30 (64%)

The basic, essential activities of lying down (d4100), sitting up (d4103), maintaining the sitting position (d4153) and transferring (d4200) were performed by all the subjects. Only a few subjects (2/47, 2/47, 3/47 and 10/47 respectively) reported some difficulty with performing these activities.

The majority of the subjects (70%, 72%, 74% respectively) reported having some upper limb function (d430, d440, d445).

Twenty of the 47 subjects (43%) managed to walk short distances (d4500). Walking long distances (d4501) was the most difficult walking activity, as only nine of the 20 subjects (45%) who could walk short distances, were able to walk long distances. In total, 81% of the subjects could not walk long distances compared to 57% of the subjects who could not walk short distances.

Moving around within their homes (d4600) was not identified as a problem by the subjects as only three subjects (6%) had complete difficulty in performing the activity. However, of the remaining 45 subjects, 10 subjects (21%) reported some difficulty with this activity. Moving around buildings other than home (d4601) was more difficult, as 25 subjects (53%) either did not, or could not, perform the activity at the time of discharge. Utilizing public transport (d4702) seems to be a major problem for persons with SCI, as 33 subjects (79%) reported complete difficulty with performing this activity (Table 4.12).

Table 4.13 Participation profile for mobility at six months (n=27)

Mobility					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d4100	Changing basic body position: Lying down	26 (96%)	1 (4%)	0 (0%)	0 (0%)
d4101	Changing basic body position: Squatting	3 (11%)	10 (37%)	14 (52%)	0 (0%)
d4102	Changing basic body position: Kneeling	2 (7%)	11 (41%)	14 (52%)	0 (0%)
d4103	Changing basic body position: Sitting	24 (89%)	3 (11%)	0 (0%)	0 (0%)
d4104	Changing basic body position: Standing	10 (37%)	4 (15%)	13 (48%)	0 (0%)
d4105	Changing basic body position: Bending	22 (81%)	1 (4%)	4 (15%)	0 (0%)
d4153	Maintaining a body position: Sitting	26 (96%)	1 (4%)	0 (0%)	0 (0%)
d4154	Maintaining a body position: Standing	11 (41%)	3 (11%)	13 (48%)	0 (0%)
d4200	Transferring oneself while sitting	24 (89%)	3 (11%)	0 (0%)	0 (0%)
d430	Lifting and carrying objects	22 (81%)	5 (19%)	0 (0%)	0 (0%)

ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d440	Unilateral fine hand use	20 (74%)	4 (15%)	3 (11%)	0 (0%)
d445	Unilateral hand and arm use	23 (85%)	3 (11%)	1 (4%)	0 (0%)
d4500	Walking short distances	9 (33%)	5 (19%)	13 (48%)	0 (0%)
d4501	Walking long distances	4 (15%)	6 (22%)	17 (63%)	0 (0%)
d4502	Walking on different surfaces	8 (30%)	5 (19%)	14 (52%)	0 (0%)
d4503	Walking around obstacles	8 (30%)	5 (19%)	14 (52%)	0 (0%)
d4600	Moving around within the home	22 (81%)	5 (19%)	0 (0%)	0 (0%)
d4601	Moving around within buildings other than home	23 (85%)	4 (15%)	0 (0%)	0 (0%)
d4602	Moving around outside the home and other buildings	16 (59%)	11 (41%)	0 (0%)	0 (0%)
d465	Moving around using equipment	13 (48%)	4 (15%)	0 (0%)	10 (37%)
d4701	Moving around using private motorized transportation	21 (78%)	5 (19%)	1 (4%)	0 (0%)
d4702	Moving around using public motorized transportation	7 (26%)	5 (19%)	12 (44%)	3 (11%)
d475	Driving	1 (4)	0 (0)	10 (37)	16 (59%)

The basic, essential activities of lying down (d4100), sitting up (d4103), maintaining the sitting position (d4153) and transferring (d4200) were performed by all the subjects. The majority of the subjects (96%, 89%, 96% and 89% respectively) had no difficulty in performing these activities.

The majority of the subjects (81%, 74% and 85% respectively) reported to have some upper limb function (d430, d440, d445).

Fourteen of the 27 subjects (52%) managed to walk short distances (d4500). Walking long distances (d4501) was the most difficult walking activity as 17 of the 27 subjects (63%) were not able to

perform this activity. In total 63% (17/27) of the subjects could not walk long distances, compared to 48% (13/27) of the subjects who could not walk short distances. Walking on different surfaces (d4502) or around obstacles (d4503) was equally difficult for all the subjects, but still easier than walking long distances.

Moving around within their homes (d4600) was not a problem for subjects as all 27 subjects were able to perform this activity, although five subjects (19%) reported some difficulty in doing so. Moving around buildings other than home (d4601) and moving around outside the home and other buildings (d4602) was performed by all the subjects, although it was significantly more difficult to move outside the house and other buildings (41%), compared to inside the home and other buildings (19% and 15% respectively). Utilizing public transport (d4702) is still a problem for persons with SCI, as 12 subjects (44%) reported complete difficulty with performing this activity at six months after discharge from the WCRC (Table 4.13).

Table 4.14: Difference in participation for mobility between discharge and six months after discharge

Mobility						
ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P - value
d4100	Changing basic body position: Lying down	47	0.06 (0.32)	27	0.04 (0.19)	0.25
d4101	Changing basic body position: Squatting	47	3.02 (1.44)	27	2.70 (1.54)	0.21
d4102	Changing basic body position: Kneeling	47	3.13 (1.36)	27	2.70 (1.51)	0.11
d4103	Changing basic body position: Sitting	47	0.11 (0.52)	27	0.19 (0.62)	0.83
d4104	Changing basic body position: Standing	47	2.49 (1.82)	27	2.15 (1.90)	0.09
d4105	Changing basic body position: Bending	47	0.85 (1.56)	27	0.63 (1.45)	0.84
d4153	Maintaining a body position: Sitting	47	0.06 (0.25)	27	0.04 (0.19)	0.35
d4154	Maintaining a body position: Standing	47	2.51 (1.78)	27	2.07 (1.94)	0.04
d4200	Transferring oneself while sitting	47	0.38 (0.82)	27	0.22 (0.70)	0.07
d430	Lifting and carrying objects	47	0.51 (0.91)	27	0.22 (0.51)	0.04
d440	Unilateral fine hand use	47	0.87 (1.53)	27	0.70 (1.38)	0.15
d445	Unilateral hand and arm use	47	0.60 (1.19)	27	0.30 (0.87)	0.12

ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P - value
d4500	Walking short distances	47	2.74 (1.66)	27	2.33 (1.86)	0.21
d4501	Walking long distances	47	3.38 (1.34)	27	2.85 (1.63)	0.20
d4502	Walking on different surfaces	47	3.06 (1.58)	27	2.44 (1.83)	0.06
d4503	Walking around obstacles	47	2.98 (1.64)	27	2.44 (1.83)	0.07
d4600	Moving around within the home	47	0.77 (1.34)	27	0.33 (0.78)	0.17
d4601	Moving around within buildings other than home	47	2.28 (1.90)	27	0.19 (0.48)	<0.001
d4602	Moving around outside the home and other buildings	47	1.06 (1.33)	27	0.59 (0.84)	0.02
d465	Moving around using equipment	37	0.76 (0.98)	17	0.29 (0.59)	0.03
d4701	Moving around using private motorized transportation	47	1.11 (1.36)	27	0.59 (1.19)	0.03
d4702	Moving around using public motorized transportation	43	3.49 (1.12)	24	2.46 (1.79)	<0.001
d475	Driving	17	3.94 (0.24)	11	3.55 (1.21)	0.21

In seven of the 23 items (d4154, d430, d4601, d4602, d465, d4701, d4702) in the mobility domain, the subjects showed a significant improvement ($p < 0.05$) in level of participation at discharge and six months after discharge. In four of the items (d4104, d4200, d4502, d4503) the improvement in level of participation is worth mentioning ($0.05 > p < 0.1$). All the items in the mobility domain, except changing the sitting position (d4103), showed a positive improvement in participation, although not all significant, from discharge to six months after discharge (Table 4.14).

Table 4.15: Activity profile for mobility in relation to amount and type of assistance at discharge and at six months

Mobility											
ICF code	Activity	<i>n</i> (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	<i>n</i> (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d4100	Changing basic body position: Lying down	47	41 (87%)	0 (0%)	6 (13%)	0 (0%)	27	24 (89%)	0 (0%)	3 (11%)	0 (0%)
d4101	Changing basic body position: Squatting	17	9 (53%)	8 (47%)	0 (0%)	0 (0%)	13	9 (69%)	4 (31%)	0 (0%)	0 (0%)
d4102	Changing basic body position: Kneeling	16	6 (38%)	10 (63%)	0 (0%)	0 (0%)	13	5 (38%)	8 (62%)	0 (0%)	0 (0%)
d4103	Changing basic body position: Sitting	47	40 (85%)	0 (0%)	7 (15%)	0 (0%)	27	22 (81%)	0 (0%)	5 (19%)	0 (0%)
d4104	Changing basic body position: Standing	21	13 (62%)	8 (38%)	0 (0%)	0 (0%)	14	10 (71%)	4 (29%)	0 (0%)	0 (0%)
d4105	Changing basic body position: Bending	39	37 (95%)	2 (5%)	0 (0%)	0 (0%)	23	23 (100%)	0 (0%)	0 (0%)	0 (0%)
d4153	Maintaining a body position: Sitting	47	39 (83%)	8 (17%)	0 (0%)	0 (0%)	27	25 (93%)	2 (7%)	0 (0%)	0 (0%)
d4154	Maintaining a body position: Standing	21	12 (57%)	9 (43%)	0 (0%)	0 (0%)	14	11 (79%)	3 (21%)	0 (0%)	0 (0%)
d4200	Transferring oneself while sitting	47	35 (74%)	3 (6%)	6 (13%)	3 (6%)	27	22 (81%)	1 (4%)	3 (11%)	1 (4%)
d430	Lifting and carrying objects	47	11 (23%)	1 (2%)	35 (74%)	0 (0%)	27	6 (22%)	0 (0%)	21 (78%)	0 (0%)
d440	Unilateral fine hand use	40	40 (100%)	0 (0%)	0 (0%)	0 (0%)	24	24 (100%)	0 (0%)	0 (0%)	0 (0%)
d445	Unilateral hand and arm use	44	44 (100%)	0 (0%)	0 (0%)	0 (0%)	26	26 (100%)	0 (0%)	0 (0%)	0 (0%)
d4500	Walking short distances	20	8 (40%)	12 (60%)	0 (0%)	0 (0%)	14	9 (64%)	5 (36%)	0 (0%)	0 (0%)
d4501	Walking long distances	9	6 (67%)	2 (22%)	1 (11%)	0 (0%)	10	8 (80%)	1 (10%)	1 (10%)	0 (0%)
d4502	Walking on different surfaces	13	7 (54%)	5 (38%)	1 (8%)	0 (0%)	13	8 (62%)	4 (31%)	1 (8%)	0 (0%)
d4503	Walking around obstacles	14	7 (50%)	6 (43%)	1 (7%)	0 (0%)	13	8 (62%)	4 (31%)	1 (8%)	0 (0%)

ICF code	Activity	n (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	n (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d4600	Moving around within the home	44	8 (18%)	32 (73%)	0 (0%)	4 (9%)	27	10 (37%)	16 (59%)	0 (0%)	1 (4%)
d4601	Moving around buildings other than home	22	6 (27%)	15 (68%)	0 (0%)	1 (6%)	27	8 (30%)	14 (52%)	0 (0%)	5 (19%)
d4602	Moving around outside the home and other buildings	44	7 (16%)	21 (48%)	1 (2%)	15 (34%)	27	8 (30%)	11 (41%)	1 (4%)	7 (26%)
d465	Moving around using equipment	37	18 (49%)	0 (0%)	19 (51%)	0 (0%)	17	7 (41%)	0 (0%)	10 (59%)	0 (0%)
d4701	Moving around using private motorized transportation	43	10 (23%)	0 (0%)	30 (70%)	3 (7%)	26	9 (35%)	0 (0%)	17 (65%)	0 (0%)
d4702	Moving around using public motorized transportation	10	2 (20%)	3 (30%)	5 (50%)	0 (0%)	12	5 (42%)	3 (25%)	4 (33%)	0 (0%)
d475	Driving	1	0 (0%)	1 (100%)	0 (0%)	0 (0%)	1	0 (0%)	1 (100%)	0 (0%)	0 (0%)

Activity profile at discharge (n=47)

Although all 47 subjects (100%) were able to perform the activities of lying down (d4100), sitting up (d4103), maintaining sitting (d4153) and transferring oneself (d4200), six (13%), seven (15%), eight (17%) and 12 subjects (26%) respectively could not execute the task without some assistance.

Of all the walking activities, walking long distances (d4501) was the most difficult activity to perform as only nine of 47 subjects (19%) were able to do this. However, of that nine subjects, six (67%) were able to execute the activity without assistance, compared to walking short distances (d4500), walking on different surfaces (d4502) and walking around obstacles (4503) where fewer subjects (40%, 54% and 50% respectively) were able to execute the activity without any assistance.

Of the 47 subjects only 11 subjects (23%) were able to lift and carry objects (d430), while the remaining 36 subjects (77%) needed assistance to execute the task. As only unilateral fine hand use (d440) and unilateral hand and arm use (d445) were tested, all the subjects who can perform the activity could do it without any assistance.

Thirty-six of the 44 subjects (82%) who could move inside their own homes (d4600), were unable to do so without personal and/or non-personal assistance. The majority of the subjects who were able to perform the activities of moving around buildings other than home (d4601) and moving outside the home and other buildings (d4602) needed assistance to execute these activities. Capacity for moving around using equipment i.e. a wheelchair (d465) was fairly poor as not even half of the subjects (18 of 37 subjects or 49%) who could perform this activity were able to do it without any personal assistance.

Capacity for using public transport (d4702) was very low as only two of the 10 subjects (20%) who were able to perform this activity could do it without any assistance. Only one subject of 47 (2%) was able to drive (d475) at discharge and that subject needed assistance to execute the activity (Table 4.15).

Activity profile at six months (n=27)

Although all 27 subjects (100%) were able to perform the activities of lying down (d4100), sitting up (d4103), maintaining sitting (d4153) and transferring oneself (d4200), three (11%), five (19%), two (7%) and five subjects (19%) respectively still needed assistance to execute these tasks.

Of all the walking activities, walking long distances (d4501) was the most difficult activity to perform as only 10 of 27 subjects (37%) were able to do this activity. However, of the 10 subjects, eight (80%) were able to execute the activity without any assistance. For walking short distances (d4500), walking on different surfaces (d4502) and walking around obstacles (4503) fewer subjects (64%, 62% and 62% respectively) were able to execute the activity without any assistance.

All 27 subjects were able to perform the activity of lifting and carrying objects (d430), but only six subjects (22%) had the ability to execute the activity without any assistance. The remaining 21 subjects (78%) needed assistance to execute the task. As only unilateral fine hand use (d440) and unilateral hand and arm use (d445) were tested, all of the subjects who could perform the activity were able to do it without any assistance. For the remainder of the subjects, performance and capacity for this activity was impossible.

Of the 27 subjects who could move inside their own homes (d4600), only 10 (37%) had the capacity to execute the task without any assistance. The majority of the subjects (19/27 or 70% for each activity) who were able to perform the activities of moving around buildings other than home (d4601) and moving outside the home and other buildings (d4602) needed assistance to execute these activities. Capacity for moving around using equipment i.e. a wheelchair (d465) was not so

good, as only seven of the 17 subjects (41%) who could perform this activity were able to do it without any personal assistance.

Capacity for using public transport (d4702) was poor as more than half of the 12 subjects (58%) who were able to perform this activity needed assistance. Only one subject of 27 (4%) was able to drive (d475) at six months after discharge and that subject needed assistance to execute the activity (Table 4.15).

Amount and type of assistance at discharge (n=47) and six months after discharge (n=27)

For the majority of the activities (16/23 or 70%), more subjects needed no assistance at six months after discharge. Seven of the 16 activities (44%) i.e. d4101, d4153, d4501, d4503, d4600, d4602 and d4701 showed an average increase in the number of subjects who needed no assistance of between and including 10% and 19%, and three activities (19%) i.e. d4154, d4500 and d4702 between 20% and 30%. The remaining activities either needed the same amount of assistance (d4102, d440, d445, d475) or more assistance (d4103, d430, d465) six months after discharge.

The type of assistance mainly utilized at discharge and six months after discharge was non-personal assistance (15/23 activities or 65%). Eighty-seven percent (13/15) of the activities for which subjects needed non-personal assistance, showed an improvement at six months. For two of the 15 activities for which the subjects needed non-personal assistance (d4702, d475) the percentages remained unchanged.

Personal assistance was utilized by the subjects for 11 of the 23 activities (48%). For five of the 11 activities (d4100, d4200, d4501, d4701, d4701) the subjects needed less personal assistance at six months, for another five (d4103, d430, d4503, d4602, d465) the subjects needed more personal assistance at six months, and for one activity (d4502) the subjects required the same amount of personal assistance at discharge and at six months.

For four activities (d4200, d4600, d4601, d4602) the subjects utilized personal and non-personal assistance. Of the four activities, only one activity (d4601) required more personal and non-personal assistance by the subjects to perform the activity.

For only two of the 23 activities (d4200, d4602), the subjects reported to have utilized all three types of assistance (Table 4.15).

4.6.2 Activity and participation profile for self care

A summary of the subjects' capacity and performance levels for self care at discharge and six months after discharge is displayed in Tables 4.16 to 4.19. The percentages do not always equal 100% because of rounding.

Table 4.16: Participation profile for self care at discharge (n=47)

Self care					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d510	Washing oneself	37 (79%)	10 (21%)	0 (0%)	0 (0%)
d520	Caring for body parts	40 (85%)	7 (15%)	0 (0%)	0 (0%)
d5300	Toileting: Regulating urination	42 (89%)	5 (11%)	0 (0%)	0 (0%)
d5301	Toileting: Regulating defecation	44 (94%)	3 (6%)	0 (0%)	0 (0%)
d5302	Toileting: Menstrual care	2 (4%)	1 (2%)	0 (0%)	44 (94%)
d540	Dressing	35 (74%)	12 (26%)	0 (0%)	0 (0%)
d550	Eating	42 (89%)	5 (11%)	0 (0%)	0 (0%)
d560	Drinking	44 (94%)	3 (6%)	0 (0%)	0 (0%)
d570	Looking after one's health	32 (68%)	14 (32%)	1 (2%)	0 (0%)

Activities of daily living such as washing oneself (d510), caring for body parts (d520), toileting (d5300, d5301, d5302), dressing, eating and drinking were performed by all the subjects. Performing the activities of washing oneself and dressing appears to be slightly more difficult than the others as 10 (21%) and 12 (26%) of the 47 subjects respectively reported some difficulty with performing these activities.

One subject did not have the necessary knowledge to look after his/her own health (d570), while 14 subjects (32%) had some difficulty with performing this activity (Table 4.16).

Table 4.17 Participation profile for self care at six months (n=27)

Self care					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d510	Washing oneself	23 (85%)	4 (15%)	0 (0%)	0 (0%)
d520	Caring for body parts	23 (85%)	4 (15%)	0 (0%)	0 (0%)
d5300	Toileting: Regulating urination	26 (96%)	1 (4%)	0 (0%)	0 (0%)
d5301	Toileting: Regulating defecation	26 (96%)	1 (4%)	0 (0%)	0 (0%)
d5302	Toileting: Menstrual care	0 (0%)	1 (4%)	0 (0%)	26 (96%)
d540	Dressing	23 (85%)	4 (15%)	0 (0%)	0 (0%)
d550	Eating	25 (93%)	2 (7%)	0 (0%)	0 (0%)
d560	Drinking	27 (100%)	0 (0%)	0 (0%)	0 (0%)
d570	Looking after one's health	18 (67%)	8 (30%)	1 (4%)	0 (0%)

Activities of daily living such as washing oneself (d510), caring for body parts (d520), toileting (d5300, d5301, d5302), dressing, eating and drinking were performed by all the subjects. Only a few subjects (15% or less) reported some difficulty when performing these activities. One subject did not have the necessary knowledge to look after his/her own health (d570), while eight of the remaining 26 subjects (31%) had some difficulty with performing this activity (Table 4.17).

Table 4.18: Difference between participation profile for self care at discharge and six months after discharge

Self-care						
ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P - value
d510	Washing oneself	47	0.34 (0.70)	27	0.22 (0.58)	0.14
d520	Caring for body parts	47	0.23 (0.63)	27	0.19 (0.48)	0.10
d5300	Toileting: Regulating urination	47	0.13 (0.45)	27	0.04 (0.19)	0.23
d5301	Toileting: Regulating defecation	47	0.13 (0.54)	27	0.04 (1.19)	0.30
d5302	Toileting: Menstrual care	-	-	-	-	-
d540	Dressing	47	0.34 (0.67)	27	0.19 (0.48)	0.07
d550	Eating	47	0.19 (0.65)	27	0.15 (0.60)	0.78
d560	Drinking	47	0.09 (0.46)	27	0.00 (0.00)	0.34
d570	Looking after one's health	47	0.72 (1.17)	27	0.70 (1.14)	0.56

In the self care domain for only one item i.e. dressing (d540), the change in level of participation between discharge and six months after discharge, although not statistically significant, is worth mentioning ($p < 0.1$). Meaningful analysis for one item (d5302) was not possible due to inadequate data, as for the majority of the subjects this item was not applicable. Although all of the items showed a positive improvement in participation at six months none was statistically significant (Table 4.18).

Table 4.19: Activity profile for self care in relation to amount and type of assistance at discharge and at six months

Self care											
ICF code	Activity	n (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	n (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Personal and non-personal
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d510	Washing oneself	47	34 (72%)	0 (0%)	13 (28%)	0 (0%)	27	19 (70%)	0 (0%)	8 (30%)	0 (0%)
d520	Caring for body parts	47	28 (60%)	0 (0%)	19 (40%)	0 (0%)	27	18 (67%)	0 (0%)	9 (33%)	0 (0%)
d5300	Toileting: Regulating urination	47	37 (79%)	0 (0%)	10 (21%)	0 (0%)	27	23 (85%)	0 (0%)	4 (15%)	0 (0%)
d5301	Toileting: Regulating defecation	47	35 (74%)	0 (0%)	12 (26%)	0 (0%)	27	22 (81%)	0 (0%)	5 (19%)	0 (0%)
d5302	Toileting: Menstrual care	3	0 (0%)	0 (0%)	3 (100%)	0 (0%)	1	0 (0%)	0 (0%)	1 (100%)	0 (0%)
d540	Dressing	47	36 (77%)	0 (0%)	11 (23%)	0 (0%)	27	20 (74%)	0 (0%)	7 (26%)	0 (0%)
d550	Eating	47	36 (77%)	0 (0%)	8 (17%)	3 (6%)	27	23 (85%)	0 (0%)	2 (7%)	2 (7%)
d560	Drinking	47	41 (87%)	0 (0%)	6 (13%)	0 (0%)	27	25 (93%)	0 (0%)	2 (7%)	0 (0%)
d570	Looking after one's health	46	34 (74%)	0 (0%)	12 (26%)	0 (0%)	26	19 (73%)	0 (0%)	7 (27%)	0 (0%)

Activity profile at discharge (n=47)

Although all the self care activities were performed by all the subjects, a small percentage needed some form of assistance to execute the activities. Of the 47 subjects 34 (72%), 28 (60%), 37 (79%), 35 (74%), 36 (77%), 36 (77%) and 41 (87%) were able to execute the activities of washing (d510), caring for body parts (d520), urination (d5300), defecation (d5301), dressing (d540), eating (d550) and drinking (d560) respectively without any assistance. Of the 46 subjects who were able to look after their own health (d570), 34 subjects (74%) did not need any assistance executing this activity (Table 4.19).

Activity profile at six months (n=27)

Although all the self care activities were performed by all the subjects, a small percentage needed some form of assistance to execute the activities. Of the 27 subjects 19 (70%), 18 (67%), 23 (85%), 22 (81%), 20 (74%), 23 (85%) and 25 (93%) had the capacity to execute the activities of washing (d510), caring for body parts (d520), urination (d5300), defecation (d5301), dressing (d540), eating (d550) and drinking (d560) respectively without any assistance. Of the 26 subjects who were able to look after their own health (d570), 19 subjects (73%) did not need any assistance executing this activity (Table 4.19).

Amount and type of assistance at discharge (n=47) and six months after discharge (n=27)

For five of the nine activities (56%) included in the domestic life domain i.e. d520, d5300, d5301, d550 and d560, more subjects were able to perform these activities without any assistance at six months. The average increase in the number of subjects who needed no assistance to perform these activities at six months is 6.8% (median= 7%).

Subjects for only one activity i.e. eating (d550), utilized personal and non-personal assistance to perform the activity. For the remaining eight activities the subjects needed only personal assistance. None of the activities were performed with non-personal assistance alone.

Of the eight activities for which the subjects utilized only personal assistance, five activities i.e. d520, d5300, d5301, d550 and d560 showed an average increase of 7.2% (median=7%). For the remaining four activities, one activity i.e. menstrual care (d5302), the subjects needed the same amount of personal assistance and for washing (d510), dressing (d540) and looking after own health (d570) an average of 2% of the subjects needed more personal assistance at six months (Table 4.19).

4.6.3 Activity and participation profile for domestic life

A summary of the subjects' capacity and performance levels for domestic life at discharge and six months after discharge is displayed in Tables 4.20 to 4.23. The percentages do not always equal 100% because of rounding.

Table 4.20: Participation profile for domestic life at discharge (n=47)

Domestic life					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d620	Acquisition of goods and services	11 (23%)	2 (4%)	34 (72%)	0 (0%)
d630	Preparing meals	17 (36%)	2 (4%)	17 (36%)	11 (23%)
d640	Doing housework	10 (21%)	5 (11%)	16 (34%)	16 (34%)
d650	Caring for household objects	11 (23%)	3 (6%)	20 (43%)	13 (28%)
d660	Assisting others	5 (11%)	1 (2%)	14 (30%)	27 (57%)

The acquisition of goods and services (d620) was the only activity in the domestic life domain that was applicable for all the subjects. The majority of the subjects (34/47 or 72%) however, could not or had not performed this activity at the time of discharge from the WCRC.

The activities of preparing meals (d630), doing housework (d640) and caring for household objects (d650) were applicable for the majority of the subjects, although at the time of discharge from the WCRC 47% (17/36), 52% (16/31) and 59% (20/34) of the subjects who were performing these activities prior to their SCI, had not been able to perform them.

Assisting others (d660) was the least applicable activity of the domestic life domain and also the activity that the majority of the subjects (70% or 14/20) had complete difficulty in performing at discharge (Table 4.20).

Table 4.21 Participation profile for domestic life at six months (n=27)

Domestic life					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d620	Acquisition of goods and services	25 (93%)	2 (7%)	0 (0%)	0 (0%)
d630	Preparing meals	21 (78%)	2 (7%)	0 (0%)	4 (15%)
d640	Doing housework	14 (52%)	4 (15%)	0 (0%)	9 (33%)
d650	Caring for household objects	19 (70%)	4 (15%)	0 (0%)	4 (15%)
d660	Assisting others	13 (48%)	2 (7%)	0 (0%)	12 (44%)

The acquisition of goods and services (d620) was the only activity in the domestic life domain that is applicable for all the subjects. The majority of the subjects (25/27 or 93%) were able to perform this activity with no difficulty and only one subject (4%) had some difficulty. Of the subjects who were involved with preparing meals (d630), doing housework (d640) and caring for household objects (d650), 91%, 78% and 83% respectively had no difficulty with performing these activities. The majority of the subjects (87%) who were still involved with assisting others (d660) reported no difficulty in doing so (Table 4.21).

Table 4.22: Difference between participation profile for domestic life at discharge and six months after discharge

Domestic life						
ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P - value
d620	Acquisition of goods and services	47	2.98 (1.71)	27	0.22 (0.85)	<0.001
d630	Preparing meals	36	2.03 (1.98)	23	0.13 (0.46)	<0.001
d640	Doing housework	31	2.42 (1.82)	18	0.39 (0.78)	<0.001
d650	Caring for household objects	34	2.47 (1.89)	23	0.39 (0.94)	<0.001
d660	Assisting others	20	2.95 (1.76)	15	0.33 (1.40)	<0.001

All items in the domestic life category showed a highly significant improvement in the level of participation ($p < 0.001$) from discharge to six months after discharge (Table 4.22).

Table 4.23: Activity profile for domestic life in relation to amount and type of assistance at discharge and at six months

Domestic life											
ICF code	Activity	<i>n</i> (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	<i>n</i> (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Personal and non-personal
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d620	Acquisition of goods and services	13	4 (31%)	0 (0%)	9 (69%)	0 (0%)	26	9 (35%)	0 (0%)	17 (65%)	0 (0%)
d630	Preparing meals	19	11 (58%)	0 (0%)	8 (42%)	0 (0%)	23	16 (70%)	0 (0%)	7 (30%)	0 (0%)
d640	Doing housework	15	5 (33%)	0 (0%)	10 (67%)	0 (0%)	18	8 (44%)	0 (0%)	10 (56%)	0 (0%)
d650	Caring for household objects	14	2 (14%)	0 (0%)	12 (86%)	0 (0%)	23	6 (26%)	0 (0%)	17 (74%)	0 (0%)
d660	Assisting others	6	3 (50%)	0 (0%)	3 (50%)	0 (0%)	14	5 (36%)	0 (0%)	9 (64%)	0 (0%)

Activity profile at discharge (n=47)

The majority of the subjects (9/13 or 69%) who were able to perform the activities of acquisition of goods and services (d620), doing housework (d640) (10/15 or 67%), and caring for household objects (d650) (12/14 or 86%) were not able to do these activities without assistance. Capacity for preparing meals (d630) was better, as 11 of the 19 subjects (58%) who were able to perform this activity could do it without any assistance (Table 4.23).

Activity profile at six months (n=27)

The majority of the subjects who were able to perform the activities of acquisition of goods and services (d620) (17/26 or 65%), doing housework (d640) (10/18 or 56%), and caring for household objects (d650) (17/23 or 74%) are not able to do these activities without assistance. Capacity for preparing meals (d630) was much better, as 16 of the 23 subjects (70%) who were able to perform this activity could do it without any assistance (Table 4.23).

Amount and type of assistance at discharge (n=47) and six months after discharge (n=27)

For the activities of acquisition of goods and services (d620), preparing meals (d630), doing housework (d640) and caring for household objects (d650), an average of 9.8% more subjects (median=11.5%) were able to perform the activities without any assistance at six months. With regard to assisting others (d660), 14% more subjects were able to perform the activity at discharge compared to the percentage at six months.

For all of the activities the subjects utilized personal assistance only (Table 4.23).

4.6.4 Activity and participation profile for interpersonal interactions and relationships

A summary of the subjects' capacity and performance levels for interpersonal interactions and relationships at discharge and six months after discharge is displayed in Tables 4.24 to 4.27. The percentages do not always equal 100% because of rounding.

Table 4.24: Participation profile for interpersonal interactions and relationships at discharge (n=47)

Interpersonal interactions and relationships					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d750	Informal social relationships	28 (60%)	14 (30%)	5 (11%)	0 (0%)
d760	Family relationships	42 (89%)	4 (9%)	1 (2%)	0 (0%)
d770	Intimate relationships	21 (45%)	5 (11%)	21 (45%)	0 (0%)

The subjects' relationships with family members (d760) appeared to be good as 89% (42/47) reported no difficulty with performing this activity. Although only 5 subjects (11%) reported complete difficulty with maintaining informal social relationships (d750), these types of relationships are more difficult to maintain, as 33% (14/42) of the remaining subjects reported some difficulty with performing this activity compared to 9% (4/46) in family relationships.

However, maintaining intimate relationships (d770) were the most difficult, as 45% of the subjects (21/47) were not able to perform this activity at discharge (Table 4.24).

Table 4.25: Participation profile for interpersonal interactions and relationships at six months (n=27)

Interpersonal interactions and relationships					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d750	Informal social relationships	16 (59%)	8 (30%)	3 (11%)	0 (0%)
d760	Family relationships	22 (81%)	4 (15%)	1 (4%)	0 (0%)
d770	Intimate relationships	16 (59%)	0 (0%)	11 (41%)	0 (0%)

The subjects' relationships with family members (d760) appeared to be good as 81% (22/27) reported no difficulty with maintaining these family relationships. One subject (4%) had no contact with his family anymore. Although the majority of subjects (16/27 or 59%) had good informal relationships (d750), eight subjects (30%) struggled to maintain informal relationships and three subjects (11%) were unable to maintain them.

Intimate relationships (d770) were important to all the subjects, however only 16 of the 27 subjects (59%) were able to maintain this relationship (Table 4.25).

Table 4.26: Difference between participation profile for interpersonal interactions and relationships at discharge and six months

Interpersonal interactions and relationships						
ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P-value
d750	Informal social relationships	47	1.04 (1.47)	27	1.00 (1.47)	0.75
d760	Family relationships	47	0.32 (0.96)	27	0.56 (1.22)	0.12
d770	Intimate relationships	47	2.06 (1.93)	27	1.63 (2.00)	0.31

In this domain participation in informal social relationships (d750) and intimate relationships (d770) showed a positive, although not significant, improvement at six months. However, maintaining family relationships (d760) was more difficult at six months compared to at discharge (Table 4.26).

Table 4.27: Activity profile for interpersonal interactions and relationships in relation to amount and type of assistance at discharge and at six months

Interpersonal interactions and relationships											
ICF code	Activity	<i>n</i> (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	<i>n</i> (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Personal and non-personal
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d750	Informal social relationships	42	42 (100%)	0 (0%)	0 (0%)	0 (0%)	24	24 (100%)	0 (0%)	0 (0%)	0 (0%)
d760	Family relationships	46	46 (100%)	0 (0%)	0 (0%)	0 (0%)	27	27 (100%)	0 (0%)	0 (0%)	0 (0%)
d770	Intimate relationships	26	24 (92%)	0 (0%)	2 (8%)	0 (0%)	16	16 (100%)	0 (0%)	0 (0%)	0 (0%)

Activity profile at discharge (n=47)

Capacity for maintaining informal social relationships (d750) and family relationships (d760) was excellent, as 100% of the subjects who were able to perform this activity did not need any assistance. Two of the 26 subjects (8%) who were still involved in intimate relationships (d770) needed assistance to maintain these relationships (Table 4.27).

Activity profile at six months (n=27)

Capacity for maintaining informal social relationships (d750), family relationships (d760) and intimate relationships (d770) was excellent, as 100% of the subjects who were able to perform these activities do not need any assistance (Table 4.27).

Amount and type of assistance at discharge (n=47) and six months after discharge (n=27)

All of the subjects at discharge and at six months after discharge were able to maintain informal social relationships (d750) and family relationships (d760) without any assistance. At discharge 8% (2/26 subjects) needed personal assistance with their intimate relationships (d770), however, at six

months no subjects needed any assistance. No other types of assistance were utilized for activities in this domain (Table 4.27).

4.6.5 Activity and participation profile for major life areas and community, social and civic life

A summary of the subjects' capacity and performance levels for major life areas and community, social and civic life at discharge and six months after discharge is displayed in Tables 4.28 to 4.31. The percentages do not always equal 100% because of rounding.

Table 4.28: Participation profile for major life areas and community, social and civic life at discharge (n=47)

ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
Major life areas					
d820	School education	0 (0%)	0 (0%)	2 (4%)	45 (96%)
d850	Remunerative employment	2 (4%)	0 (0%)	45 (96%)	0 (0%)
d855	Non-remunerative employment	0 (0%)	0 (0%)	5 (11%)	42 (89%)
d870	Economic self-sufficiency	6 (13%)	2 (4%)	39 (83%)	0 (0%)
Community, social and civic life					
d920	Recreation and leisure	2 (4%)	8 (17%)	37 (79%)	0 (0%)
d930	Religion and spirituality	8 (17%)	2 (4%)	23 (49%)	14 (30%)

Schooling (d820) was not applicable for 96% (45/47) of the subjects. The remaining two subjects wanted to continue their school education, but were not able to at the time of discharge. Two of the subjects (4%) were employed (d850) at discharge, while the majority of the subjects (96%) did not succeed in either maintaining employment or finding new employment. The majority of the subjects (89% or 42/47) were not involved in non-remunerative employment (d855) at the time of their SCI. To be economically self-sufficient (d870) was very difficult for most of the subjects as 83% (39/47) had no income at discharge.

Although all the subjects were involved in recreation and leisure activities (d920) prior to their SCI, 37 of the 47 subjects (79%) did not manage to perform at this level at the time of discharge from the WCRC. Of the 33 subjects who were involved in religious or spiritual activities (d930) prior to their injury, only 10 subjects (30%) managed to perform this activity at discharge (Table 4.28).

Table 4.29 Participation profile for major life areas and community, social and civic life at six months (n=27)

Major life areas					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d820	School education	1 (4%)	0 (0%)	0 (0%)	26 (96%)
d850	Remunerative employment	2 (7%)	1 (4%)	24 (89%)	0 (0%)
d855	Non-remunerative employment	0 (0%)	0 (0%)	3 (11%)	24 (89%)
d870	Economic self-sufficiency	19 (70%)	1 (4%)	7 (26%)	0 (0%)
Community, social and civic life					
ICF code	Activity	No difficulty	Some difficulty	Complete difficulty	Not applicable
		0	1+2+3	4	9
d920	Recreation and leisure	7 (26%)	10 (37%)	10 (37%)	0 (0%)
d930	Religion and spirituality	15 (56%)	0 (0%)	5 (19%)	7 (26%)

Schooling (d820) was not applicable for 96% (26/27) of the subjects. The remaining one subject had no difficulty in continuing his schooling career. The majority of the subjects (24/27 or 89%) were not employed (d850) six months after discharge from the WCRC. The majority of the subjects (89% or 24/27) were never involved in non-remunerative employment (d855), while the three subjects (11%) who were involved in this activity at the time of injury had not been able to perform

this activity six months after discharge. Of the 27 subjects seven (26%) were not economically sufficient (d870).

Although all 27 subjects were involved in recreation and leisure activities (d920) prior to their SCI, only 17 of the subjects (63%) were able to participate in these activities at six months. Although 20 subjects (74%) had a desire to be involved in religious and spiritual activities (d930), five subjects (19%) were unable to perform this activity at six months after discharge (Table 4.29).

Table 4.30: Difference between participation profile for major life areas and community, social and civic life at discharge and at six months

Major life areas						
ICF code	Activity	d/c (n)	d/c average (sd)	6/12 (n)	6/12 Average (sd)	P - value
d820	School education	-	-	-	-	-
d850	Remunerative employment	47	3.83 (0.82)	27	3.59 (1.19)	0.15
d855	Non-remunerative employment	-	-	-	-	-
d870	Economic self-sufficiency	47	3.45 (1.35)	27	1.15 (1.81)	<0.001
Community, social and civic life						
d920	Recreation and leisure	47	3.55 (1.02)	27	2.30 (1.66)	<0.001
d930	Religion and spirituality	33	2.91 (1.76)	20	1.00 (1.78)	<0.001

Improvement in level of participation for ‘economic self-sufficiency’ (d870), ‘recreation and leisure’ (d920) and ‘religion and spirituality’ (d930) was highly significant ($p < 0.001$). Meaningful analysis for two items (d820, d855) was not possible due to inadequate data as for the majority of the subjects this item was not applicable (Table 4.30).

Table 4.31: Activity profile for major life areas and community, social and civic life in relation to amount and type of assistance at discharge and at six months

Major life areas											
ICF code	Activity	<i>n</i> (d/c)	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	<i>n</i> (6/12)	No assistance needed	Non-personal assistance	Personal assistance	Personal and non-personal
			d/c	d/c	d/c	d/c		6/12	6/12	6/12	6/12
d820	School education	0	0 (0%)	0 (0%)	0 (0%)	0 (0%)	1	1 (100%)	0 (0%)	0 (0%)	0 (0%)
d850	Remunerative employment	2	2 (100%)	0 (0%)	0 (0%)	0 (0%)	3	3 (100%)	0 (0%)	0 (0%)	0 (0%)
d855	Non-remunerative employment	0	0 (0%)	0 (0%)	0 (0%)	0 (0%)	0	0 (0%)	0 (0%)	0 (0%)	0 (0%)
d870	Economic self-sufficiency	8	6 (75%)	0 (0%)	2 (25%)	0 (0%)	20	20 (100%)	0 (0%)	0 (0%)	0 (0%)
Community, social and civic life											
d920	Recreation and leisure	10	4 (40%)	0 (0%)	6 (60%)	0 (0%)	17	9 (53%)	0 (0%)	8 (47%)	0 (0%)
d930	Religion and spirituality	10	6 (60%)	0 (0%)	4 (40%)	0 (0%)	15	10 (67%)	0 (0%)	5 (33%)	0 (0%)

Activity profile at discharge (n=47)

Both subjects who were involved in remunerative employment (d850) at discharge did not need any assistance with this activity. Although performance for economic self-sufficiency (d870) was poor, capacity was good as six of the eight subjects (75%) did not need any financial assistance.

Although an equal number of subjects were involved in recreation and leisure activities (d920%) and practising religion and spirituality (d930), more subjects needed assistance for recreation and leisure (60%) compared to religion and spirituality (40%) (Table 4.31).

Activity profile at six months (n=27)

All three subjects who were involved in remunerative employment (d850) at discharge did not need any assistance with this activity. Of the 20 subjects who were economically self-sufficient (d870) six months after discharge, 100% did not need further financial assistance.

Only 15 of the 27 subjects (56%) are able to practice their religion (d930) compared to 17 of the 27 subjects (63%) who were able to engage in recreational and leisure activities (d920) at six months after discharge. However, fewer subjects (5/15 or 33%) needed assistance to take part in religious activities compared to recreational activities (8/17 or 47%) (Table 4.31).

Amount and type of assistance at discharge (n=47) and six months after discharge (n=27)

None of the subjects who were employed (d850) required any assistance to perform this activity at discharge and at six months. At discharge 75% (6/8) of the subjects needed no assistance to be economically self-sufficient (d870), while the remaining 25% needed personal assistance. At six months all of the subjects were financially independent.

More subjects (13% and 7% respectively) who were involved in recreational and leisure activities (d920) and religious and spiritual activities (d930) were able to perform these activities without any assistance at six months. Both activities showed a decrease in the number of subjects who needed personal assistance to perform these activities at six months.

Personal assistance only was utilized for all of the activities in the major life areas and community, social and civic life domains (Table 4.31).

SECTION THREE

This section reports on the environmental factors identified as barriers by the sample at six months after discharge from the WCRC.

4.7 ENVIRONMENTAL FACTORS

The ICF consists of two parts i.e. Functioning and Disability and Contextual Factors. Contextual Factors represent the complete background of an individual's life and living (WHO, 2001). Environmental factors form part of the Contextual Factors and according to the ICF "make up the physical, social and attitudinal environment in which people live and conduct their lives" (WHO, 2001:171). These factors can have a positive (facilitator) or negative (barrier) influence on the individual's performance as a member of the society (WHO, 2001). The different domains of the

environmental factors component addressed in this study i.e. products and technology, support and relationships, attitudes and services, systems and policies will be displayed separately.

A summary of the environmental factors identified as barriers by the 27 subjects at six months after discharge from the WCRC are displayed in Tables 4.32 to 4.35. Codes from zero (no barrier) to four (complete barrier) were attached to indicate the extent to which an environmental factor serves as a barrier when performing activities of daily life in the subject's current environment. A code of nine was attached if the environmental factor was not applicable or was not experienced. However, for analysis purposes codes one (mild barrier), two (moderate barrier) and three (severe barrier) are combined into one category i.e. some barrier. The adaptation of the original scale will not affect the results. Complete data for environmental factors can be seen in Appendix XIX.

4.7.1 Products and technology

Table 4.32: Products and technology identified as barriers (n=27)

Products and technology					
ICF code	Environmental factor	No barrier	Some barrier	Complete barrier	Not applicable
		0	1+2+3	4	9
e110	Products or substances for personal consumption	23 (85%)	4 (15%)	0 (0%)	0 (0%)
e115	Products and technology for personal use in daily living	26 (96%)	0 (0%)	1 (4%)	0 (0%)
e120	Products and technology for personal indoor and outdoor mobility and transportation	21 (78%)	5 (19%)	1 (4%)	0 (0%)
e125	Products and technology for communication	25 (93%)	1 (4%)	1 (4%)	0 (0%)
e130	Products and technology for education	1 (4%)	0 (0%)	0 (0%)	26 (96%)
e135	Products and technology for employment	3 (11%)	1 (4%)	5 (19%)	18 (67%)
e140	Products and technology for culture, recreation and sport	14 (52%)	1 (4%)	2 (7%)	10 (37%)
e145	Products and technology for the practice of religion and spirituality	14 (52%)	1 (4%)	0 (0%)	12 (44%)

ICF code	Environmental factor	No barrier	Some barrier	Complete barrier	Not applicable
		0	1+2+3	4	9
e150	Design, construction and building products and technology of buildings for public use	18 (67%)	8 (30%)	0 (0%)	1 (4%)
e155	Design, construction and building products and technology of buildings for private use	23 (85%)	4 (15%)	0 (0%)	0 (0%)
e160	Products and technology of land development	18 (67%)	6 (22%)	2 (7%)	1 (4%)

Products and technology are “about the natural or human-made products or systems of products, equipment and technology in an individual’s immediate environment that are gathered, created, produced or manufactured” (WHO, 2001:173).

In the category “Products and technology” the majority of the subjects (more than 50%) reported most of the environmental factors (e110, e115, e120, e125, e140, e145, e150, e155, e160) as no barrier to their everyday functioning. Although the number of subjects who identified products and technology for culture, recreation and sport (e140) and for the practice of religion and spirituality (e145) as no barrier appears to be quite low, it is still 82% (14/17 subjects) and 93% (14/15 subjects) of the total number of subjects who were involved in this activity prior to their SCI. Sixty-nine percent of the applicable subjects identified the environmental factors of design, construction and building products and technology of buildings for public use (e150) and products and technology for land development (e160) as not being a barrier. Products and technology for education (e130), employment (e135) and assets (e165) were not applicable for the majority of the subjects, as they were not productively active and did not own any financial or tangible assets. A significant number of subjects identified products and technology for personal indoor and outdoor mobility and transportation (n=5), employment (n=6), design and construction of buildings for public use (n=8) and land development (n=6) as some barrier (Table 4.32).

4.7.2 Support and relationships**Table 4.33: Support and relationships identified as barriers (n=27)**

Support and relationships					
ICF code	Environmental factor	No barrier	Some barrier	Complete barrier	Not applicable
		0	1+2+3	4	9
e310	Immediate family	25 (93%)	1 (4%)	1 (4%)	0 (0%)
e315	Extended family	15 (56%)	0 (0%)	4 (15%)	8 (30%)
e320	Friends	17 (63%)	5 (19%)	5 (19%)	0 (0%)
e325	Acquaintances, peers, colleagues, neighbors and community members	22 (91%)	1 (4%)	1 (4%)	3 (11%)
e330	People in positions of authority	7 (26%)	0 (0%)	0 (0%)	20 (74%)
e340	Personal care providers and personal assistants	3 (11%)	0 (0%)	0 (0%)	24 (89%)
e355	Health professionals	27 (100%)	0 (0%)	0 (0%)	0 (0%)

The category “Support and relationships” is about the amount of physical and/or emotional support provided by people or animals in their home, work place, school or at play, or in other aspects of the subjects’ daily activities (WHO, 2001).

Health professionals (e355) (27/27 or 100%), immediate family (e310) (25/27 or 93%), neighbours (e325) (22/24 or 92%) are the most supportive. Although friends (e329) and extended family members (e315) are also fairly supportive, five (19%) and four (21%) subjects respectively did not receive any support from these people. For the majority of the subjects, the support received from people in positions of authority (e330) (74%) and personal care providers and assistants (e340) (89%) was not applicable (Table 4.33).

4.7.3 Attitudes

Table 4.34: Attitudes identified as barriers (n=27)

Attitudes					
ICF code	Environmental factor	No barrier	Some barrier	Complete barrier	Not applicable
		0	1+2+3	4	9
e410	Individual attitudes of immediate family members	24 (89%)	2 (7%)	1 (4%)	0 (0%)
e415	Individual attitudes of extended family members	15 (56%)	0 (0%)	4 (15%)	8 (30%)
e420	Individual attitudes of friends	17 (63%)	5 (19%)	0 (0%)	5 (19%)
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	21 (78%)	2 (7%)	0 (0%)	4 (15%)
e430	Individual attitudes of people in positions of authority	7 (26%)	0 (0%)	0 (0%)	20 (74%)
e440	Individual attitudes of personal care providers and personal assistants	3 (11%)	0 (0%)	0 (0%)	24 (89%)
e450	Individual attitudes of health professionals	22 (81%)	5 (19%)	0 (0%)	0 (0%)
e460	Societal attitudes	18 (67%)	9 (33%)	0 (0%)	0 (0%)

The category “Attitudes”: “is about attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs” (WHO, 2001:190). It is about the specific or general opinions or beliefs of people who influence individual behaviour towards other people (WHO, 2001).

The majority of the subjects did not perceive the attitudes of neighbours (e425) (78%), immediate family members (e410) (89%), health professionals (e450) (81%), extended family members (e415)(15/19 subjects or 79%) and society (e460) (67%) to be a barrier. However, a significant number of subjects (33%) did report the attitudes of society (e460) as some barrier. Although 17 subjects (63%) were satisfied with the attitudes of friends (e420), five subjects (19%) reported not

having any friends and five subjects (19%) reported it as some barrier. Attitudes of people in positions of authority (e430), personal care providers and assistants were not applicable for the majority of the subjects as they were not supported by them (Table 4.34).

4.7.4 Services

Table 4.35: Services identified as barriers (n=27)

Services					
ICF code	Environmental factor	No barrier	Some barrier	Complete barrier	Not applicable
		0	1+2+3	4	9
e5250	Housing services	4 (15%)	0 (0%)	2 (7%)	21 (78%)
e5300	Utilities services	26 (96%)	0 (0%)	1 (4%)	0 (0%)
e5350	Communication services	26 (96%)	1 (4%)	0 (0%)	0 (0%)
e5400	Transportation services	14 (52%)	3 (11%)	10 (37%)	0 (0%)
e5450	Civil protection services	2 (7%)	1 (4%)	1 (4%)	23 (85%)
e5550	Associations and organizational services	0 (0%)	0 (0%)	0 (0%)	27 (100%)
e5700	Social security services	17 (63%)	1 (4%)	3 (11%)	6 (22%)
e5750	General social support services	0 (0%)	0 (0%)	27 (100%)	0 (0%)
e5800	Health services	24 (89%)	3 (11%)	0 (0%)	0 (0%)
e5850	Education and training services	1 (4%)	0 (0%)	26 (96%)	0 (0%)
e5900	Labour and employment services	2 (7%)	0 (0%)	3 (11%)	22 (81%)

For the category “Services, systems and policies”, only services were evaluated as none of the subjects had any knowledge of systems and policies that control and monitor services (systems) or the governing and regulation of services (policies). Services “provide benefits, structured programmes and operations, in various sectors of society, designed to meet the need of individuals” (WHO, 2001:192).

Twenty-six of the subjects (96%) reported utility (e5300) and communication services (e5350) as no barrier. For 21 subjects housing services were not applicable. Of the 21 subjects for whom social security services (e5700) were applicable, 17 (63%) did not experience these services as a barrier. Three subjects (11%) however, reported this service as a complete barrier. For 14 subjects (52%) transportation services (e5400) acted as no barrier and 10 subjects (37%) as a complete barrier. Associations and organizational services were not applicable for all 27 subjects (100%), social support services (e5700) for 26 subjects (96%), civil protection services (e5450) for 23 subjects (85%) labour and employment services (e5900) for 22 subjects (81%) and housing services (e5250) for 21 subjects (78%) (Table 4.35).

4.8 CONCLUSION

According to this study, a person sustaining a traumatic SCI in the Cape Metropolitan area of the Western Cape Province is most likely to be a male, young (20 to 29 years), of the Black or Coloured race, with a grade eight to ten level of education and living in the Cape Flats suburbs. The leading cause of acute traumatic SCI was found to be acts of violence accounting for 58% of the subjects followed by road traffic accidents. Regarding the medical characteristics of the sample the majority of the subjects were paraplegic and had incomplete lesions. The severity of the spinal cord involvement changed from discharge (majority ASIA A) to six months after discharge (majority ASIA D). The most common secondary complication found was pain, which was present on admission, at discharge and at six months after discharge.

The results of this study indicated that basic functional activities in the mobility and self-care domains were performed with or without assistance by all the subjects at discharge and at six months after discharge. The ability to execute these activities without any assistance improved at six months, except for washing and dressing, moving into the sitting position, lifting and carrying objects and moving around using a wheelchair. At discharge very few subjects were involved in domestic, religious, recreational and productive activities. Although the majority of the subjects were integrated at domestic and community level at six months after discharge, a significant percentage were still not participating in community activities. Only 11% of the subjects were employed at six months after discharge.

Inaccessibility of public transport, the lack of recreational and sport facilities, lack of social support structures in the community and inadequate financial resources were the main environmental barriers experienced by these individuals.

CHAPTER 5: DISCUSSION

The findings of the study are discussed in this chapter. When appropriate, reference to the literature is made to link the outcomes of this study to other research in this field. Due to a paucity of information on SCI in South Africa in general and aspects researched in this study, reference will be made to available information on physical disability in this country. Regarding the demographic and socio-economic characteristics, results will be discussed in the context of the situation in South Africa, the Western Cape province and more specifically the Cape Metropole region.

The results will be discussed in three main sections. In the first section findings on the demographic, medical and socio-economic characteristics of the subjects and the living environment after discharge are discussed. In the second section findings are discussed on the activity and participation profile of the subjects at discharge and at six months after discharge from the WCRC. The second section also includes findings on the comparisons of outcomes made at these different points in time, i.e. on discharge and at the six month follow-up point. The activity profile will be discussed in terms of the amount of assistance utilized to execute activities plus elaboration on the amount and type of assistance needed. In the third section, findings on the environmental factors identified as barriers by the subjects will be discussed.

5.1 THE STUDY POPULATION AND SAMPLE

The study population was defined as all adults with traumatic SCI who were discharged from the WCRC after completion of rehabilitation. For transport reasons only patients who were discharged to the Cape Metropole were considered for the study. According to existing medical records, 81% of all adults with traumatic SCI admitted to the WCRC within a 12-month period, are from the Cape Metropole (Cloete, 2007). As consecutive sampling was used for this study, the study population was sufficiently represented and the results can therefore be generalised to the population of people with SCI as a whole who have received rehabilitation within the WCRC.

SECTION ONE

Findings on demographic-, medical- and socio-economic characteristics and the living environment after discharge will be discussed in this section. The sample size for this section equals 47 subjects on admission and discharge and 27 subjects at the six month follow-up date.

5.2 DEMOGRAPHIC CHARACTERISTICS

5.2.1 Age

Age at the time of the SCI showed a unimodal age distribution with a peak found in the 20 to 29 years age group (Figure 4.1). Internationally the figures are similar to these findings. Earlier studies conducted by Chen and Lien (1985), Biering-Sorensen *et al.* (1990), Hart and Williams (1994) and Karamehmetoglu *et al.* (1995) showed a peak occurrence in age distribution ranging from 15 to 24 years to 16 to 30 years, but with a gradual decrease thereafter. However, a number of more recent studies on traumatic SCI show a bimodal age distribution with peaks found in younger adults between 15 and 29 and a second peak in older adults (65 years and older) (van den Berg *et al.*, 2010; Pickett *et al.*, 2006; Burt, 2004). According to a systematic review on the incidence of traumatic SCI conducted by van den Berg *et al.* (2010), the peak occurrence in young adults was mainly due to motor vehicle accidents, and the second peak in people aged 65 years and older mainly due to falls on level ground. The occurrence of a second peak in people over 65 years, found in most studies published more recently and not in older studies, can possibly be explained by methodological differences, an increase in number of elderly people who survive the acute stage of SCI and/or an increase in the worldwide population of people older than 65 years. This study did not provide any information regarding a possible peak in occurrence of traumatic SCI in this age group and could therefore not confirm the bimodal age distribution in traumatic SCI found in most international studies. It is unclear why persons representing this age group (65 years and older) were not found in this study. Possible reasons for this could be that older people are not referred for rehabilitation at the WCRC, but rather to chronic care facilities or old age homes. There might be an assumption that their prognosis for successful rehabilitation is not as good as “younger” people due to the presence of co-morbidities, or that resources should rather be allocated elsewhere as they cannot contribute economically anymore. It is also possible that the WCRC gives preference to people who are likely to be more successful with rehabilitation. These aspects should however be investigated.

The peak occurrence of traumatic SCI in young adults is expected as people of this age have a much more active lifestyle with a higher risk of trauma. According to the 2001 National Census (SSA, 2005), 56.1% of the population in Western Cape province were aged 29 years or younger, which could possibly explain the large number of subjects in the 20 to 29 years age group found in this study. This result is also corroborated by an epidemiological study on SCI in South Africa conducted by Hart and Williams (1994) where 46% of the patients (236/616) were in the age group 20 to 29 years. However, caution should be applied in comparing these results, as the 1994 study by

Hart and Williams included non-traumatic SCI, although a very small percentage (11%). Although it is mentioned that the main non-traumatic cause of SCI in their study is spinal tuberculosis, the age distribution of these cases is not known. No other statistics on the epidemiology of SCI in South Africa could be found to compare with the findings of the current study.

The mean age of 31.7 years (Figure 4.2) found in this study is slightly lower than some international figures for mean age at onset of SCI, but very similar to others. Lan *et al.* (1993) reported a mean age of 45 years in a rural area of Taiwan, which was significantly higher than the mean age of 35 years reported by Chen and Lien (1985) in an urban area of Taiwan. This was attributed to the unequal population compositions of the two areas. Pickett *et al.* (2006) reported a mean age of 42.2 years (SD 20.9). Dawodu (2001) reported the mean age of onset of SCI as 31.7 years, which is exactly the same as for this study. Although the mean age of the subjects, in the study conducted by Hart and Williams (1994) is not known, the age distribution of the subjects was very similar to this study.

It is evident that the mean age of patients at onset of SCI is slowly increasing. According to NSCISC (2011), there has been an increase in the mean age at time of injury in the United States since 1973. From 1973 to 1997 the mean age at injury was 28.7 years. Since 2005 the mean age at injury has increased to 40.7 years (NSCISC, 2011).

The increase in mean age of the general population of the United States of nine years since the mid 1970s, could explain the increase in mean age at injury. Other possible reasons for this trend, as mentioned by the NSCISC (2011), might include changes in referral patterns, survival rates of older people at the scene of the accident or age-specific incidence rates. According to Ho *et al.* (2007) the increase in mean age at injury has been found in all etiology groups with the exception of violence, but possible reasons for this were not mentioned.

As no information is available on the mean age at time of SCI in South Africa, it is not possible to determine whether this gradual increase in mean age at time of SCI is true for traumatic SCI in South Africa.

5.2.2 Gender

In this study 91% of the subjects were men and 9% women (Figure 4.3). According to the 2001 National Census (SSA, 2005) the gender distribution of the Cape Metropole is 48% males and 52% females. The prevalence of all types of disability in this region is 4% for men and 3.5 % for women, whereas for physical disability which includes SCI, the prevalence is 1.2% for men and 0.9% for women (SSA, 2005). With an almost equal gender distribution in the Cape Metropole, one would

have expected a much more equal distribution of men and women in this study. The 10.8:1 male to female ratio could be attributed to the etiological findings of this study, where acts of violence accounted for the majority of the injuries (58%). According to Burt (2004), intentional violence is approximately 20 times more common in men than in women. This correlates with the findings of Hart and Williams (1994), who found a male to female ratio of 4:1 in their SCI cohort, and the main cause of injury to be violence-related. These results should again be cautiously compared, as non-traumatic pathology was present in 11% of the cases in the Hart and Williams study.

No other information on gender ratios in SCI in South Africa could be found to compare with the findings of this study.

The fact that the majority of traumatic SCI are sustained by males, as in this study, correlates with the findings of other studies (Dawodu, 2007; Sekhon & Fehlings, 2001; Karamehmetoglu *et al.*, 1995; Hart & Williams, 1994; Biering-Sorensen *et al.*, 1990; Chen & Lien, 1985), however, the male to female ratios, ranging from 3 to 4:1 reported in these studies, are much smaller than the findings in this study (10.8:1). Although the majority of SCI are sustained by men (80 to 85%), the percentage of females has increased since the 1970s, from 18,2% between 1973 and 1979 to 21% between 2000 and 2003 (Ho *et al.*, 2007). Wyndaele and Wyndaele (2006) confirm this trend in that the male to female ratio has decreased from 4.8:1 in 1995 to a current ratio of 3.8:1. Whether this is true for South Africa is not known due to a paucity of information on this matter.

5.2.3 Race

Statistics South Africa or SSA (2005) continues to classify people by racial group in order to monitor progress in moving away from the discriminations of the past. By including race as part of the demographic characteristics of the sample, the study can provide some insight into the utilization of health, and specifically rehabilitation, services in the Western Cape, by the previously disadvantaged population groups. It is important to note that membership of a racial group is now based on self-perception and self-classification and not on a legal definition (SSA, 2005).

The results of this study showed that the majority of the subjects are from the Coloured racial group, followed by the Black, White and Asian/Indian racial groups (Figure 4.4). According to the 2001 National Census (SSA, 2005), 53.9% of the population of the Western Cape were Coloured, 26.7% Black, 18.4% White, 1% Asian/Indian. In 2001, a physical disability, which included SCI, was reported for 53 752 persons of which 59% were Coloured, 21.9% Black, 18.5% White and 0.7% Indian/Asian (SSA, 2005), which reflects the racial distribution of the population in the Western Cape. The results of this study regarding incidence of traumatic SCI by racial group

(Figure 4.4), partially reflect the actual racial distribution in the Western Cape in that the highest incidence is found in the majority race group and the lowest incidence in the minority race group. This is similar to the United States where the incidence of SCI per racial group is also a reflection of the actual racial distribution, in that the highest incidence is found in the White majority racial group and the lowest incidence in the Native American minority group (Dawodu, 2007; United States Census Bureau (USCB), 2010). The higher incidence of SCI found in the Black racial group and the lower incidence found in the White racial group, compared to the actual racial distribution of the Western Cape, can be due to differences in socio-economic status, as the majority of the subjects in this study reside in the poverty-stricken and crime-infested Cape Flats suburbs (Figure 4.5) where the population mainly consists of people from the Black and Coloured racial groups (Williams, 1996). People living in the Cape Flats suburbs are more prone to sustain a SCI through acts of violence which was found to be the main cause of traumatic SCI in this study (Figure. 4.6).

The WCRC is the only government rehabilitation institution in the Western Cape and provides services to the disadvantaged people in the Western Cape. According to the 2001 National Census (SSA, 2005), 60.2% of the White population of the Western Cape are employed, compared to a lower employment rate of Black (37.3%) and Coloured (50.1%) people respectively. Therefore, for socio-economic reasons it is possible that more Black and Coloured people will use a public facility such as the WCRC than White people. This could have contributed to the large number of Black and Coloured subjects in this study. The only other epidemiology study, conducted in South Africa on SCI by Hart and Williams (1994), did not investigate racial distribution.

5.2.4 Residential address

This study showed that the majority of the subjects reside in the Cape Flats suburbs of the Cape Metropole (Figure 4.5), which explains the large percentage of Black and Coloured subjects found in this study, since the Cape Flats suburbs became home to people the apartheid government classified as non-White. Over a million people of colour were relocated to the Cape Flats suburbs during the 1950s in terms of the infamous Group Areas Act (Williams, 1996).

5.3 MEDICAL CHARACTERISTICS

5.3.1 Etiology

In this study the leading cause of acute traumatic SCI was acts of violence accounting for 58%, followed by road traffic accidents (Figure 4.6).

These findings are similar to the study conducted by Hart and Williams (1994) at the Natalspruit Hospital where the most common cause of traumatic SCI was violent acts at 56%, followed by road traffic accidents at 25%. Violent acts included gunshots and stabbing, where gunshots (36%, compared to 28% in this study) accounted for more injuries than stabbing (20%, compared to 30%). The larger sample size of the Hart and Williams (1994) study could have contributed to the different results, as well as the period and setting where data were collected. The Natalspruit hospital served the East Rand townships which had been the scene of increasing politically motivated violence in South Africa after 1990. It was also found that etiological patterns changed over the six year period covered in the study, in that gunshot injuries increased markedly and stab wounds decreased in number. This phenomenon was as a result of the increase in violence at all levels, the accompanying release of unlicensed firearms intended for the political struggle into the communities, and the fact that gunshot injuries were more likely to damage the spinal cord in its bony canal than stab wounds (Hart & Williams, 1994).

According to Burt (2004), the etiology of traumatic SCI is a reflection of the social and economic circumstances in individual countries around the world; the character of accidents causing SCI will therefore vary from country to country. Globally and in economically developed countries the main cause of traumatic SCI is road traffic accidents (van den Berg *et al.*, 2010; Dawodu, 2007; Ho *et al.*, 2007; Pickett *et al.*, 2006; Burt, 2004; Lan *et al.*, 1993; Biering-Sorensen *et al.*, 1990). These findings are different from the findings of this study and of the Hart and Williams (1994) study where, in South Africa, violent acts exceed road traffic accidents as a cause of traumatic SCI. According to the NSCISC (2008) falls were more common in the United States as a cause of traumatic SCI than violent acts.

In Turkey, falls exceeded road traffic accidents as a cause of SCI (Karamemetoglu *et al.*, 1995). The majority of the falls in Turkey were work related. In Bangladesh and India falls from a height were reported as the most common cause of injury and in Bangladesh the second largest group were those tripping and falling while carrying a heavy load (Burt, 2004). In this study and the study conducted by Hart and Williams (1994), falls as a cause of traumatic SCI were in the minority, accounting for only 6% and 2.4% of SCI respectively.

Sports-related and other injuries were the least common cause of traumatic SCI found in this study. Very few international studies report on the percentage of SCI as a result of participation in sport. According to Burt (2004) sports-related injuries are sustained in a number of sports such as diving, horse riding, trampolining, rugby and gymnastics. In the study conducted by Hart and Williams (1994) sports-related injuries causing SCI were not mentioned at all. In the United States, sports-

related injuries account for 12.7% of traumatic SCI, of which diving injuries occurred most frequently (Dawodu, 2007; Biering-Sorensen *et al.*, 1990). This matches the findings of this study, in that all the sports-related injuries were also due to diving accidents. The only other cause of traumatic SCI found in the literature was attempted suicide as reported in studies conducted in Canada and Denmark (Pickett *et al.*, 2006; Biering-Sorensen *et al.*, 1990). It is unknown if any of the other causes of traumatic SCI found in this study were due to attempted suicide.

Etiology by population group

The findings of this study show clearly that the Black and Coloured racial groups are more likely to sustain a SCI from violence compared to other etiologies (Table 4.1). A possible explanation for this, as mentioned before, is that the majority of the subjects in this study reside in the Cape Flats suburbs of the Cape Metropole, where the risk of getting shot or stabbed are extremely high due to the relative high levels of crime (Williams, 1996).

Further research, on the epidemiology of road traffic accidents causing SCI, is needed to be able to draw any conclusions regarding the high incidence of road traffic accidents causing SCI amongst the Black and Coloured racial groups. It is possible that a large percentage of the motor vehicle accidents found in this study involve mini-bus taxis, which are the main mode of transport amongst the Coloured, and in particular the Black racial groups to and from the townships (Govender & Allopi, 2006). Travelling by minibus taxi poses a great risk of being involved in a motor vehicle accident, as minibus taxis are involved in 8.6% of all crashes in South Africa, which indicates that minibus taxis account for double the rate of crashes than all other passenger vehicles (National Department of Transport (NDT), 2001).

No literature on the etiology of spinal cord injury by population group was found outside or inside South Africa. As a result of the apartheid regime in South Africa, the socio-political and socio-economic circumstances in this country are very unique compared to the rest of the world, which could account for the fact that research on the relationship between etiology and specific racial groups has not been a priority in other countries.

5.3.2 Level and nature of spinal cord involvement

Level of spinal cord involvement

In this study the majority of the subjects were paraplegic (Table 4.2). This is in agreement with international findings where two-thirds of traumatic SCI patients have been reported to have paraplegia (Wyndaele & Wyndaele, 2006). The literature review conducted by Wyndaele and

Wyndaele (2006) is based on data collected from 1995 to 2000. However, according to the NSCISC (2008), the number of persons with tetraplegia in the United States has increased to more than 50%. A later systematic review conducted by van den Berg *et al.* (2010) found that in some countries, such as Canada, tetraplegia was more common and in other countries, such as Turkey, paraplegia was more common. According to van den Berg *et al.* (2010) these figures could be related to non-registered deaths before hospital admission. For example, mortality before admission is expected to be higher among tetraplegic patients and it is possible that more tetraplegic patients survive in developed countries such as Canada and the United States due to quicker access to hospital care.

The Hart and Williams (1994) study aimed to investigate the epidemiology of spinal cord injuries admitted to a spinal rehabilitation unit of a hospital in the south of Johannesburg and came to the same conclusion: the majority of spinal cord injuries (75%) resulted in paraplegia and 25% in tetraplegia.

In this study it was found that 36% of the injuries occurred in the cervical cord, 55% in the thoracic cord and only 9% in the lumbar cord. This is in contrast with findings from a systematic review conducted by van den Berg *et al.* (2010) and Pickett *et al.* (2006) where the most common site of SCI was the cervical cord followed by the thoracic. It is however in agreement with findings by van den Berg *et al.* (2010), Pickett *et al.* (2006) and Hart and Williams (1994) which established that the lowest number of injuries occur in the lumbar cord. The lower percentage of cervical lesions found in this study might be explained by the fact that the WCRC does not admit patients who are artificially ventilated, which is more common in tetraplegia. In the study conducted by Hart and Williams (1994), 25% of the cases had a cervical cord injury and 63% of the thoracic cord. This is similar to the findings in this study. Admission criteria for Natalspruit Hospital, where the Hart and Williams (1994) study was conducted, are not known, and as no other information on the epidemiology of traumatic SCI in South Africa is available, it is impossible to state that the findings in this study are a reflection of what is applicable in the rest of South Africa.

Nature of spinal cord involvement

The completeness of traumatic SCI is one of the most important prognostic indicators for neurological recovery and functional outcomes after SCI (Lim & Tow, 2007). These authors emphasize the importance of an accurate baseline clinical assessment, as these findings correlate with self-care and walking scores which are determined by the extent of neurological deficit. Patients who have incomplete lesions at baseline have a better prognosis for neurological recovery compared to patients with a complete lesion (Lim & Tow, 2007).

In this study it was found that 45% of the subjects had complete lesions at discharge and at six months after discharge from the WCRC (Figures 4.2, 4.3). This is similar to Wyndaele and Wyndaele's (2006) findings, where an equal number of patients sustained complete and incomplete lesions, and to the findings of the NSCISC (2008) where 41% of persons with traumatic SCI in the United States had complete lesions. The findings of this study are however in contrast with the Hart and Williams' (1994) study where 66% of the total cases were complete lesions. It is possible that etiology of the SCI could have contributed to the findings of the Hart and Williams' (1994) study.

As mentioned earlier, incomplete paralysis was the most common neurological diagnosis in this study and was more frequent in the cervical area. Complete paralysis was more common in the thoracic group. This is in agreement with findings by the NSCISC (2008) and Pickett *et al.* (2006), in that the majority of thoracic lesions are complete in nature and cervical lesions are more likely to be incomplete. Pickett *et al.* (2006) confirmed the findings of this study that the majority of lumbar lesions are incomplete.

Neurological deficit related to etiology of SCI

In this study it was found that gunshot injuries were more likely to cause paraplegia than tetraplegia (Table 4.4). The likelihood of stab injuries causing paraplegia was slightly higher than tetraplegia. Neurological deficit caused by road traffic accidents was almost equally distributed between paraplegia and tetraplegia. Road traffic accidents were more likely to cause complete paralysis and stab injuries incomplete paralysis. Almost the same number of complete and incomplete injuries was caused by gunshot injuries.

The only result found in this study that is in agreement with other studies is that stab injuries are more likely to cause incomplete spinal cord injuries (Burt, 2004). No other literature was found that determined the neurological deficit in relation to the etiology of spinal cord injuries.

5.3.3 Severity of spinal cord involvement

The AIS is used to classify the severity of the SCI in descending order of severity from a grade A through to a grade E. The AIS provides information on the functional ability of the patient and potential for functional recovery. For more information on the AIS refer to Appendix I.

In this study the majority of the patients were classified as ASIA A followed by ASIA D at discharge from the WCRC (Figure 4.8). At six months after discharge more patients were classified as ASIA D compared to ASIA A (Figure 4.9). Although the ASIA A group were still represented by a large percentage at six months, the reason for the ASIA D group being in the majority is probably

because the ASIA D patients can ambulate functionally, which makes the use of public transport easier in order to return for assessment at six months. Patients graded as ASIA A have a complete neurological SCI and are therefore wheelchair dependent which makes it more difficult or even impossible to utilize public transport. Another possible explanation is that the patients with ASIA grades B and C had improved to an ASIA grade D.

A small percentage of the subjects (4%) were classified as ASIA B and ASIA C (17%) at discharge. At six months after discharge none of the subjects were represented in the ASIA B group and only 7% in the ASIA C group. The reason for the decrease in representation of the ASIA groups B and C at six months could be due to the reasons mentioned in the paragraph above. It is however more likely that patients in the ASIA C group had improved to an ASIA D, as the prognosis for improvement from a ASIA grade C to an ASIA grade D is extremely good (Lim & Tow, 2007; Burns & Ditunno, 2001; Marino *et al.*, 1999).

In this study the number of subjects classified as ASIA A at discharge (45%) is almost identical to the number classified as ASIA A at six months (44%). A compelling explanation for this finding could be that the prognosis is poor for a patient with an ASIA A to become incomplete (Lim & Tow, 2007; Burns & Ditunno, 2001; Marino *et al.*, 1999), and that the majority of incidences of neurological recovery in patients with complete lesions (ASIA A) occurs during the first six to nine months after injury (Burns & Ditunno, 2001).

5.3.4 Incidence of secondary complications

Data for the incidence of secondary complications were collected on admission to, at discharge from and at six months after discharge from the WCRC. The subjects had to report on the presence of secondary complications on the days of admission and discharge. At six months after discharge, they needed to report on the presence of secondary complications for the period from discharge up to and including the day of their six-month follow-up appointment. Reasons for collecting data on these days were to determine whether specific secondary complications are unique to certain phases of rehabilitation, and then to identify these complications. However, of more importance was to determine the incidence and type of secondary complications present during the six-month period after discharge from the WCRC, as subjects are only followed-up at one year after discharge for urological investigations (Roodt, 2011).

5.3.4.1 Secondary complications on admission to the WCRC

It is important to note that patients are admitted to the WCRC from various acute or step-down facilities when they are medically stable and ready to start with rehabilitation or as soon as a bed is

available at the WCRC. Therefore the time after injury to admission to WCRC will be different for each patient (it ranged between seven and 278 days). It will however be of value for the WCRC to learn which secondary complications are more likely to develop during the patients' stay at WCRC.

It was found that back pain, neuralgia and shoulder pain were the most common secondary complications reported by the subjects on admission to the WCRC (Figure 4.10). Only 21% did not have any secondary complications present on admission, which is a fairly low percentage, taking into consideration that all of the subjects, except one, were admitted from a medical institution and for the majority of subjects it was relatively soon after the injury occurred. As expected, the prevalence of pressure sores on admission was fairly low as this would have hindered their rehabilitation.

Spasticity limiting function was present in 19% of the subjects on admission, which is very interesting as spasticity tends to become more problematical with the passage of time (Maynard, Karunas & Waring, 1990). However, although no statistical evidence is available, anecdotal evidence indicates that spasticity may be problematical earlier than the one year follow-up evaluation as determined by Maynard *et al.* (1990). These authors also found that while time after injury and level of injury were significantly related to the severity of spasticity; age, gender and AIS grades were not. The epidemiology of spasticity after traumatic spinal cord injury was not an objective of this study, therefore no comparisons with other related studies were done. However, as the presence and severity of spasticity with spinal cord injury is a determining factor for functional outcomes and safety after SCI, more research should be conducted on this matter.

The prevalence of other secondary complications, such as DVT, bowel obstruction and chest infections was very low. According to Chen *et al.* (1999) the occurrence of respiratory complications is very frequent at both the acute and rehabilitation phase and patients with complete tetraplegia are at a greater risk. This might explain the low percentage of respiratory complications on admission in this study as only 11% of the subjects were classified as complete tetraplegics (Table 4.4).

5.3.4.2 Secondary complications at discharge from the WCRC

At discharge from the WCRC, spasticity limiting function occurred most frequently and was reported by 43% of the subjects to be a problem (Figure 4.11) compared to 19% on admission. The reason for this large increase can be that spasticity tends to develop later (Maynard *et al.*, 1990) or that patients are more aware of the limiting effect of spasticity as they become more functional with the passage of time. The regular occurrence of spasticity is of concern as it not only affects

function, but it may also cause secondary complications such as pressure sores, contractures and bony deformities (Adams & Hicks, 2005).

The frequency at which back pain and neuralgia occurred at discharge is almost the same as on admission. Although the occurrence of back pain is similar at these two time points, it is necessary to determine the cause of the pain before any conclusions can be drawn. It is possible that back pain during acute rehabilitation can be experienced as a result of orthopaedic surgery, and during sub-acute rehabilitation as pain of a more mechanical nature because of poor postural control and/or poor seating.

It is of concern that such a large percentage of the subjects complained of back pain and neuralgia at discharge, as both these conditions can have a disabling effect on functioning on a daily basis and subsequent quality of life and life satisfaction (Tonack *et al.*, 2008; Chiodo *et al.*, 2007). Pain is a serious problem for many people with spinal cord injuries (Spinal cord injury model systems consumer information, 2009) and the most frequently reported reason for decreased quality of life (Widerstrom-Noga, Felipe-Cuervo & Yeziarski, 2001). Addressing this problem at a bio-medical, psychological and psychosocial level should therefore be considered a priority (Widerstrom-Noga *et al.*, 2001).

Taking into consideration that until the time of discharge the subjects were still in a sheltered, supervised environment at the WCRC, it was to be expected that a much higher percentage of subjects would have no secondary complications at discharge. The high percentage of subjects who did report the presence of secondary complications at discharge confirms the extent of the regular occurrence of secondary complications at any stage of rehabilitation, despite the greater awareness, recognition and improved treatment of secondary complications after spinal cord injury (Chen *et al.*, 1999).

As found by Chen *et al.* (1999), the incidence of pressure sores remains a major problem even during the acute rehabilitation phase, but the location and proportion of pressure sores might vary at the different stages of management. In this study a very small percentage of subjects reported having pressure sores on discharge from the WCRC. What is however not known is the number of patients who actually developed pressure sores during their stay at the WCRC which had healed prior to discharge.

The incidence of shoulder pain was found to be fairly low. This was expected as shoulder pain as a result of overuse increases in the years after the initial period post-injury of about 7 years up to about 20 years (Chiodo *et al.*, 2007; Noreau *et al.*, 2000). Shoulder pain of a more acute nature, due

to the spinal cord injury or associated trauma, is also more common during the acute phase of rehabilitation (Salisbury *et al.*, 2003). Characteristics of shoulder pain after SCI are associated with the etiology of the shoulder pain (Chiodo *et al.*, 2007). As the characteristics of the pain were not investigated in this study and the etiology is not known, no further conclusions can be drawn. Findings in this study regarding the incidence of shoulder pain at different times during rehabilitation are therefore in agreement with findings in the literature, as mentioned before, (Chiodo *et al.*, 2007; Salisbury, Choy & Nitz, 2003; Noreau *et al.*, 2000). Another possible reason for the low percentage of shoulder pain at discharge in this study is that the majority of subjects at discharge were paraplegic (Table 4.4). According to Salisbury *et al.* (2003), shoulder pain is more common in acute tetraplegia.

Contractures were present in 15% of the subjects at discharge, which is very similar to the percentage at admission. The contractures that were present in the five subjects on admission were still present at discharge. Two other subjects developed contractures during their stay at WCRC. It is however possible that these subjects had the contractures on admission, but were unaware of it, or that they forgot about it, as information on the presence of contractures on admission was provided by the subjects only at the time of their discharge. The fact that so few subjects developed contractures during their stay at WCRC could possibly be attributed to the extensive and effective rehabilitation program they were engaged in.

The incidence of pain in the neck, joints of the lower limbs and elbow and wrist joints in this study was found to be very low. As the majority of studies on the matter of pain after spinal cord injury only refer to back pain, it is not possible to compare these results to international findings. It is however mentioned that chronic neck pain can occur, although not common, in people with tetraplegia and especially those who use chin- or mouth-operated devices (Spinal cord injury model systems consumer information, 2009; Northwest Regional Spinal Cord Injury System (NRSCIS), 2005).

5.3.4.3 Secondary complications at six months after discharge

In this study shoulder and back pain were the most common secondary complications present at six months after discharge from the WCRC, followed by spasticity limiting function and neuralgia (Figure 4.12).

The incidence of shoulder pain was considerably greater six months afterwards than it had been at discharge. Five of the 14 subjects who presented with shoulder pain at six months had experienced the same pain already on admission to, and at discharge from, the WCRC. A further two subjects

had the same pain at discharge. Therefore, the remaining subjects must have developed the shoulder pain after discharge from the WCRC. Eight of the 14 subjects who complained of pain at six months were tetraplegic. This could explain the high percentage of reported shoulder pain at six months, since shoulder pain is more common in tetraplegic patients (Salisbury *et al.*, 2003). The most common reasons for shoulder pain, associated with tetraplegic patients are, amongst others, impaired muscle innervations resulting in impaired movement patterns, inadequate rotator cuff function resulting in decreased stability of the humeral head, reduced external rotation resulting in potential tendon impingement, poor handling and positioning of the already unstable shoulder joint and referred pain from the cervical spine (Salisbury *et al.*, 2003). As the etiology of the shoulder pain was not investigated in this study, the positive association between shoulder pain and tetraplegia cannot be confirmed. However, the large percentage of subjects complaining of shoulder pain on admission, at discharge and especially at six months after discharge, is of great concern as shoulder pain limits participation in rehabilitation and the degree of functional independence, which may have a detrimental psychological effect and financial consequences (Salisbury *et al.*, 2003).

The high incidence of back pain found in this study is in agreement with international literature (Spinal Cord Injury Model Systems Consumer Information, 2009; NRSCIS, 2005; Widerström-Noga *et al.*, 2001). According to these authors, back pain as a result of musculoskeletal problems is a common issue following spinal cord injury. Although more common in people with paraplegia, people with tetraplegia, especially incomplete tetraplegia, may also experience mechanical back pain due to imbalances of muscles or poor seating posture (NRSCIS, 2005). These findings are very similar to what was found in this study, as 63% of the subjects at six months were paraplegic and 80% of the remaining subjects had incomplete tetraplegia.

A large percentage of subjects reported having neuropathic pain or neuralgia at six months after discharge, which is in agreement with international findings (Spinal cord injury model systems consumer information, 2009; NRSCIS, 2005). This is of great concern as this type of pain is the most difficult to treat (Spinal cord injury model systems consumer information, 2009; NRSCIS, 2005). In this study the neuralgia at six months was more common in subjects with incomplete lesions.

Forty-six percent of subjects in this study reported having spasticity limiting their function, which is very similar to the findings at discharge. The high percentage at discharge and even higher percentage at six months could be explained by the findings of Maynard *et al.* (1990) that spasticity tends not only to develop as time passes after SCI, but also to become more severe. Another

possible explanation is that some of the subjects stopped taking their anti-spasmodic medication after discharge from the WCRC.

A very small percentage of subjects reported to have developed urinary tract infection (UTI) and pressure sores after discharge from the WCRC. Throughout the literature it is clear that the development of these two secondary conditions are very common after SCI, especially after discharge from the rehabilitation setting (Chiodo *et al.*, 2007; Kroll *et al.*, 2007; Bloemen-Vrencken *et al.*, 2005). Not only did Kroll *et al.* (2007) find in their study that the presence of UTI and pressure sores showed remarkable consistency over time, but also that the occurrence of earlier UTI and pressure sores were the strongest predictors for recurrence. Although findings in this study show that pressure sores and UTIs did occur after discharge from the rehabilitation setting, they cannot be compared to other studies because of differences in the methods of data-collection. Further research should be conducted to investigate the epidemiology of pressure sores and UTIs. Not only is it important to know at which stage of rehabilitation the development of pressure sores and UTIs are more common, but of even greater importance are the findings of Kroll *et al.* (2007) that the early occurrence of these two conditions are strong predictors of recurrences. It is therefore suggested that further research on this matter be conducted, since the early implementation of educational programmes could decrease the incidence of these conditions as time passes after injury. Findings in this study, regarding the presence of pressure sores and UTIs after discharge from the rehabilitation setting, partly support the findings of previous studies (Chiodo *et al.*, 2007; Bloemen-Vrencken *et al.*, 2005).

5.4 SOCIO-ECONOMIC CHARACTERISTICS

Socio-economic status is “a composite measure that typically incorporates economic status, measured by income; social status, measured by education; and work status, measured by occupation” (Dutton & Levine, 1989:30). The results found in this study on the socio-economic characteristics of the sample will not be compared to any of the other studies conducted on this matter, since these aspects are unique to specific populations. The reasons for including this objective in the study are to describe the socio-economic characteristics of the sample and the population it represents and to investigate the effect of traumatic SCI on the socio-economic circumstances of individuals in South Africa living with SCI.

Gainful employment is regarded as an important rehabilitation outcome after SCI, in particular, not only for the individual concerned, but also for the state in terms of tax and unemployment or disability benefits (Tasiemski *et al.*, 2000). Return to productive activity, including employment and vocational capacity, will be discussed in more detail by referring to existing literature. It is

important to note that the available information pertains to developed countries and should therefore be cautiously compared to the findings of developing countries. According to Lidal *et al.* (2007) there is a lack of information on employment and SCI in less-industrialized and developing countries, which is understandable considering the high national unemployment rates, poverty and cultural differences in most of these countries.

5.4.1 Level of education

The singular epidemiological study on SCI in South Africa by Hart and Williams (1994) did not include level of education at injury, as with all the international epidemiological studies on SCI that have been conducted. The level of education of a person at time of injury was however identified as one of the most important predictive factors which can influence long-term outcomes after SCI, such as employment (Hess, Ripley, McKinley & Tewksbury, 2000; Krause, Sternberg, Maides & Lottes, 1998; Krause, 1992). Since employment after SCI is considered one of the most important rehabilitation goals due to its association with better self-esteem, higher life satisfaction and sense of well-being (Hess, Meade, Forchheimer & Tate, 2004) it was included as a demographic characteristic in this study.

Although some comparison to statistics from the 2001 National Census (SSA, 2005) is possible, the educational categories in this study are unfortunately slightly different from the National Census.

The majority of the subjects in this study had a grade eight to ten education (Table 4.7), which can be cautiously compared to the “some secondary” category of the 2001 National Census (SSA, 2005). This category represents the level of education of the majority of the population of the Western Cape Province (SSA, 2005). Although the “some secondary” category of the 2001 National Census includes grade 11 and this study only included grade 10, both these categories are in the majority. Therefore it appears that the findings of this study reflect the findings of the 2001 National Census (SSA, 2005) with regard to levels of education.

The findings of this study regarding the two categories “no formal education” and “tertiary education” also reflect the findings of the 2001 National Census (SSA, 2005) in the Western Cape. Not only are the findings similar in general, but also as per racial group (Table 4.8). The White population in the Western Cape has the highest percentage of tertiary education (33.4%) and the lowest percentage of no formal education (0.6%) of all the racial groups (SSA, 2005). The imbalances in education left behind by the apartheid regime are evident in the level of education of the different racial groups in South Africa, where only 14% of the Black and 17% of the Coloured race have a high school or higher education compared to 65% of the White population. The findings

in this study regarding the level of education reflect the statistics on education in South Africa (Education in South Africa, 2010).

5.4.2 Level of productive activity

There are two general tracks to employment after SCI, i.e. returning to pre-injury work or finding a (new) work. Although the results were not statistically analysed due to the small sample size, hopefully this study will shed some light on the possibility and reasons for achieving or not achieving this outcome in a developing country such as South Africa.

At the time of injury, 60% of the subjects in this study were in paid employment, of which only 28% were permanently employed with a fixed monthly income (Figure 4.13). At the time of discharge from the WCRC none of the subjects were actively involved in their careers. Some of the subjects could not return to their previous employment due to their disability or were still in the process of recovery and were unsure if they could return even in another capacity. At six months after discharge from the WCRC, 85% of the subjects were unemployed (Figure 4.14). One subject returned to school although he did not attend school at the time of his injury. The remaining subjects were employed, although none of them were in casual employment or on probation.

Regarding the level of productive activity by race, the results show that more subjects of the Black and Coloured racial groups were employed at the time of injury than unemployed (Table 4.9). These two racial groups were represented by 94% of the subjects in the study (Figure 4.4). However, at six months after discharge from the WCRC, the majority of the subjects in these two racial groups were unemployed (Table 4.10). The one subject of the Asian racial group remained unemployed at six months. Interestingly enough, the one subject of the White racial group, who was unemployed at the time of injury, was in permanent employment at six months after discharge from the WCRC. The second subject of the White racial group who was self-employed at the time of injury could not continue with his work due to his disability.

There could be a few possible reasons for these findings. Although a large percentage of the subjects of the Black and Coloured racial groups were in some form of employment at the time of injury (Table 4.9), the assumption can be made that the type of work they did was more physical in nature due to their generally low levels of education. As a result of their disability caused by SCI, they were unable to do the same work and/or could not find other work that was less physical, because of the need for higher levels of education. Therefore only one subject of the Black and one of the Coloured racial groups were employed at six months after discharge from the WCRC (Table 4.10). The one subject of the White racial group who had a tertiary education prior to the SCI even

managed to be permanently employed at six months after discharge from the WCRC, although he was unemployed at the time of the injury (Table 4.9). By looking at the above statistics the question can be asked whether there is a relationship between level of education, types of work, physical ability or severity of the injury and gainful employment after SCI.

Return to, and factors related to employment as a non-medical outcome after SCI has been studied extensively in rehabilitation research (Krause, 2003). Employment after SCI was found to be positively related to life satisfaction, adjustments after SCI, level of activity, overall health after SCI, self-esteem, sense of well-being and quality of life (Lidal *et al.*, 2007; Targett *et al.*, 2004; Krause, 1992). According to reviews on return to work after SCI conducted by Yasuda *et al.*, (2002), levels of education have been consistently reported to be positively correlated to return to work after SCI. Krause (1992) found that almost 95% of persons with at least 16 years of education have worked at some point after their injury. Hess *et al.* (2000) stated that education also increases the range of jobs to which an individual may return. Persons with physical limitations are more likely to return to jobs that require less physical labour (Yasuda *et al.*, 2002), but higher levels of education. Although further investigation on this matter is necessary in order to draw any final conclusions, this could explain the findings of this study, that the majority of the subjects were unemployed at six months after discharge.

Another possible reason for the low percentage employment at six months after discharge from the WCRC is that the majority of the subjects qualified for a disability grant from the state due to the extent of their disability. A large percentage of the subjects, especially of the Black and Coloured racial groups, did not have a fixed monthly income prior to the SCI (Table 4.9). Although the amount of R1140 per month, provided by the state in the form of a disability grant, could be less than the amount they occasionally earned before, at least it does ensure a fixed monthly income in the long term. The fact that the subjects who do receive a disability grant from the state run the risk of losing a part or all of their grant if they should find employment, could discourage these individuals from seeking employment (South African Government Services, 2011).

Other characteristics positively correlated to return to work after SCI, as identified by Yasuda *et al.* (2002), are age less than 29 years at time of injury and paraplegia and/or incomplete lesions, which are in contrast with the findings of this study (Figure 4.1; Table 4.5; Figure 4.14). Another very interesting finding by Yasuda *et al.* (2002) that could explain the low employment rates found in this study, is that persons who sustained SCI through violence, and more specifically gunshot injuries, were less likely to be employed compared to other etiologies. Acts of violence including gunshot injuries were responsible for 58% of the spinal cord injuries in this study (Figure 4.6). A

reason for this positive correlation, according to Yasuda *et al.* (2002), is that persons who sustain gunshot injuries in many cases may have poorer pre-morbid adjustment and are less motivated to seek employment. Whether this is a reason for the low employment rates found in this study, should be investigated.

5.4.3 Income

Gross monthly income, main source of income and contribution to household income

Monthly income varied considerably at the time of injury, at discharge and at six months after discharge from the WCRC. At the time of injury, 38% of the subjects had no income compared to 79% at discharge and 22% at six months after discharge (Figures 4.15, 4.16, 4.17). A possible explanation for this is that 32% of the subjects employed at the time of the injury were in non-permanent paid employment with no benefits on termination of employment. As a result, more subjects had no income at discharge due to their inability to maintain their jobs while recovering from the SCI. At the time of their discharge, the majority of subjects had not received a disability grant pay-out (Figure 4.18), possibly because of the timeframe of three months to process a new application (South African Government Services, 2011). At six months after discharge, 67% of the subjects were receiving a disability grant, hence the low percentage of subjects who did not have any income at this time (Figure 4.19). Reasons for not receiving a disability grant at this point can be attributed to the subject either not qualifying or never having applied for a grant. Reasons for not qualifying, amongst others, are not being a South African citizen, not in the possession of a legal identification document, disability not being severe enough and/or a spouse receiving a salary (South African Government Services, 2011). Although the ultimate aim for persons with disabilities is not to receive money, but rather to earn it through gainful employment, at least the majority of the subjects had an income of at least R1140 per month to support not only him/herself, but in many cases possibly a whole family.

Although a monthly income is important to survive, what is more important, especially for persons with disabilities is the source of income. In general society, people are expected to work and being employed is regarded as a key indicator to social integration (Lidal *et al.*, 2007). It is also considered a major determinant of success in society (Yasuda *et al.*, 2002). Among the most important consequences of being employed, especially after SCI, is the association of employment with better self-esteem, higher life-satisfaction and sense of well-being (Hess *et al.*, 2004).

A monthly salary was the main source of income at the time of the injury for the majority of the subjects, as 60% of the subjects were in paid employment. At discharge 10 subjects (21%) had a

monthly income and for only five subjects (10%) was the income generated through employment (Figure 4.18). At six months after discharge 21 subjects (77%) had an income, but for only two subjects (7%) was the income due to employment. The remaining subjects receive a government grant. These results paint a bleak picture for employment after SCI in South Africa.

5.5 DESCRIPTION OF THE LIVING ENVIRONMENT AFTER DISCHARGE

Where persons with SCI live once discharged from the rehabilitation setting is very important, as this can have an effect on not only successful residential reintegration or independent living, but also social participation and engagement in occupation (Welage & Liu, 2008). The type of residence the person with SCI is discharged to can have an effect on his/her quality of life by influencing aspects such as opportunity for community reintegration, privacy, independence, safety and access to family and friends (Bergmark *et al.*, 2008). Discharge to a nursing home should be the last option as individuals living in a nursing home have a lower quality of life compared to individuals living in a community dwelling (Putzke & Richards, 2001). None of the subjects in this study were discharged to a nursing care facility, despite the fact that some of the subjects could not return to their previous homes.

The home is considered a place for the protection and privacy of its residents (Bozzolini & Cassibba, 2008) and spaces inside the house must be safe and comfortable and suited to any of the resident's conditions (Angus, Kontas, Dyck, McKeever & Poland, 2005). To acknowledge the importance of the discharge setting, patients with SCI in Hong Kong are kept longer in hospital to allow time due for home modification and equipment prescription and to prepare for home and community reintegration (Chan & Chan, 2005).

The majority of the subjects (79%) were discharged to the same home they were living in at the time of injury. The remaining subjects could not return to their previous homes for various reasons as mentioned in Chapter 4, paragraph 4.5.2, but mainly because the house was not suitable for a person with physical disabilities (13%). Two of the subjects could not return to the same area because of the prevalence of violence. Being discharged to a different home in a different area means that the individual moves from a familiar neighbourhood and surroundings to something new (Charlifue & Gerhart, 2004). The physical as well as the emotional community change with such a move (Charlifue & Gerhart, 2004), making it even more difficult for the individual with SCI to deal with all the changes in his/her life as a result of the SCI. This might slow down or even prevent the reintegration process after discharge.

Seventy percent of the subjects were discharged to a permanent structure made of bricks and the remaining subjects to informal dwellings (Figure 4.20). Despite the fact that the houses are relatively small with a median number of four rooms (Figure 4.21) and a range of one to 13 people per residence (Figure 4.22), the majority of the subjects (81%) reported that they had adequate space for mobility inside their houses. A possible explanation for this finding is that nearly half of the subjects were able to walk short distances at discharge (Table 4.12) and were therefore not using a wheelchair inside the house.

Although the majority of the subjects have a bathroom (Figure 4.24) and a toilet (Figure 4.25) inside or outside their residences, 29% and 25% of these subjects cannot use their bathrooms (Figure 4.23) and toilets (Figure 4.26) respectively. The main reason for this being that the bathroom was not accessible with a wheelchair. For the remaining 32% of the subjects, alternative toileting and washing arrangements had to be made (Figures 4.23, 4.26).

All the subjects had access to running water and 96% to electricity (Table 4.13). Although seven subjects had no personal assistance available to them, they were able to function independently. All the subjects had access to a telephone including, their own and/or public phones within 50 metres of the house.

SECTION TWO

In this section the activity and participation profile of the sample will be discussed for each domain or life situation at discharge and at six months after discharge from the WCRC. A discussion of the statistical differences between the ability to participate in each life situation at the two points in time will follow. The ability to participate within different domains is measured by the degree of difficulty with which the activities (used to participate in that domain) were performed.

The activity profile for each domain or life situation at discharge and at six months after discharge from the WCRC will also be discussed. The activity profile is expressed in terms of the type and amount of assistance that was needed to perform the activities in the different domains.

5.6 ACTIVITY AND PARTICIPATION PROFILE

Participation according to the ICF (WHO), 2001:10) is defined as the “involvement in a life situation”. To describe the participation profile, the first qualifier for the Activities and Participation component of the ICF i.e. performance with assistance (personal and non-personal) was used. The performance construct indicates what an individual does in his/her current environment in a given domain at a given moment. The participation profile, as described by the first qualifier, will provide

information on what an individual does in the actual context in which he/she lives (WHO, 2001). The participation profile will provide information on what the individual does in his/her current environment and not what he/she can do in a standard environment such as the WCRC. The participation profile is therefore the main objective of this study, because the gap between what an individual can do in a standard environment and does in the current environment reflects the impact of the environment on his/her functioning (WHO, 2001). The level of functioning after SCI therefore does not depend on the physical ability of the individual alone, but the availability of resources in the different domains in which he/she is functioning. The performance qualifier however does not give any information on the amount and type of assistance utilized to perform the activity.

Activity according to the ICF (WHO, 2001:10) is defined as “the execution of a task or action by an individual”. To describe the activity profile, the second qualifier for the Activities and Participation component i.e. capacity without assistance (personal and non-personal assistance) was used. The capacity construct is an indication of the highest possible level of functioning an individual can reach in a given domain at a given moment (WHO, 2001). The activity profile will be discussed in terms of the assistance needed to execute a specific task. The reason for including the activity profile in this study is to establish whether the ability to execute a task without assistance changed with time.

5.6.1 Activity and participation profile for mobility

See tables 4.12, 4.13, 4.14 and 4.15.

Changing and maintaining body positions and transfers

At discharge and at six months, basic activities such as maintaining the sitting position (d4153) and moving between the sitting and lying positions (d4100, d4103) were performed (first qualifier) by all the subjects. However, at six months more subjects found the activity of sitting up (d4103) slightly more difficult to perform compared to the other two activities. To support this it was found that capacity for moving into the sitting position deteriorated while for the other two activities it improved. Possible reasons for this are that some of the subjects relied on the personal assistance available at home to execute the activity, although they were able to, and forced to do the activity independently until their discharge. Furthermore, it was found in this study that the incidence of spasticity limiting function was higher at six months, which could have contributed to the degree of difficulty needed to execute activities such as changing position. For moving between sitting and

lying, the subjects utilized only personal assistance and for maintaining the sitting position non-personal assistance was used, including a specially adapted wheelchair.

Performance and capacity for transferring oneself into a sitting position (d4200) improved from discharge to six months. Although not significant, the decrease in difficulty needed to perform this activity at six months is worth mentioning ($p=0.07$). More subjects were able to execute this activity without any assistance at six months. Non-personal and personal assistance were utilized to perform this activity at discharge and at six months.

The degree of difficulty experienced during standing activities was greater than expected, when compared to activities in the lying and sitting positions, as more postural control is needed for activities when standing. Although performance levels for both the activities of maintaining (d4154) and changing the standing position (d4104) improved from discharge to six months, the change was, as expected, statistically more significant for maintaining the standing position ($p=0.04$) compared to moving into the standing position ($p=0.09$). Possible reasons for this finding are that less motor control is needed to maintain a position compared to moving into that position. The increase in spasticity found at six months could also have facilitated standing, but hindered moving into the standing position. Capacity for both these activities improved as more subjects were able to execute these activities without any assistance at six months. A possible reason for improved performance and capacity at six months for both these activities could be neurological recovery. This could have resulted in an increased ability to do standing activities. Only non-personal assistance was utilized for performing these activities.

Although performance and capacity for squatting (d4101) and kneeling (d4102) had improved at six months it was found that not many subjects utilized these activities during activities such as praying and toileting or they had found alternative ways to perform these activities.

Although performance and capacity had improved for all except one of these activities, what is not known is whether the contribution of the subjects who still needed assistance to perform these activities, had changed between discharge and six months. This is however of less impact as the necessary assistance is currently available for these activities to be performed. However, it would be beneficial if over time the subjects could do more of these activities with less carer assistance.

Carrying, moving and handling objects

At discharge and six months, the activities of carrying or moving objects (dd430) from one place to another were performed by all the subjects either independently or with assistance. Although performance remained the same at the two points, it was significantly easier for the subjects to

perform the activity at six months ($p=0.04$). Objects could be carried in the hands or arms, on the shoulders, hip, back or head or on the lap when seated. Capacity remained almost the same at six months, which was expected as some objects are too heavy to carry around with one arm or on the lap or on the body. Of interest is that more subjects utilized personal assistance to perform this activity at six months. A possible reason for this could be that the subjects found it easier to ask someone else to perform the activity. This is supported by the finding that the ability to execute the activity without assistance had not decreased at six months.

Six percent of the subjects at discharge, and four percent at six months did not have the capacity to manipulate objects with one arm or hand (d445) without assistance and therefore did not find any need to perform the activity. The remaining subjects had the capacity to execute the activity without any assistance at discharge and at six months. It seems that moving objects with your arm or hand is not an important functional activity as no subjects found the need to ask for assistance if they were not able to do the activity. The majority of the subjects (85%) were able to use at least one hand for activities such as picking up, manipulating and releasing objects using their hands, fingers and thumb (fine hand use) (WHO, 2001). Exactly the same scenario was found with this activity (d440) as described with the previous activity (d445). None of the subjects utilized any assistance, including non-personal assistance, to facilitate fine hand use. If they did not have the capacity to do the activity it was not performed. It was however found that subjects found it easier, although not significantly, to perform both these activities at six months.

Walking and moving around in different locations

Walking, according to the ICF (WHO, 2001:144) is defined as: “moving along a surface on foot, step by step, so that one foot is always on the ground”. At discharge forty-two percent of the subjects were able to walk short distances (less than 1 km.) (d4500). More than half of the subjects who were able to walk, could not walk a distance of one kilometre or more (d4501). Walking on different surfaces and around obstacles (d4502, d4503) was also more difficult compared to walking on smooth, even surfaces (d4500). At six months not only did subjects find walking short distances easier, but more subjects were able to perform this activity. Performing the other three activities improved at six months, as well as the degree of difficulty needed, although it is worth mentioning that walking on uneven surfaces ($p=0.06$) and around obstacles ($p=0.07$) was easier at six months compared to walking short ($p=0.21$) and long distances ($p=0.2$) at six months. Although capacity for all the above-mentioned activities improved at six months, the greatest improvement was seen in walking short distances. Non-personal assistance was mainly utilized for walking, except for long distances, on uneven surfaces and around obstacles where personal assistance was also required.

Moving around different locations, according to the ICF (WHO, 2001), includes walking and any other way of moving the body forward such as crawling, climbing, running, jogging, jumping and swimming. Although the ICF (WHO, 2001) excludes moving forward in a wheelchair from this activity, it was included for the purpose of this study to investigate whether subjects in wheelchairs were also able to move around in the different locations. All the subjects in this study were either walking or using a wheelchair to move forward. At discharge the majority of the subjects (94%) had moved around inside their homes (d4600). Reasons, as reported by the remaining subjects, for not having performed this activity at discharge were that the house was too small or they had not been home prior to their discharge. At six months all the subjects were able to move around inside their homes. The subject whose house was too small at discharge utilized personal assistance at six months to move around his house. Capacity for moving inside the house had improved at six months, as fewer subjects were dependent on assistance (personal and non-personal) for mobility inside their homes.

Only 47% of the subjects had been moving and were able to move around other buildings apart from their homes (d4601). The remaining 53% had not performed this activity by the time of their discharge. At six months all the subjects had performed this activity, although not all the subjects had the ability to execute it without assistance. Capacity had however improved at six months. Although the same number of subjects were able to move outside buildings compared to inside their homes, more subjects found it difficult to perform this activity independently. A possible explanation for this could be the difficulty some of the subjects experienced when walking or propelling a wheelchair on uneven surfaces as some subjects reported to have done. However, at six months it was significantly easier for the subjects to perform this activity ($p=0.02$).

Moving around using equipment (d465) is described in the ICF (WHO, 2001:146) as: “moving the whole body from place to place, on any surface or space by using specific devices designed to facilitate moving”. Wheelchairs were the only device used by all the non-ambulating subjects. All the wheelchair dependent subjects (79%), some with more difficulty than others, were able to move around with their wheelchairs with or without assistance at discharge and at six months. For some reason capacity for this activity decreased at six months as more subjects utilized personal assistance to execute this activity. A possible explanation is that some subjects found it easier and/or more convenient to ask someone else to move them around within their wheelchairs. The significant improvement in ($p=0.03$) in the degree of difficulty in which this activity was performed, as reported by the subjects, supports this presumption. The subjects could have also experienced the execution of the activity as less difficult, because they were not doing the work.

Moving around using transportation

Only 21% of the subjects had used public transport (d4702) by the time they were discharged compared to 45% at six months. The low level of performance found at discharge is attributed to the fact that 70% of the remaining subjects had not attempted this activity and 9% had private transport available. It should also be mentioned that only 4% of the subjects who had used public transport at discharge were wheelchair dependent while the rest were walking. Although performance and capacity improved from discharge to six months, caution should be applied when drawing any conclusions regarding the accessibility of public transport for persons with disabilities. All the subjects, except one, who performed this activity at six months, were walking functionally. Accessibility of public transport for physically disabled people remains problematical, as this was identified as one of the environmental barriers for community reintegration after SCI (Table 4.35). For the subjects who were able to use public transport, performing this activity became significantly easier as time passed ($p < 0.001$).

Ninety-one percent of the subjects had used private transport (d4701) at discharge and 97% at six months. At six months only 4% of the subjects had not used private transport as none was available. The majority of the subjects utilized personal assistance to perform this activity. More subjects were able to execute the activity without assistance at six months and performing the activity became significantly easier ($p = 0.03$). Although the majority of the subjects had used private transport at six months, it could not be seen as a long-term alternative for public transport, as this form of transport was reported to be extremely expensive and unaffordable when the only income is a government grant. Sixty-four percent of the subjects did not have their own transport at discharge (Table 4.12) and therefore had to pay when utilizing private transport.

Driving (d475), according to the ICF (WHO, 2001:147), is defined as “being in control of and moving a vehicle or the animal that draws it” including cars, bicycles, boats or animal-powered vehicles. It was found that only one of the seventeen subjects who had been driving prior to the SCI was able to drive at discharge and at six months. In this case the car was specially adapted for his use. The majority of the remaining subjects had not tried or could not perform the activity due to a lack of resources. None of the remaining subjects who were driving prior to the SCI had been driving at six months due to lack of financial resources.

5.6.2 Activity and participation profile for self-care

See tables 4.16, 4.17, 4.18 and 4.19.

All the self-care activities, except “looking after one’s health” (d570), were performed at discharge and six months. Performing these activities is essential for maintaining a healthy body, therefore assistance was provided when necessary. Capacity for all the activities improved except for washing oneself (d510) and dressing (d540). More subjects needed personal assistance to perform washing and dressing at six months. The reason for the decrease in capacity for washing oneself and dressing is possibly due to the fact that it is easier and quicker if someone else is doing the activity, especially for subjects with increased sensory-motor impairment. The decrease in degree of difficulty needed to execute these activities, especially dressing ($p=0.07$) found at six months either supports or contradicts this presumption. It may have felt easier to perform the activity, because someone else was doing it, or it may genuinely have been easier for some subjects to perform the activity themselves. Another explanation is that the higher incidence of spasticity found at six months could have made the execution of the activity more difficult for the subjects and therefore they might have needed more assistance, which then explains the decrease in difficulty. Personal assistance was utilized for performing all the self-care activities, except for eating where non-personal assistance in the form of a feeding strap was also utilized.

For “looking after one’s health” both performance and capacity decreased. “Looking after one’s health” according to the ICF (WHO, 2001:152) is: “ensuring physical comfort, health and physical and mental well-being...”. Almost a third of the subjects at discharge and at six months did not have the knowledge to perform this activity. This is of concern as the occurrence of secondary complications is the main cause of mortality after the acute phase of SCI (DeVivo *et al.*, 1999).

5.6.3 Activity and participation profile for domestic life

See tables 4.20, 4.21, 4.22 and 4.23.

“Acquisition of goods and services” (d620) according to the ICF (WHO, 2001:153) is: “selecting, procuring and transporting all goods and services required for daily living ...” This was the only activity in the domestic life domain that was performed by all of the subjects prior to the SCI and that was still applicable at discharge and six months. For 72% of the subjects, this activity had not been performed at discharge. At six months it had been performed with or without assistance by all of the subjects. There was a significant improvement ($p<0.001$) in the degree of difficulty with which this activity was performed at six months. Although capacity showed a slight improvement at six months, two-thirds of the subjects needed personal assistance to execute this activity.

Performing the remaining activities in this domain was not the responsibility of all the subjects prior to the SCI. At discharge few subjects had performed or attempted to perform these activities. At six months these activities had been performed either by themselves or by someone else. Capacity for all the activities in the domestic life domain had improved except for “assisting others” (d660), where more subjects needed personal assistance to perform this activity. Participation in this domain had improved significantly ($p < 0.001$) at six months. Only personal assistance was utilized to perform these activities.

5.6.4 Activity and participation profile for interpersonal interactions and relationships

See tables 4.24, 4.25, 4.26 and 4.27.

Maintaining informal relationships (d750) seemed to be as difficult at discharge as at six months. Sixty percent of the subjects reported not having any problems with this activity at discharge and at six months, while 30% had some difficulty with maintaining relationships, especially with friends. Eleven percent of the subjects did not have any friends at these points in time. At discharge a large percentage of the subjects had not had regular contact with their friends or it had been too difficult to engage in the activities they were used to prior to the SCI. Some other reasons reported at discharge were that the subject had to move to a new area, that the subject did not feel part of the circle of friends anymore, that they were ashamed of their disability, that it was too difficult to maintain friendship as friends did not visit anymore and that they felt different as if they were not the same persons anymore. At six months some subjects had few or no friends left and had not managed to make new friends, as they seldom socialized outside their homes. Some of the subjects terminated friendships out of free will as they did not feel comfortable with the friendship due to their disability or lack of mutual interests. There was no noticeable difference in degree of difficulty needed to interact with friends between discharge and six months. The degree of difficulty seemed to depend on the type of relationship they had with their friends prior to the SCI, availability of resources such as money and transport, interests they shared before and the level of acceptance and understanding of the disability, not only by their friends, but by the subjects themselves as well.

The majority of subjects had no difficulty in interacting and maintaining relationships with family members (d760) at discharge and six months. However at six months, a few more subjects reported some difficulty with performing this activity compared to at discharge. Although statistically not significant, participation in this activity did appear to be more difficult as time passed. All of the subjects who reported some difficulty at discharge and at six months had problematical relationships with family members prior to the SCI. After the injury it either stayed the same or deteriorated, but did not improve. For the small percentage of the subjects who had good

relationships with family members prior to the injury, especially parents and spouses, the relationships improved with time.

Maintaining intimate relationships with others was found to be the most difficult of all the relationships investigated. Forty-five percent of the subjects at discharge and 41% at six months had not resumed intimate relationships. A reason for the low level of participation even at six months could be that it was too difficult to resume intimacy with a partner, especially if it was not the same partner as before the SCI. Some subjects also reported that they found this activity too difficult and not worth continuing with. It was found that both participation and capacity had improved at six months, which means that more subjects found this activity easier to perform and needed less assistance. The results of this study, although not significant, show that maintaining intimate relationships after SCI was not easy.

5.6.5 Activity and participation profile for major life areas and community, social and civic life

See tables 4.28, 4.29, 4.30 and 4.31.

Statistical analysis of the activities “school education” (d820) and “non-remunerative employment” (d855) in the major life areas domain was not possible due to inadequate data, as these activities were not performed by the majority of the subjects before or after the SCI. What is worth mentioning is that one subject managed to resume his school education in a normal school despite the many barriers he had to confront. This success can be attributed, not only to environmental resources, but also to personal resources, which are currently not described in the ICF (WHO, 2001). The results of this study showed that participation in recreation and leisure activities (d920) is a real challenge after SCI. At discharge 79% of the subjects were not participating at this level and the majority of the remaining subjects found this activity difficult to perform. Although the majority of the subjects (63%) were involved in these activities, 37% of the subjects reported some difficulty. The results showed a significant improvement in participation at six months ($p < 0.001$) and capacity improved from 40% to 53%. Of concern however is the large percentage (37%) of subjects who were not involved in recreational activities at six months. Similar results were found with participation in religious and spiritual activities, although some subjects did not participate in this activity even before the SCI. It also seemed easier to perform these activities, compared to recreational activities, as the majority of the subjects reported no difficulty with performance. A possible reason for this finding could be that support structures amongst people worshipping together were already in place before the SCI. The small improvement in capacity to perform this activity at six months supports this presumption, rather than the notion that it became easier to perform this activity, although the level of participation had improved significantly ($p < 0.001$) at six

months. The improvement in participation, despite the fact that a large percentage of the subjects still needed assistance, showed that the necessary resources were available enabling the subjects to perform this activity.

Despite the small number of subjects who were in paid employment (d850) at six months, economic self-sufficiency (d870) had improved significantly ($p < 0.001$). This finding could be attributed to the large percentage of subjects (67%) who were receiving a disability grant at six months, whereas at discharge they had no income. This is supported by the finding that at discharge 83% of the subjects were not economically self-sufficient compared to 26% at six months. Participating in paid employment, especially at a permanent level, seems to have been a major problem even before being injured, but more so after the SCI. At the time of the injury, 60% percent of the subjects were in paid employment compared to 11% at six months. Possible reasons for this finding, as discussed in Section Two, point 5.4.2, were that the majority of the subjects were labourers doing physical work and in casual employment, because of their low levels of education. It is worth mentioning that the majority of the subjects were not seeking employment after sustaining a SCI. The degree of difficulty needed to perform this activity had decreased slightly at six months, although none of the subjects needed any assistance, even at discharge.

SECTION THREE

In this section the environmental factors identified as barriers by the sample at six months after discharge from the WCRC are discussed in detail. The different domains of the environmental factors component addressed in this study i.e. products and technology, support and relationships, attitudes and services, systems and policies will be discussed separately.

5.7 ENVIRONMENTAL FACTORS

Environmental factors are organized in the ICF to focus on two different levels i.e. individual and societal (WHO, 2001). The individual level represents the immediate environment of the individual including settings such as home, workplace and school. This level includes the physical and material features of the environment that the individual will experience as well as direct contact with other individuals in that environment (WHO, 2001). The societal level represents the formal and informal structures, services and overarching approaches or systems in the community or the society that have an impact on the individual. This level includes organizations and services related to the work environment, community activities, government agencies, communication and transportation services, informal social networks as well as laws, regulations, formal and informal rules, attitudes and ideologies (WHO, 2001).

Disability is characterized as the outcome or result of a complex relationship between an individual's health condition and the environmental factors that represent the circumstances in which the individual lives (WHO, 2001) and is therefore not static. This outcome provides information on whether the intervention should be at the level of the individual (e.g. providing assistive technology), the level of society (e.g. implementing anti-discrimination laws) or at both levels (Schneidert, Hurst, Millers & Ustun, 2003). Although changes in the physical environment will improve the ability of people with mobility impairments to participate in society, factors including family support, self-esteem, informational support and coping styles have a much greater impact on social participation (Scelza, Kirshblum, Wuermsler, Ho, Priebe & Chiodo, 2007).

5.7.1 Products and technology

Definition: "The natural or human-made products or systems of products, equipment and technology in an individual's immediate environment that are gathered, created, produced or manufactured" (WHO, 2001:173).

Specific barriers in this category identified by a significant number of subjects are personal consumption, indoor and outdoor mobility and transportation, employment, design of buildings for public and private use and land development (Table 4.32). These results support findings of a study conducted by Maart *et al.* (2007) on barriers experienced by people with disabilities living in the Western Cape. Although it also support findings of studies conducted elsewhere (Target *et al.*, 2004; Boschen *et al.*, 2003; Liese *et al.*, 2002), the findings of this study and of the Maart *et al.* (2007) study are of particular concern, since these studies were conducted many years after the publication of the INDS (1997).

Although the majority of subjects did not experience the availability of food or medication (e110) as a barrier (Table 4.32), it is unacceptable that four subjects reported that the absence of these substances had a moderate to severe impact on their lives. Two subjects had to beg for food and another two subjects, who were already struggling financially, had to buy medication privately as it was not regularly available at the relevant day hospitals. It is of great concern that people, especially with SCI, are denied the right to basic products necessary to maintain a healthy life style and to prevent secondary complications related to SCI. In their study conducted on environmental barriers experienced by persons with disabilities, Maart *et al.* (2007) found that twice as many people in the urban Western Cape, as in rural Eastern Cape reported barriers with the item eating and medicine. Possible reasons according to Maart *et al.* (2007) are that rural populations are for the most part farmers and have easier access to food they themselves have produced. In urban areas such as the Western Cape, people have to buy food. Without any financial resources because of unemployment,

this is very difficult. The two subjects of concern in this study did not qualify for a disability grant due to their minimal physical impairment after SCI, but according to them, they were too disabled to find a work suitable for their low levels of education.

Almost a quarter of the subjects identified indoor and outdoor mobility and transportation (e120) as a barrier (Table 4.32) for reasons such as an unsuitable wheelchair, inaccessibility of public transport for wheelchair users and inability to negotiate the terrain around their homes. The ability to function in the community is largely dependent on the ability to access and use public transport for the majority of the subjects in this study (Table 4.12). Unfortunately public transport in South Africa is not wheelchair or disability friendly which prevents people with disabilities who are dependent on public transport from participating in their communities. Community integration and participation is important as it has been proven to increase life satisfaction and quality of life after SCI (Whiteneck *et al.*, 2004). External factors which can be changed are therefore preventing these subjects from reaching their full functioning potential. In this case environmental barriers are causing the disability and not the physical impairment as a result of the SCI.

The majority of the subjects (Table 4.32) were not employed at six months, because they were not interested and therefore had not sought employment. According to them they could not work anymore due to their disability and were happy with receiving a disability grant. In many cases this was more than they would have earned before the SCI. For four subjects this item was a complete barrier, because although they were permanently employed at the time of injury, they were unable to perform the physical work required for their jobs and did not have the necessary level of education to perform any other work. One subject who could return to his previous job did not have transport to get to work and therefore his employment had been terminated. One subject who reported this item as a moderate barrier managed to keep his job, but the negative attitudes of his colleagues towards him for not being able to do everything that he was supposed to do, made his work environment very unpleasant. Of the six subjects who reported employment as a barrier, five had a grade eight to ten level of education and one subject a grade four to seven level of education. It is of concern that more than 60% of the subjects who wanted to work after the SCI, could not maintain their old jobs or find new jobs, mainly due to lack of education, transport and support from the employers/workplace.

A significant number of subjects identified the design and construction of buildings for public use (e150) and for private use (e155) as barriers to their daily functioning. With public buildings, accessibility was the main problem as reported by the subjects, and with private buildings the size was a problem. This often resulted in inadequate space to function with a wheelchair. Inaccessibility

and absence of toilets in private homes also had a negative impact on successful residential integration. Although these barriers do not prevent the subjects from social participation, it denies them their right to function independently and will eventually result in them avoiding these areas with a negative impact on their social integration. Maart *et al.* (2007) found in their study that more than 50% of the sample reported barriers with access to public buildings, which according to the authors is of concern, since their study was done seven years after the publication of the INDS of South Africa (1997) in which barrier-free access to all public buildings is recommended.

Eight subjects (Table 4.32) identified the item land-development (e160) as a barrier to community integration due to problems such as lack of pavements, too much sand, water drains that are not level or without lids, areas generally not wheelchair friendly and no ramps off pavements. For two of the subjects, the land development item posed a complete barrier to community integration as they were now dependent on others for mobility. Had the areas been wheelchair-friendly, all the subjects would have reported independent functioning with their wheelchairs.

In this study it was found that products and technology for communication (e125) and personal use in daily living (e115) had the smallest impact on the subjects' functioning (Table 4.32). The one subject with a high cervical lesion could not use any appliances in his house, including the telephone, as nothing was especially adapted to suit his needs due to lack of financial resources.

Products and technology for the practice of culture, recreation and sport (e140), and religion and spirituality (e 145), were not reported to be a huge barrier (Table 4.32). What is of more concern is that a significant number of subjects could not report on these items as they were, even at six months after discharge, not involved in any of these activities. Some of the reasons for identifying these items as either some or complete barriers are lack of transport, lack of sporting facilities for the disabled and/or lack of finances, and attitudes of friends. They also commented that asking for assistance made them feel like a burden to other people and especially to their friends.

5.7.2 Support and relationships

Definition: "People or animals that provide practical, physical or emotional support, nurturing, protection, assistance and relationships to other person in their home, place of work, school or at play or in other aspects of the daily activities" (WHO, 2001:187).

Ninety-three percent of the subjects in this study were extremely happy with the amount of support they received from immediate family members (e310) (Table 4.33). The two subjects, who had difficult relationships with their immediate families prior to the injury, experienced a

deterioration/worsening after the SCI, mainly because they (the subjects) could not contribute to the household income anymore.

Extended family members (e315) such as siblings, cousins, aunts and uncles were less supportive after the SCI as the subjects could not continue supporting the family members financially anymore.

Although the majority of the subjects still received support from the friends (e320) they had prior to the injury, only 63% reported this item to be no barrier. Five of the remaining subjects (19%) reported some barrier as the majority of friends had disappeared since the injury and therefore did not even provide emotional support. The other five subjects reported this item as being a complete barrier because they did not have any of the original friends left. These subjects also reported not being able to form new friendships as they felt they did not have anything to offer. Other reasons for experiencing difficulty with maintaining friendships, as reported by the subjects, were that they did not have money to contribute, that they could not do the same activities that the friends were doing and they did not agree with the friends' lifestyles anymore. However, all the subjects reported to still have a need for friends in their lives. The amount of support and the manner in which the support is provided by friends and extended family members seemed to be dependent on what they got in return.

All the subjects reported to be satisfied with the amount of support they received from caregivers (e340) and health professionals (e355) at all levels of care, especially at the WCRC.

One subject reported support of colleagues (e325) as a complete barrier as they were not willing to help him with things he could not do at work as a result of his disability (Table 4.33).

5.7.3 Attitudes

Definition: "The attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs" (WHO, 2001:190). The attitudes classified are those of the people external to the person whose situation is being described and not those of the person themselves.

In this study it was found that the attitudes of the immediate family members (e410) towards the subjects were generally good (Table 4.34). Although the majority of the subjects did not identify this item as a barrier as yet, some subjects did mention that although the amount of support was still the same at six months, the attitude in which the support was given was slowly starting to change. If this is already happening at six months after discharge, the likelihood that the attitudes and therefore the amount of support by the immediate family members will deteriorate as time passes, increases.

Two subjects however had already experienced the changing attitudes in such a way that they preferred not to ask for assistance anymore.

The result for the amount of support given by extended family members (e315) was the same as the result for the attitudes of the extended family members (e415) (Tables 4.33, 4.34). A possible reason for this is that the extended family members who were still supporting the subjects at six months want to, and are not required to support them as they are not the primary caregivers.

Although the majority of the subjects were still happy with the attitudes of their friends (e420) towards them, five subjects reported this item to be a barrier. According to these subjects their friends became irritated, frustrated and unhelpful towards them. As the attitudes changed, the support decreased. Five subjects reported not having any friends left and found it difficult to make new friends due to limited social participation.

The majority of the subjects did not experience the attitudes of health professionals (e450) as a barrier. Five subjects reported the attitudes of the health workers at their day hospitals and clinics as a barrier. According to them, these health professionals were impatient and made them feel as if they were doing them a favour by helping them. They also reported feeling humiliated as they were forced to wait until last or as if they did not have any rights.

The attitudes of people in positions of authority such as employers and lawyers (e430), personal caregivers (e440) and neighbours (e425) were considered to be generally good.

A significant number of subjects reported the attitudes of society (e460) as a moderate barrier (Table 4.34). They reported that people would become impatient if the subjects moved too slowly in shopping malls and if their wheelchairs took up too much space especially in public areas and taxis. This could be one of the reasons for the slow reintegration at community level as found in this study.

5.7.4 Services

Definition: “Services that provide benefits, structured programmes and operations, in various sectors of society, designed to meet the needs of individuals. (Included in services are the people who provide them). Services may be public, private or voluntary and may be established at a local, community, regional, state, provincial, national or international level by individuals, associations, organizations, agencies or governments” (WHO, 2001:192).

It was decided after the pilot study not to include systems and policies in this component as none of the subjects had any information about systems and policies which are in place or in the process of development in general, and especially for people with disabilities.

The findings with regard to the services component of the environmental factors only will now be discussed (Table 4.35). Specific barriers, in the services category identified by more than 40% of the subjects, were housing (e5250), labour and employment (e5900), transportation (e5400), general social support (e5750) and education and training services (e 5850).

The majority of the subjects reported that housing services (e 5250) were not applicable as they did not own any property or need to obtain property. It seemed as if they were accepting that they might not be able to possess a house due to their own poor socio-economic circumstances and in general the housing problem in South Africa (Rhodes, 2000). All the subjects lived with family members or friends despite the fact that the majority of these houses were already densely populated. Two subjects reported this item to be a complete barrier as they were living in temporary structures that were not suitable for persons with disabilities. They did not have any other refuge and according to them there were no government houses available. Only four subjects either possessed their own houses or could afford to pay rent. Although over one million houses have been built since 1994, the government estimates that an additional two to three million houses still need to be provided to the poor in South Africa (Knight, 2001). According to Rhodes (2000), the housing backlog in South Africa is double that of Zimbabwe. The backlog is exacerbated by high unemployment and leaves millions of people unable to afford houses and basic necessities (Knight, 2001). The result for the housing services item is not a true reflection of the problem regarding housing in South Africa. The fact that 78% of subjects accepted their circumstances with regard to possessing their own houses reflects the major problem of providing houses for the poor in this country.

The same problem regarding housing services also applies for labour and employment services (e5900). Eighty-one percent of the subjects reported that this item was not applicable (Table 4.35). The reason why the subjects identified this item as “not applicable” is because they were not employed at the time of data collection nor have they sought employment. But, what are the reasons for not seeking employment? Prior to the SCI the majority of these subjects were either unemployed or in casual employment, when it was available (Figure 4.13), therefore not earning a fixed monthly salary. After the SCI, the majority of the subjects received a monthly grant from the state (Figure 4.19) which they run the risk of losing if they become employed. This risk, their generally low levels of education (Table 4.7), a high national unemployment rate (SSA, 2005) and other contributing factors such as inaccessibility of public transport (Table 4.35), means that there is no

guarantee that they will be employed soon. Labour and employment services in South Africa, especially for people with disabilities, can therefore be seen as a huge barrier to a meaningful life after SCI.

The objective of sheltered employment is to offer short- to long-term employment to people with disabilities who wish to participate in the economy (Ramutloa, 2010). Currently in South Africa there are 12 sheltered employment factories (SEF) managed by the Department of Labour (DOL) operating in all the provinces except Mpumalanga and Limpopo. The SEF, according to Ramutloa (2010), were established to provide employment opportunities for persons with disabilities who are unable to work in the open labour market due to their disabilities, and to provide a haven for the emotionally, psychologically and physically challenged. In addition, according to Ramutloa (2010) the SEF could be a skills development route for people with disabilities, who could then enter the open labour market. This sounds very promising, however, to only provide temporary employment is not the answer if barriers such as transportation to and from work, accessibility of the work place and low levels of education and skill still exist.

Whether SEF provide the solution for unemployment after SCI is debatable and a subject for another study. In sheltered employment, “disabled” workers may be seen primarily as sick people who need to take part in some occupational activity for the sake of social participation for the rest of their working lives. More appropriately they should be seen as ordinary workers with rights and obligations, who are using sheltered employment as a transition to unsheltered employment (Ramutloa, 2010).

Public transportation services (e5400) were identified by a significant number of subjects as some or complete barrier, which is of concern as the majority of subjects are dependent on public transport. Nine of the 10 subjects that reported public transport to be a complete barrier were in wheelchairs. Some of the subjects had not tried to use public transport because they were not sure if they would be able to use it, and the ones that did try would never use it again, as it was too difficult to get in and out of the taxi and drivers were not keen on assisting them. Minibus taxi transport is quite expensive when you are in a wheelchair because you have to pay for yourself and the space the wheelchair takes up. None of the wheelchair dependent subjects had tried to utilize public buses or trains due to their inaccessibility and the distance from their homes. Fourteen subjects did not experience public transport as a barrier (Table 4.35). Interestingly all these individuals were functional walkers except for three who had their own transport.

The only alternative for those individuals who needed transport, but could not use public transport, was to use private transport provided by friends, neighbours or acquaintances. They however did

not have the financial ability to pay for private transport as it is expensive. As the availability and accessibility of transport for people with disabilities is key to social participation, including productive activity, these individuals have not managed to function at community level even after six months at home (Table 4.29).

General social support services (e5750) were identified as a complete barrier by all the subjects for the reason that although they actually need such a service, they are not aware of any such services within their communities. This type of service would be of great assistance to individuals who do not have transport available for the acquisition of goods and services or who need a caregiver, but cannot afford it.

Ninety-six percent of the subjects identified education and training services (e5850) to be a complete barrier. There is a great need for these individuals to receive further training and education as their general, pre-existing low levels of education (Table 4.7) and skills limit their employment opportunities after SCI.

Utility services (e5300), including running water and electricity and communication services (e5350) do not pose as barriers for the majority of the subjects (Table 4.35). Only one subject did not have an electricity supply to his dwelling. Since 1994 one and a half million electrification connections have been established and four million more people were given access to clean running water (Knight, 2001). The problem is that very few poor people can afford to pay for these services and community taps in informal settlements are not wheelchair accessible due to the uneven terrain. People with disabilities are therefore still dependent on family members or neighbours for clean water. All the subjects but one had access to either private phones or public phones within 50 metres of their homes. What is not known is whether they have the finances to utilize these phones.

Health services for individuals with SCI are provided mainly at primary level, unless specialized care is needed, which will then be provided at either secondary or tertiary facilities. A large percentage of individuals will also attend the outpatient department of the WCRC for specific problems that are related to spinal cord injuries. For the majority of the subjects, health services (e5800) especially at the WCRC, were not a barrier, although three subjects identified this item as either a moderate or a severe barrier because they did not receive the necessary supplies, including urinary catheters from the day hospitals (primary level) (Table 4.35). This is in agreement with findings of a study conducted in the urban areas of the Western Cape by Maart *et al.* (2007), but in contrast to studies conducted in the United States, in which health services were identified as one of the top five environmental barriers for persons with disabilities (Lysack *et al.*, 2007; Whiteneck *et al.*, 2004).

The majority of the subjects were satisfied with the social security services (e5700) provided by the government. Sixty-seven percent of the subjects (18/27) had been receiving a disability grant. Although they did not identify the service as a barrier, they all agreed that the amount they received was not sufficient to cover their expenses. For a large percentage of these individuals the disability grant was the only source of income for the whole family. One subject (4%) identified the service as a moderate barrier for the reason that although he was receiving a disability grant on a regular basis, his wife had been struggling for the past seven months to get a child support grant. The three subjects (11%) who identified this item as a complete barrier had been waiting more than six months for their first disability grant payout.

None of the subjects belonged to any associations or organizations (e5550), because they were not aware of these services and even if there were any available, they did not have the transport to attend the meetings. It is the opinion of the principal researcher that structured associations and organizations can provide an excellent opportunity for individuals with SCI to become part of society again. They would provide the opportunity not only to function away from home, but also to increase their resources for future functioning and reintegration at community and productive activity level.

5.8 ASSUMPTIONS

The principal researcher assumed that the necessary arrangements were made to ensure that the majority of the subjects will return for their six-month follow-up. This assumption proved to be incorrect. Although three contact telephone numbers were obtained for each subject, some subjects could not be contacted as numbers were discontinued, subjects were not living at the same addresses anymore or subjects did not receive messages. Some subjects were not interested in taking part in the study anymore as they felt that their participation in the study did not benefit them.

Subjects were also given a cash amount of fifty rand for transport at their six-month follow-up appointment, but some subjects did not have the money to get to the centre or the amount was not adequate to cover their expenses. As was proven later in the study, public transport was not accessible for especially wheelchair dependent subjects and private transport was too costly. The last option was to use Dial-A-Ride, a government subsidized transport service for persons with disabilities, but none of the subjects were registered with this service even at six months after discharge from the WCRC.

This resulted in a much lower return rate at six months than expected.

5.9 LIMITATIONS OF THE STUDY

- 1) The main limitation of this study was its small sample size. Based on a power calculation done prior to the study, a sample size of 50 was deemed sufficient for significant results to be obtained. This sample size could not be achieved mainly due to time constraints and the fact that a large number of subjects did not return for their follow-up appointment at six months after discharge. Important information was lost and although the results are representative of the study population, they could have been more significant with a larger sample at baseline to ensure a bigger sample size and compensate for drop-out.
- 2) A further limitation was the paucity of information on traumatic SCI in South Africa. Very few studies have been conducted in South Africa on the issues addressed in this study. Results of this study could therefore not be compared to other local studies. Due to the trends identified in this study, the results point to areas that need further attention (research and policy related). However, the paucity of information in South Africa on this topic clearly shows the lack of research in this area and therefore emphasises the importance of this study.
- 3) The study is further limited by the researcher's decision to only use the WCRC as the study setting. The reason for having chosen this particular setting for this study was that it is the only government-funded institution in the Western Cape for the provision of rehabilitation services, and therefore the institution where the majority of government-subsidized spinal cord injured persons will receive their rehabilitation after their SCI. Although the WCRC also accepts private patients, none of the subjects in this study were classified as private. One of the reasons for this is that there might be a perception regarding the safety of the institution, since it is located in Mitchell's Plain which is known as a high crime area. For this reason the results found in this study were not representative of the higher socio-economic group of people in the Cape Metropolitan area of the Western Cape.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 CONCLUSIONS

One of the aims of the ICF is "... to provide a basis for understanding and studying health and health-related states, outcomes and determinants..." (WHO, 2001:5). Through the use of the ICF and other measuring tools, this present study succeeded in establishing a demographic profile of the study population and providing a description and understanding of the level and determinants of functioning of a defined group of persons living with SCI in the Cape Metropolitan district of the Western Cape province. The main aim of this study was to establish the level of participation at different levels of society, within an urban area, after SCI. The results of this study are not necessarily applicable to people living with SCI in the rural areas of South Africa.

Results obtained in this study could have been influenced by the small sample size. Therefore general assumptions cannot be made for this study population nor for SCI populations in general. However, as the researcher could not find evidence of other studies with similar objectives that were conducted on persons with spinal cord injuries nationally or internationally, results could still be deemed relevant. Some results, especially those for the activity and participation profile, were clinically and statistically so significant that these issues should be addressed in order, not only to prevent traumatic SCI, but also to manage SCI optimally to ensure life satisfaction and quality of life after sustaining this devastating and life-changing injury.

In order to have a better understanding of the activity and participation profile of the sample, the demographic, medical and socio-economic characteristics were investigated. A demographic profile of traumatic SCI in South Africa is essential to describe this group and allows identification of focused areas for the prevention of SCI. The main conclusions will be outlined below.

6.1.1 Demographic and socio-economic characteristics

A person sustaining a traumatic SCI in the Cape Metropolitan area of the Western Cape province is most likely to be a male, young (20 to 29 years of age), of the Black or Coloured race and living in the Cape Flats suburbs. Seventy percent of the subjects were residing in the Cape Flats suburbs of the Western Cape where extreme poverty exists. The demographic profile of the subjects in this study is in the main comparable to international findings. However, more recent international studies showed that persons older than 65 years have become increasingly more at risk of sustaining a traumatic SCI, which was not found in this study. The high incidence of SCI amongst males in the 20 to 29 year category is of concern, as this is the time when these individuals should be

productively active supporting not only themselves, but in many cases also their families and as well as contributing to the economy of the country.

In this study it was found that more than half of the subjects, mainly represented by the Black and Coloured racial groups had only a grade eight to ten level of education, while the only two subjects of the White racial group had some tertiary education. These figures reflect the differences in the level of education amongst the different racial groups in South Africa.

At the time of injury, 60% of the subjects were in paid employment with the majority of these subjects employed as labourers on a casual basis, which could be explained by the generally low level of education amongst the Black and Coloured racial groups. At six months after discharge, only 11% of the subjects were employed, of which only seven percent were employed on a permanent basis. None of the subjects who were in casual employment at the time of the injury maintained their jobs, possibly due to their inability to perform a physical type of work and/or the complete lack of responsibility employers often have towards casual employees. With low levels of education and high unemployment rates amongst able-bodied individuals, of the Black and Coloured racial groups in South Africa in particular (SSA, 2005), there is virtually no need for employers to employ persons with physical disabilities. There is also less motivation to seek or create employment after the SCI as most of the subjects qualify for a disability grant, which in many cases is more than what they earned prior to the injury and furthermore guarantees a fixed monthly income. Sixty-seven percent of the subjects in this study received a disability grant from the government as a result of their SCI.

According to reviews on return to work after SCI conducted by Yasuda *et al.* (2002), levels of education have been consistently reported to be positively correlated to return to work after SCI. It does seem from the results of this study that a tertiary level of education, and not necessarily race, is positively associated with employment after SCI as both subjects, one of the Black and one of the White racial group, with some form of tertiary education were in permanent employment at six months after discharge from the WCRC.

6.1.2 Medical characteristics

According to Burt (2004), the etiology of traumatic SCI is a reflection of the social and economic circumstances in individual countries around the world. In the current study, acts of violence including gunshot and stab injuries were found to be the leading cause of traumatic SCI, especially amongst the Black and Coloured racial groups, followed by road traffic accidents. These conclusions support the findings of a previous study conducted in South Africa by Hart and

Williams (1994), but contradict findings of international studies where road traffic accidents and falls were the leading etiology of traumatic SCI in developed and developing countries respectively.

In this study it was found that the majority of the subjects were paraplegic, which is in agreement with data collected internationally before 2000. However, data collected after 2000, showed that the incidence of tetraplegia is increasing internationally and sometimes even exceeds paraplegia. There were more incomplete neurological lesions compared to complete (55% vs. 45%). Complete paraplegia was the most common neurological disability found in this study and occurred mainly in the thoracic cord. This is in agreement with international findings where injuries of the thoracic cord tend to be of a complete nature.

The importance of an accurate baseline clinical assessment is emphasized as the completeness of traumatic SCI is one of the most important prognostic indicators for neurological recovery and functional outcomes after SCI (Lim & Tow, 2007). The subjects in this study were mainly from the ASIA A, C and D impairment groups at discharge and A and D groups at six months. The number of subjects classified as ASIA A at discharge is almost identical to the number classified as ASIA A at six months, which supports the theory that the prognosis for a patient with an ASIA A to become incomplete is poor (Lim & Tow, 2007; Burns & Ditunno, 2001; Marino *et al.*, 1999). Fewer subjects were classified as ASIA grade C at six months compared to the number in this grade at discharge. An explanation for this could be that some of the subjects of the ASIA C group have improved to an ASIA D, as the prognosis for improvement from an ASIA grade C to an ASIA grade D is extremely good (Lim & Tow, 2007; Burns & Ditunno, 2001; Marino *et al.*, 1999). As subjects from the ASIA D group are not wheelchair dependent, it could have been easier for them to utilize public transport to come to the WCRC for their follow-up appointment compared to subjects from the ASIA A, B and C groups who were wheelchair dependent.

Due to the enormous impact that a spinal cord injury has on the functioning of several body systems, i.e. urinary, cutaneous, respiratory, cardiovascular and musculo-skeletal systems, secondary medical conditions are extremely common in patients with SCI. Cardenas *et al.* (2004) found that the incidence of re-hospitalisation after traumatic SCI in the first year after discharge was significantly higher than in any of the other follow-up years, especially for patients funded by state programmes. In this study it was found that at six months after discharge, secondary conditions had occurred in the majority of the subjects and that 96% of the subjects' medical care was funded by the state, thus putting them at a high risk for developing secondary conditions.

Not only does this put an extra burden on the economy of the state, but the occurrence of secondary conditions has a profoundly negative impact on the quality of life (Anson & Shephard, 1996) and

the development of secondary conditions in the post-acute stage is the leading cause of death in persons with SCI (DeVivo *et al.*, 1999). The existence of a specific primary condition such as SCI is a strong risk factor for specific secondary conditions to develop and due to this causal relationship between the primary and secondary conditions, preventative measures can be introduced to reduce the risk of developing these secondary conditions (Pope & Tarlov, 1991). One of the objectives of this study was therefore to identify and describe the occurrence of secondary complications at specific points in time after SCI.

As this study is the first study of its kind in South Africa, a local comparison was not possible and international comparisons are limited by different study objectives and sample sizes. Despite these limitations, the findings of this study did support, or sometimes contradict the available literature on this matter, and therefore provided some perspective on the incidence and type of secondary complications that occur after SCI in South Africa.

The most common secondary condition found in this study on admission, at discharge and at six months after discharge from the WCRC was pain. The highest incidence of musculo-skeletal and neuropathic pain was found at six months after discharge from the WCRC. Back pain was on average the most common pain reported at all three points in time, followed by neuralgia and shoulder pain. The incidence of shoulder pain was slightly higher at six months compared to that reported at discharge although still fairly low in general. These findings were expected, since shoulder pain as a result of overuse is more common during later years after SCI (Chiodo *et al.*, 2007; Noreau *et al.*, 2000) and shoulder pain of a more acute nature due to the spinal cord injury or associated trauma is more common during the acute phase of rehabilitation (Salisbury *et al.*, 2003). Pain is a serious problem for many people with spinal cord injuries (Spinal Cord Injury Model Systems Consumer Information, 2009) and the most frequently reported reason for decreased quality of life (Widerstrom-Noga *et al.*, 2001). Addressing this problem at a bio-medical, psychological and psychosocial level should therefore be considered as a priority (Widerstrom-Noga *et al.*, 2001). Although this study does not provide information on the underlying pathology causing the pain, it does show that chronic or long-standing pain is a significant occurrence after SCI, which supports the existing literature.

The second most common secondary complication found was spasticity limiting function, which supports international findings. Spasticity is a symptom of an upper motor-neuron lesion and is therefore a common occurrence after SCI. Spasticity however, can cause problems such as soft tissue contractures, pain resulting in poor positioning and hygiene, amongst others, as well the reduced ability to perform functional activities (Adams & Hicks, 2005). Not only is the occurrence

and severity of spasticity after SCI important, but even more important is the need to investigate the influence of the spasticity on body structures and the ability to perform useful work with the preserved motor function (Adams & Hicks, 2005).

The low incidence of pressure sores and urinary tract infections found in this study contradicts findings of previous studies. The reason for this could be the differences in the methodology utilized in this study. As the occurrence of these two conditions, according to Kroll *et al.* (2007), are strong predictors of recurrences, further research on this matter is necessary to decrease the incidence of these conditions as the passage of time after injury increases.

Due to improvements in medical, surgical and rehabilitation care, the life-expectancy of people with SCI has increased since 1950 and now often exceeds 30 years ((Bloemen-Vrencken *et al.*, 2005; Noreau *et al.*, 2000; Charlifue *et al.*, 1999; Anson & Shepherd, 1996; Pope & Tarlov, 1991). These individuals' potential to develop secondary complications related to the SCI are now greater (Pope & Tarlov, 1991) as well as health conditions associated with the aging process (Charlifue *et al.*, 1999). As older people are more susceptible to the development of secondary complications after SCI, the extra cost of ongoing medical care after SCI also puts an extra burden on the state and on the families.

As this study has demonstrated, secondary complications after SCI do occur within the first six months after discharge from the rehabilitation setting; it is therefore suggested that patients are followed up sooner than one year after discharge from the rehabilitation setting to minimize these problems.

6.1.3 Living environment after discharge

Successful residential reintegration is the first step to resuming previous roles and responsibilities in society, post-injury. All the subjects were discharged to homes not always suitable for persons with physical disabilities, but with the necessary personal and/or non-personal resources available to function in their current environment. The ultimate outcome for an individual living with SCI is to be as independent as possible at all levels of functioning. Factors unrelated to physical impairment often had an impact on an individual's independence. Due to the inaccessibility or lack of facilities at residential level, some of these individuals were dependent on the personal resources available to them to function. Dependency can have a severe emotional impact, especially if environmental factors are the only factor preventing individuals from becoming more independent. Being dependent on others for activities as basic as washing yourself, preparing a meal or as private as emptying your bowels might result in feelings of humiliation and frustration. Personal resources by

way of carers were found to be available at six months after discharge. It is disconcerting however, that a rising trend of negative attitudes and less availability was already appearing upon follow up of these subjects. Concern is therefore raised about the sustainability of the independence of persons with SCI in the long term. With the publication of the White Paper on the INDS (1997), the government of South Africa recognized equal rights for all members of society and committed themselves to promote the quality of life of each citizen, including the most vulnerable in society, i.e. persons with disabilities, senior members and children. Through the establishment of the Office on the Status of Disabled Persons, the government furthermore committed themselves to the upliftment and improvement of the conditions of the disabled members of society through extensive changes in the environment to accommodate their diverse needs (INDS, 1997).

Fourteen years after the publication of the White Paper on the INDS (1997) it was found in this study that 19% of the subjects were discharged to informal dwellings or shacks. Sixty-six percent of the subjects had no bath or shower facility in which to wash and were dependent on others to bring them a basin with water. For 47% of the subjects water had to be collected from outside taps. Thirty-two percent of the subjects did not have a toilet or could not use it due to structural barriers and were forced, on occasion to use their beds or the neighbours' toilets. The quality of life of these persons with SCI is therefore severely curtailed by the lack of basic services such as water and sanitation. With the publication of the INDS (1997) the government of South Africa committed themselves through the development of legislation to ensure equal participation of persons with disabilities; however the implementation of these policies has lagged behind. This delay has not assisted the realization of an improved quality of life for all individuals with disabilities, including persons with SCI.

6.1.4 Activity and participation

The goal of rehabilitation is to promote the full inclusion and participation of people with disabilities in their physical and psychosocial environment (Stiens *et al.*, 2002), enabling them to re-establish previously existing roles and relationships (Dijkers, 1998). The main objective of this study was to describe the level of participation or the extent to which the subjects have managed to resume their social roles and relationships at six months after discharge from the WCRC. The present study succeeded in establishing an activity and participation profile of the study population at these points in time. Since associations between the activity and participation profile, specific characteristics and environmental barriers were not investigated, a conclusion about the reasons for the level of participation found in this study could not be made. However, information gathered in this study on these aspects provided some insight into possible reasons for the level of reintegration

into residential, community and civic life. The ICF (WHO, 2001) was found to be an excellent tool to gather the necessary information for this study on the reintegration of persons with SCI disability into society.

The results of this study indicated that basic functional activities in the mobility and self-care domains, such as maintaining and changing body positions, transfers and activities of daily living were performed with or without assistance and with various degrees of difficulty by all the subjects at discharge and at six months. The ability to execute these activities (capacity) without any assistance improved at six months for all the activities in these domains, except for washing (d510) and dressing (d540), moving into the sitting position (d4103), lifting and carrying objects (d430) and moving around using a wheelchair (d465) where fewer subjects were able to execute these activities without assistance at six months. Participation, in relation to the degree of difficulty with which these activities are performed, had improved for all the activities in these domains with the exception of moving into the sitting position. Although the activity was still performed, the degree of difficulty required for moving into the sitting position was reported to be greater at six months. A possible reason for the decrease in capacity for moving into the sitting position could be that the subjects relied on the personal assistance available at home to perform this activity, because it is much easier with help, especially for those with the more serious neurological lesions, in which case participation would have improved. As participation had decreased for this activity at six months, it is also likely that the higher incidence of spasticity limiting function found in this study at six months made it more difficult for subjects to move into the sitting position, forcing more of them to utilize personal assistance. To participate in the mobility and self-care domains at discharge and at six months, non-personal and/or personal assistance was available and therefore utilized to perform all the activities included in these domains.

At discharge very few subjects were involved in domestic, religious, recreational and productive activities. However, at six months the majority of the subjects had resumed their previous roles at residential and community levels, with the exception of productive activity. The most improvement in participation occurred in the domestic life domain. All the subjects, except one, who performed these activities prior to their SCI, were performing them at six months. The improvement in level of participation in all the activities in this domain was highly significant ($p=0.01$). Capacity for all the activities (except assisting others - d660) had improved as more subjects were able to perform these activities without assistance. Since the majority of the subjects did not have the opportunity to resume these activities prior to discharge, the subjects reported a significant improvement in participation in this domain. It is also possible that the subjects who were performing these activities at discharge found it much easier to do so at six months.

The second most improved level of participation was noted in the recreational (d920) and religious (d930) activities in the community, and in the social and civic life domain. The improvement in performance in both activities was highly significant ($p < 0,001$) at six months. Capacity had also improved, as more subjects were able to perform these activities without assistance at six months. Reasons for these findings are the same as for the domestic domain. Although participation had improved significantly at six months, it is of great concern that more than one third of the subjects were not re-integrated at community level even at six months after discharge. Reasons for this, as reported by some of the subjects, were lack of recreational facilities, lack of financial resources, termination of relationships with friends, inaccessibility of public transport, forced changes in life style and personal factors such as not wanting to be a burden to other people, poor self image and general lack of interest in functioning outside their homes. Reintegration, not only in employment, but also in recreational and sport activities is considered an important goal for rehabilitation, as these factors are strongly associated with a better quality of life and life satisfaction (Schonher *et al.*, 2005). Most of the participants in their study were found to be satisfied with their lives, even if they did not succeed in returning to work, but were able to utilize their time formerly spent on work on other activities such as sport and recreational activities. Schonher *et al.* (2005) concluded that reduced quality of life was particularly associated with an unsatisfactory vocational and leisure experience.

Returning to work after SCI is considered to be the ultimate goal of rehabilitation, as it brings both economic and intrinsic rewards and is related to greater life satisfaction, a higher level of activities and better overall health (Krause, 2003). In this study it was found that none of the subjects were actively involved at a productive level at discharge, although four percent of the subjects were employed at this point in time. The remaining subjects were unemployed. At six months 11% of the subjects were employed. The subjects who were employed at discharge were still employed at six months. Therefore only one of the subjects who returned for their six-month follow-up appointment managed to find employment after discharge from the WCRC.

According to Giaquinto and Ring (2007), individuals with SCI are generally very eager to resume their jobs despite all the barriers. Except for one subject, none of the subjects that were unemployed at six months had sought employment. According to these individuals, they were unable to do any (physical) work as a result of their disability or no longer saw the need to work as the majority (71%) were receiving a government grant. This financial resource was in many cases equal to, or more than, what they earned prior to the injury. Despite the fact that the majority of the subjects were unemployed at six months, the receipt of a grant caused a highly significant improvement ($p < 0,001$) in the experience of economic self-sufficiency for these subjects. Although not studied,

the relationship between the economic reward in the form of a grant and the perceived improvement in their quality of life, self-esteem and life satisfaction is questionable.

People classified as ASIA D, with greater functional capacity, a history of employment at the time of injury, greater motivation in returning to work, a non-violent injury and an ability to drive are more likely to work again (Giaquinto & Ring, 2007). In this study it was found that 48% of the subjects were classified as ASIA D; 60% of the subjects were employed at the time of injury; for 58% the cause of SCI was due to violent acts; 7% were able to drive at six months and 85% were not motivated to be employed. Comparing the characteristics of this sample to those of Giaquinto and Ring (2007), there is a possibility of employment for some of these individuals. It is however difficult to comment on the likelihood of employment after SCI for the study population, as 85% of the subjects had made no attempt to seek employment by the date of follow up.

Although the severity of the physical disability does play a role in being employed after SCI, personal barriers, i.e. low levels of education and lack of motivation, have a negative impact on returning to work. The physical and environmental barriers are therefore also important influential factors. The personal barriers might be more difficult to overcome than the environmental barriers especially if there is no need or motivation, since a monthly income is guaranteed as a result of the disability. These individuals' dependency on a grant places an extra burden on the economy of the country and increases poverty for a large number of people who are dependent on the disabled individual for financial support. The majority of the subjects agreed that the grant is not adequate to cover all their expenses.

The positive side to these results is that most of the subjects had an income after, and as a result of their injury. The impact it has on discouraging self efficacy and self sufficiency remains troubling.

6.1.5 Environmental factors identified as barriers

In the United States the top five environmental factors identified as barriers were the natural environment, transportation, help at home, health care and government policies (Whiteneck *et al.*, 2004), which are similar to findings by Lysack *et al.* (2007). It is very difficult to compare findings of developed countries to those of developing countries due to different government policies regarding persons with disabilities, but even more so because of the availability of resources to address the needs of such persons. However, the consequences of a SCI are the same for a person living in the United States as for a person living in Africa, therefore the needs of these individuals remain essentially the same. Successful rehabilitation of these individuals is dependent on specific

policies and the availability of resources to protect the rights and to address the needs of the disabled in their respective countries.

In this study the respondents reported the highest number of barriers within the services category, followed by products and technology. The findings of this study are similar to those of the study conducted by Maart *et al.* (2007) who investigated environmental barriers experienced by persons with disability living within the urban Western Cape region of SA. However, in their study the highest number of people reported barriers in the category natural environment and man-made changes to the environment, which was not included in this study. The reason for not including this category in the study was that during the development of the questionnaires it was seen as not really appropriate, but due to the extreme climate conditions in the Western Cape with its heavy and continuous rain in winter and the strong south-easterly wind blowing in the summer, it is understandable that the climate can pose as a barrier to their day-to-day living, especially if they live in informal settlements and if dependent on wheelchairs for mobility. It is therefore suggested that the climate item of this category should be included in further studies.

Although the majority of the subjects did not report products or substances for personal consumption as a barrier, it is of concern that the unavailability of medication and medical supplies at the day hospitals and clinics was reported as having a negative impact on some of the subjects' lives. This could result in the development of secondary conditions related to SCI which were found to be the leading cause of mortality after SCI (DeVivo *et al.*, 1999).

Results found for the employment item in both the products and technology and services, systems and policies domains can be misleading and should be explained. Employment after SCI, as mentioned before, is positively associated with quality of life, self-esteem and life satisfaction. The majority of the subjects were not working at six months nor had they sought employment, therefore they did not identify these domains as barriers. For this reason the results were documented as "not applicable", which is in fact incorrect, as for reasons mentioned before, employment after SCI is the main goal of rehabilitation and is therefore very applicable. Similar results were found for culture, recreation and sport in the products and technology domain and should be interpreted in the same way. For individuals who cannot work or find employment, involvement in recreational and leisure activities after SCI is very important. Participation in recreational activities and sport was found to be both physiologically and psychologically beneficial after SCI (Slater & Meade, 2004). Individuals with SCI who could not manage to return to work were still satisfied with their lives, as time formerly spent on employment was now spent on activities such as sport and leisure activities (Schonher *et al.*, 2005).

The fact that almost a third of the subjects reported that there are barriers related to design of buildings for public use is of concern and unacceptable fourteen years after the publication of the White Paper on the INDS (1997) which aimed to ensure the equal participation of people with disabilities. Similar results were found for land development.

The lowest number of barriers was reported in the support and relationships category. This is a positive finding as individuals with SCI are very dependent on physical, emotional and informational support and assistance. This is especially important in the absence of other environmental facilitators to ensure a good quality of life. What is of concern is that already at six months after discharge the amount of support given by extended family members and friends was decreasing, which put a much bigger burden on immediate family members. However, the attitudes of the remaining friends and extended family members who were still giving support at six months were very good compared to those of the immediate family members. The attitudes of support structures at home were deteriorating, which is similar to what was found by Lyzack *et al.* (2007). One third of the subjects also experienced the negative attitudes of society as a barrier. What is worth mentioning is that the majority of the subjects were satisfied with the amount of support and the attitudes with which the health professionals provided support.

The highest number of barriers was reported in the services, systems and policies domain and specifically for the items of transportation, general social support, education and training services. It is important to note that only services were investigated in this domain. All of the subjects reported a complete lack of general social support services in their communities. These services are essential for community reintegration and to provide some relief for the immediate family members in their caring duties. Ninety-six percent of the subjects reported education and training services to be a complete barrier as the opportunity to further their studies or training in order to increase their chances of finding employment, was not provided. The importance of employment after SCI cannot be emphasized enough and one of the possible reasons for the poor employment rate after SCI found in this study could be the low levels of education of the majority of the subjects. Almost half of the subjects (majority being wheelchair dependent) did not use public transport because it was inaccessible. As very few of the subjects had private transport available, the identification of transportation services as an environmental barrier is of concern since this could prevent reintegration at community level after SCI. Access to your community is essential for an improved quality of life.

Although general assumptions cannot be made, the results still provide some insight into environmental barriers faced by individuals with SCI living in urban settings in the Western Cape

Province. They can also be a good source of data in further research as this is the first study of its kind conducted in South Africa. The importance of the impact of environmental barriers on the lives of individuals with SCI cannot be emphasized enough, as environmental factors are risk factors for the development of secondary impairments and disabilities in addition to the disability initiated by the SCI trauma (Fougeyrollas, Noreau & Boschen, 2002).

6.1.6 The publication of the White Paper on the INDS (1997) and its role in the equalization of opportunities for people with disabilities

At this point it is necessary to view the legislation that has been developed by the government of South Africa to eliminate the environmental barriers as found in this study in order to ensure equal participation of disabled people at all levels of society. To address this issue the Offices of the Status of Disabled Persons have been established in the Office of the Presidency as well as in the Offices of the Provincial Premiers. They are responsible for the overall co-ordination and monitoring of the implementation of the INDS (DPSA, 2008). The development and publication of the White Paper on the INDS (1997) expressed the government's commitment to the development of disabled people in South Africa and the promotion and protection of their rights (INDS, 1997). The principles of the United Nations Standard Rules for the Equalization of Opportunities for Persons with Disabilities (WHO, 1993) have been endorsed by the government of South Africa and included in the White Paper. The White Paper has developed policy objectives, strategies and mechanisms for each of the key policy areas as identified. These areas include prevention, health care, rehabilitation, public education, barrier free access, transport, communications, data collection and research, education, employment, human resource development, social welfare and community development, social security, housing and sport and recreation (INDS, 1997). A large number of these key areas are included in the environmental factors component of the ICF (WHO, 2001) and therefore in this study as well. Social assistance, in the form of disability grants, has been the most successful development programme (Gathiram, 2008). The INDS (1997) claims that to break the economic dependency of disabled people requires a programme of poverty eradication which includes social grants and, of more importance, affirmative action to remove the barriers which prevent their economic participation in mainstream employment and social enterprise development. The disability grant is being used as a poverty reduction strategy for the survival of families, and other developmental initiatives such as vocational training centres, the Expanded Public Works Programme (EPWP), the skills development strategy and legislation supporting integration in the labour market have been less successful (Gathiram, 2008). It was found in this study that at six months after discharge from the WCRC only 7% of the subjects were employed and 67% were receiving a disability grant with no intention of integration into the labour market. Employment

after SCI has been found to increase quality of life, life satisfaction and self-esteem, as well as identifying who you are and giving meaning to life.

In order to achieve the vision of the INDS (1997) i.e. a society for all, there must be an integration of disability issues in all government development strategies, planning and programmes. Although the government of South Africa acknowledges the rights of disabled people in the country and shows their commitment towards the protection of these rights with the development and publication of the White Paper, the findings of this study indicate that the implementation of these policies has lagged behind. Fourteen years after the publication of the White Paper (INDS, 1997) some of the key areas included in the White Paper, such as barrier free access, transport, education, employment, social welfare, community development, housing and sport and recreation were still reported by the subjects in this study to be barriers towards playing a full, participatory role in society.

The main finding of this study was that the process of reintegration in community and productive activity is a difficult and slow process for persons after SCI living in the Cape Metropolitan district of the Western Cape Province. Based on the current study, the main reasons for this finding are inaccessibility of public transport for persons with severe physical disability, lack of recreational and sport facilities for the disabled, low levels of education and lack of skills to find new employment. Furthermore, the lack of motivation to seek employment, possibly as a result of the social security policy for disabled people in this country, is of great concern. Instead of receiving a life-long grant from the state, it is the opinion of the principal researcher that persons with disability should be empowered through education and skills-development to ensure equal access to economic opportunities.

6.2 RECOMMENDATIONS

As a direct result of the present study the researcher would like to make the following recommendations for; (a) service planning and delivery and (b) further studies:

6.2.1 Recommendations for service planning and delivery

1) Development of a national statistics register for SCI

There is a serious lack of reliable information on the prevalence of disability and specifically SCI in South Africa. SCI is viewed as one of the great calamities that can befall humans (Dijkers, 2005), often resulting in profound and long-term disability, with serious consequences for the individual, his/her family and society as a whole. Suffering a SCI poses a financial burden on the injured

individual and the healthcare system. Significant costs are involved throughout the life of a person with SCI, including initial hospitalization and re-hospitalizations due to the occurrence of secondary conditions related to the SCI. Service needs may include acute rehabilitation, assistive devices, medical supplies, medications and personal assistance. In addition to these costs there is the loss of income and productivity related to unemployment or underemployment after SCI (Priebe, Chiodo, Scelza, Kirshblum, Wuermsler & Ho, 2007). All these costs place a heavy burden not only on the individual and his family but also on the economy of the state especially when, as found in this study, the majority of these individuals are dependent on the state for health care and social security grants. Epidemiology studies and a national statistics register of SCI in South Africa should be a priority, as this will provide information on incidence and prevalence, identify high-risk groups and thus provide insight into resource allocation and preventative strategies (Pickett *et al.*, 2006).

2) Prevention of secondary conditions related to traumatic SCI

The existence of a specific primary condition such as SCI, is a strong risk factor for specific secondary conditions to develop. Due to this causal relationship between the primary and secondary conditions, preventative measures can be introduced to reduce the risk related to its development (Pope & Tarlov, 1991). In this study it was found that at six months after discharge, secondary conditions had occurred in the majority of the subjects. However, at the WCRC patients with traumatic SCI are only followed up one year after discharge, unless they develop problems before that time (Roodt, 2011).

It is therefore suggested that the patients are followed up much sooner and at regular intervals after their discharge from the WCRC to prevent the occurrence of secondary conditions. Life-long follow-up of these individuals, starting at least three months after discharge, is essential to minimize this serious problem. Attending follow-up appointments at the WCRC might be a problem for some of the patients, as transport services have been identified by the subjects as one of the major environmental barriers experienced by persons with disabilities in the Cape Metropole. It is therefore suggested that individuals with SCI are followed up by roving specialized teams at specialized clinics closer to their homes, enabling more of them to attend.

3) Assess the appropriateness of the rehabilitation services for community reintegration delivered at the WCRC

The findings of this study will be shared with the management and health professionals at the WCRC to ensure that the current rehabilitation of people with SCI is appropriate to meet their needs for reintegration. This will facilitate re-integration, not only at residential level, but also at community and productive levels.

4) Implementation of policies and legislation to ensure that persons with disabilities are treated as equal citizens

The Constitution of the Republic of South Africa Act 108 of 1996 and Bill of Rights (1996) ensure that disabled people have the same access to social and economic opportunities to improve their quality of life. Furthermore, with the publication of the INDS White Paper (1997) the government of South Africa has committed itself to the development of disabled people in South Africa and the promotion and protection of their rights. It is therefore of concern that 14 years after the publication of the INDS (1997), the commitment of the government to full integration of disabled people at all levels of society is not observed in practice (Gathiram, 2008). Notably absent in the implementation of the legislation is multi-sectoral collaboration to ensure equal access to services and upliftment of the disabled population. Findings of this study support conclusions drawn by Gathiram (2008) on the developmental approach to disability in South Africa.

It is therefore essential to enforce the implementation of legislation already in place by making stakeholders accountable for their lack or delay in implementation. This can be further strengthened through negotiations and mass action to guarantee full social reintegration, economic integration through employment and not through a social security grant.

6.2.2 Recommendations for further studies

Recommendations for further studies, resulting from this study, include:

1. Qualitative research on the experience of SCI and a more detailed exploration of the reintegration progress, environmental barriers and especially quality of life after SCI. It is therefore recommended that a quality of life questionnaire and/or focus group interviews be included in further studies as this is strongly associated with reintegration at community and productive activity levels.
2. Epidemiology studies to determine the risk factors for the occurrence of pain and secondary complications at different points in time after SCI, as pain is strongly associated with poor quality of life, and secondary conditions with mortality after SCI.
3. Studies to determine employment rates after SCI in South Africa.
4. Exploring relationships between community reintegration after SCI and medical-, socio-economic characteristics and perceived environmental factors.

5. Investigate the reasons why persons with disability are still experiencing environmental barriers that exclude them from social and economic life, despite the fact that these issues were acknowledged and addressed by government policies.
6. Include smaller centres and private rehabilitation facilities in future studies to increase the representation of the population across socio-economic levels. It is often assumed that individuals classified as private patients have more resources to facilitate community reintegration and return to work. This will provide information on the qualitative and quantitative impact of SCI on members of the different socio-economic classes.
7. Extend the study population to rural areas and other provinces to make it more representative of the population across the country.
8. Future research projects should encourage subjects to register with Dial-A-Ride prior to discharge to ensure a better return rate, as transport problems were identified as the main reason for the low return rate in this study.

REFERENCES

- Adams, M.M. & Hicks, A.L. 2005. Spasticity after spinal cord injury. *Spinal Cord* 43:577-586.
- Amsters, D.I., Pershouse, K.J., Price, G.L. & Kendall, M.B. 2005. Long duration spinal cord injury: Perceptions of functional change over time. *Disability and Rehabilitation* 27(9):489-497.
- Angus, J., Kontos, P., Dyck, I., McKeever, P. & Poland, B. 2005. The personal significance of home: habitus and the experiencing of receiving long-term home care. *Sociology of Health & Illness* 27:161-187.
- Anson, C.A. & Shepherd, C. 1996. Incidence of secondary complications in spinal cord injury. *International Journal of Rehabilitation Research* 19:55-66.
- Anzai, K., Young, J., McCullum, J., Miller, B. & Jongbloed, L. 2006. Factors influencing discharge location following high lesion spinal cord injury rehabilitation in British Columbia, Canada. *Spinal Cord* 44:11-18.
- Apple, D.F. 1998. From the Editor: The Fifth Tenet. *Topics in Spinal Cord Injury Rehabilitation: Community Reintegration: Part 1* 4(1).
- Bergmark, B.A., Winograd, C.H. & Koopman, C. 2008. Residence and quality of life determinants for adults with tetraplegia of traumatic spinal cord injury etiology. *Spinal Cord* 46:684-689.
- Bickenbach, J.E., Chatterji, S., Bradley, E.M. & Usten, T.B. 1999. Models of disablement, universalism and the International Classification of Impairments, Disability and Handicaps. *Social Science & Medicine* 48:1173-1187.
- Biering-Sorensen, F., Pedersen, V. & Clausen, S. 1990. Epidemiology of spinal cord lesions in Denmark. *Paraplegia* 28:105-118.

- Biering-Sorensen, F., Scheuringer, M., Baumberger, M., Charlifue, S.W., Post, M.W.M., Montero, F., Kostanjsek, N. & Stucki, G. 2006. Developing core sets for persons with spinal cord injuries based on the International Classification of Functioning, Disability and Health as a way to classify functioning. *Spinal Cord* 44:541-546.
- Bloemen-Vrencken, J.H.A., Post, M.W.M., Hendriks, J.M.S., De Reus, E.C.E., De Witte, L.P. 2005. Health problems of persons with spinal cord injury living in the Netherlands. *Disability and Rehabilitation* 27(22):1381-1389.
- Boschen, K.A., Tonack, M. & Gargaro, J. 2003. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 26(3):157-164.
- Bozzolini, G. & Cassibba, S. 2008. Improving home accessibility for a person with a disability after spinal cord injury. *European Journal of Physical & Rehabilitation Medicine* 44:455-459.
- Burns, A.S. & Ditunno, J.F. 2001. Establishing prognosis and maximum functional outcomes after spinal cord injury. *Spine* 26(S24):S137-S145.
- Burt, A.A. 2004. The epidemiology, natural history and prognosis of spinal cord injury. *Current Orthopaedics* 18(1):26-32.
- Cardenas, D.D., Hoffman, J.M., Kirshblum, S. & McKinley, W. 2004. Etiology and incidence of rehospitalization after traumatic spinal cord injury: A multicenter analysis. *Archives of Physical Medicine and Rehabilitation* 85:1757-63.
- Carpenter, C., Forwell, S.J., Jongbloed, L.E. & Backman, C.L. 2007. Community participation after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 88(4):427-433.
- Chan, S.C.C. & Chan, A.P.S. 2005. Rehabilitation outcomes following traumatic spinal cord injury in a tertiary spinal cord injury centre: a comparison with an international standard. *Spinal Cord* 43:489-498.
- Charlifue, S. & Gerhart, K. 2004. Community integration in spinal cord injury of long duration. *NeuroRehabilitation* 19(2):91-101.

- Charlifue, S.W., Weitzenkamp, D.A. & Whiteneck, G.G. 1999. Longitudinal outcomes in spinal cord injury: ageing, secondary conditions and well-being. *Archives of Physical Medicine and Rehabilitation* 80:1429-34.
- Chen, C.F. & Lien, I.N. 1985. Spinal cord injuries in Taipei, Taiwan 1978-81. *Paraplegia* 23(6):364-370.
- Chen, D.C., Apple, D.F. (Jr.), Hudson, L.M. & Bode, R. 1999. Medical complications during acute rehabilitation following spinal cord injury – current experience of the model systems. *Archives of Physical Medicine and Rehabilitation* 80:1397-1401.
- Chiodo, A.E., Scelza, W.M., Kirshblum, S.C., Wuermsler, L-A., Ho, C.H. & Priebe, M.M. 2007. Spinal cord injury medicine. 5. Long-term medical issues and health maintenance. *Archives of Physical Medicine and Rehabilitation* 88(S1):S76-S83.
- Cloete, M. 2007. Correspondence. 22 June, Mitchell's Plain.
- Cohen, M.E., Ditunno, J.F. (Jr.), Donovan, W.H. & Maynard, F.M. (Jr.). 1998. A test of the 1992 International Standards for Neurological and Functional Classification of Spinal Cord Injury. *Spinal Cord* 36:554-560.
- Conroy, L. & McKenna, K. 1999. Vocational outcome following spinal cord injury. *Spinal Cord* 37(9):624-33.
- Constitution of the Republic of South Africa. 1996. Bill of Rights: Chapter 2 Act 108.* [S.a.] [Online]. Available: <http://www.info.gov.za/documents/constitution/1996/a108-96>. [2010, June 17].
- Corrigan, J.D. 1994. Community integration following traumatic brain injury. *NeuroRehabilitation* 4:109-121.
- Dawodu, S.T. 2007. *Spinal cord injury: Definition, epidemiology, pathophysiology.* Available: <http://www.emedicine.com>. [Online]. [2009, February 19].

De Kleijn-de Vrankrijker, M.W. 2003. The long way from the International Classification of Impairments, Disabilities and Handicaps (ICIDH) to the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 25(11-12):561-564.

DeVivo, M.J., Krause, J.S. & Lammertse, D.E. 1999. Recent trends in mortality and causes of death among persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 80:1411-1419.

DeVivo, M.J., Richards, J.S., Stover, S.L. & Go, B.K. 1991. Spinal cord injury - rehabilitation adds life to years, in rehabilitation medicine - adding life to years [Special Issue]. *The Western Journal of Medicine* 154:602-606.

Dijkers, M. 1998. Community Integration: conceptual issues and measurement approaches in rehabilitation research. *Topics in Spinal Cord Injury Rehabilitation* 4(1):1-15.

Dijkers, M. 2005. Quality of life of individuals with spinal cord injury: review of conceptualization, measurement and research findings. *Journal of Rehabilitation Research and Development* 42:87-110.

Disabled People of South Africa (DPSA). 1993. *Disability Rights Charter of South Africa* [Online]. Available: <http://www.dpsa.org.za/documents/disabilityrightscharter.php> [2011, July 22].

Ditunno, J.F. (Jr.), Young, W., Donovan, W.H. & Creasy, G. 1994. The International Standards Booklet for Neurological and Functional Classification of Spinal Cord Injury. *Paraplegia* 32:70-80.

Drummond, A. 1996. *Research methods for therapists*. London: Chapman & Hall.

Dutton, D.B. & Levine, S. 1989. Overview, methodological critique and reformulation, in J.P. Bunker, D.S. Gomby & B.H. Kehrler (eds.). *Pathways to health* (pp. 29-69). Menlo Park, California: The Henry J. Kaiser Foundation. 29-69.

Dvorak, M.F., Fisher, C.G., Hoekema, J., Boyd, M., Noonan, V., Wing, P. & Kwon, B. 2005. Factors predicting motor recovery and functional outcome after traumatic central cord syndrome: a long-term follow-up. *Spine* 30(20):2303-2311.

Dzidic, I. & Moslavac, S. 1997. Functional skills after the rehabilitation of spinal cord injury patients: observation period of 3 years. *Spinal Cord* 35:620-623.

Education in South Africa. [S.a.] [Online]. Available: <http://www.southafrica.info> [2010, July 16].

Eltorai, I.M. 2003. *History of spinal cord medicine*. [Online]. Available: <http://www.demosmedpub.com> [2011, February 2].

Fehlings, M.G. & Perrin, R.G. 2005. The role and timing of early decompression for cervical spinal cord injury: update with a review of recent clinical evidence. *Injury* 36(S2):S13-S26.

Fougeyrollas, P., Noreau, L. & Boschen, K.A. 2002. Interaction of environment with individual characteristics and social participation: theoretical perspectives and applications in persons with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 7(3):1-16.

Furlan, J.C., Krassioukov, A.V. & Fehlings, M.G. 2003. The effects of gender on clinical and neurological outcomes after acute cervical spinal cord injury. *Journal of Neurotrauma* 20:368-381.

Gathiram, N. 2008. A critical review of the developmental approach to disability in South Africa. *International Journal of Social Welfare* 17:146-155.

Gerhart, K.A., Bergstrom, E., Charlifue, S.W., Menter, R.R. & Whiteneck, G.G. 1993. Long-term spinal cord injury: functional changes over time. *Archives of Physical Medicine and Rehabilitation* 74:1030-1034.

Giaquinto, S. & Ring, H. 2007. Return to work in selected disabilities. *Disability and Rehabilitation* 29(17):1313-1316.

Go, B.K., DeVivo, M.J. & Richards, J.S. 1995:21-55. The epidemiology of spinal cord injury. In: Stover, S.L., Delisa, J.A. & Whiteneck, G.G. (eds.). *Spinal cord injury: clinical outcomes from the model systems*. Aspen, Gaithersburg.

Govender, R. & Allopi, D. 2001. *Towards a safer minibus taxi industry in South Africa*. [Online]. Available: <http://www.up.ac.za> [2011, June 10].

Greenwald, B.D., Seel, R.T., Cifu, D.X. & Shah, A.N. 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. *Archives of Physical Medicine and Rehabilitation* 82:1181-1187.

Hart, C. & Williams, E. 1994. Epidemiology of spinal cord injuries: a reflection of changes in South African society. *Paraplegia* 32:709-714.

Hess, D.W., Meade, M.A., Forchheimer, M. & Tate, D.G. 2004. Psychological well-being and intensity of employment in individuals with a spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 9:1-10.

Hess, D.W., Ripley, D.L., McKinley, W.O. & Tewksbury, M. 2000. Predictors for return to work after spinal cord injury: a 3-year multicentre analysis. *Archives of Physical Medicine and Rehabilitation* 81:359-363.

Ho, C.H., Wuermsler, L-A., Priebe, M.M., Chiodo, A.E., Scelza, W.M. & Kirshblum, S.C. 2007. Spinal Cord Injury Medicine. 1. Epidemiology and classification. *Archives of Physical Medicine and Rehabilitation* 88(3,S1):S49-S54.

Hurlbert, R.J. 2006. Strategies of medical intervention in the management of acute spinal cord injury. *Spine* 31(SII):S16-S21.

Hurst, R. 2003. The International Disability Rights Movement and the ICF. *Disability and Rehabilitation* 25(11-12):572-576.

Integrated National Disability Strategy (INDS) White Paper (1997). [S.a.] [Online]. Available: <http://www.info.gov.za/whitepaper> [2010, April 16].

Jackson, A.B. & Groomes, T.E. 1994. The incidence of respiratory complications following spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 75:270-275.

Jelsma, J. & Sykes, C. 2008. The use of the ICF in collecting data through large scale surveys. Unpublished paper. University of Cape Town, Cape Town.

Karamehmetoglu, S.S., Unal, S., Karacan, I., Yilmaz, H., Togay, H.S., Ertiken, M., Dosoglu, M., Ziyal, M.I., Kasaroglu, D. & Hakan, T. 1995. Traumatic spinal cord injuries in Istanbul, Turkey. An epidemiological study. *Paraplegia* 33:469-471.

Kirshblum, S., Millis, S., McKinley, W. & Tulskey, D. 2004. Late neurological recovery after traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 85:1911- 1817.

Knight, R. 2001. *Housing in South Africa*. [Online]. Available: <http://www.richardknight.homestead.com>. [2011, July 17].

Krause, J.S. 1992. Employment after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 73:163-169.

Krause, J.S. 2003. Years to employment after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 84:1282-1289.

Krause, J.S., Sternberg, M., Maides, J. & Lottes, L. 1998. Employment after spinal cord injury: differences related to geographic region, gender and race. *Archives of Physical Medicine and Rehabilitation* 79:615-624.

Kroll, T., Neri, M.T. & Ho, P-S. 2007. Secondary conditions in spinal cord injury: results from a prospective survey. *Disability and Rehabilitation* 29(15):1229-1237.

Lan, C., Lai, J.S., Chang, K.H., Jean, Y.C. & Lien, I.N. 1993. Traumatic spinal cord injuries in the rural region of Taiwan: an epidemiological study in Hualien county, 1986-1990. *Paraplegia* 31:398-403.

Lee, T.T. & Green, B.A. 2002. Advances in the management of acute spinal cord injury. *Orthopedic Clinics of North America* 33(2):311-315.

Levins, S.M., Redenbach, D.M. & Dyck, I. 2004. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study. *Physical Therapy* 84(6):496-509.

- Licina, P. & Nowitzke, A.M. 2005. Approach and considerations regarding the patient with spinal cord injury. *Injury* 36(S2):S2-S12.
- Lidal, I.B., Huynh, T.K. & Biering-Sørensen, F. 2007. Return to work following spinal cord injury: a review. *Disability and Rehabilitation* 29(17):1341-1375.
- Liese, H., MacLeod, L. & Drews, J.R. 2002. Barriers to employment experienced by individuals with mobility impairments. *Spinal Cord Injury Psychosocial Process* 13:21-30.
- Lim, P.A.C. & Tow, A.M. 2007. Recovery and regeneration after spinal cord injury: a review and summery of recent literature. *Annals, Academy of Medicine, Singapore* 36:49-57.
- Lin, M-R., Hwang, H-F., Yu, W-Y. & Chen, C-Y. 2009. A prospective study of factors influencing return to work after traumatic spinal cord injury in Taiwan. *Archives of Physical Medicine and Rehabilitation* 90:1716-1722.
- Lyseck, C., Komanecky, M., Kabel, A., Cross, K. & Neufeld, S. 2007. Environmental factors and their role in community integration after spinal cord injury. *Canadian Journal of Occupational Therapy* 74:243-254.
- Maart, S., Eide, A.H., Jelsma, J., Loeb, M.E. & Ka Toni, M. 2007. Environmental barriers experienced by urban and rural disabled people in South Africa. *Disability & Society* 22(4): 357-369.
- Marino, R.J., Ditunno, J.F., Donovan, W.H. & Maynard, F. 1999. Neurologic recovery after traumatic spinal cord injury: Data from the Model Spinal Cord Injury Systems. *Archives of Physical Medicine and Rehabilitation* 80:1391-1396.
- Martz, E., Livneh, H., Priebe, M., Wuersmer, L. & Ottomanelli, L. 2005. Predictors of psychosocial adaptation among people with spinal cord injury and disorder. *Archives of Physical Medicine and Rehabilitation* 86:1182-1192.

Maynard, F.M. (Jr.), Bracken, M.B., Creasy, G., Ditunno, J.F. (Jr.), Donovan, W.H., Ducker, T.B., Garber, S.L., Marino, R.J., Stover, S.L., Tator, C.H., Waters, R.L., Wilberger, J.E. & Young, W. 1997. International Standards for the Neurological and Functional Classification of Spinal Cord Injury. *Spinal Cord* 35:266-274.

Maynard, F.M., Karunas, R.S. & Waring, W.P. 1990. Epidemiology of spasticity following traumatic spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 71:566-569.

McColl, M.A., Charlifue, S., Glass, C., Savicm, G. & Meehan, M. 2002. International differences in ageing and spinal cord injury. *Spinal Cord* 40:128-136.

McKinley, W.O. & Meade, M.A. 2004. Community integration following SCI. *NeuroRehabilitation* 19:79-80.

McMahon, B.T., Shaw, L.R., West, S.L. & Waid-Ebbs, K. 2005. Workplace discrimination and spinal cord injury: The National EEOC ADA Research Project. *Journal of Vocational Rehabilitation* 23(3):166-162.

McVeigh, S.A., Hitzig, S.L. & Craven, B.C. 2009. Influence of sport participation on community integration and quality of life: a comparison between sport participants and non-sport participants with spinal cord injury. *Journal of Spinal Cord Medicine* 32(2):115-124.

Middleton, J.W., Truman, G. & Geraghty, T.J. 1998. Neurological level effect on the discharge functional status of spinal cord injured persons after rehabilitation. *Archives of Physical Medicine and Rehabilitation* 79:1428-1432.

National Department of Transport (South Africa). *Annual transport statistics*. 2001. [Online]. Available: <http://www.transport.gov.za> [2011, June 10].

National Spinal Cord Injury Statistical Centre (NSCISC) (2008). *Spinal Cord Injury Facts and Figures at a Glance Information Sheet*. [Online]. Available: [http:// www.nscisc.uab.edu](http://www.nscisc.uab.edu) [2010, November, 16].

Nemunaitis, G., Haines, M., Rizk, T. & Clark, G. 2003. The community integration of wheelchair athletes. [Abstract]. *Journal of Spinal Cord Medicine* 26(S1):S35.

- Njoki, E., Frantz, J. & Mpfu, R. 2007. The impact of spinal cord injury on South African youth. *South African Journal of Physiotherapy* 63(2):32-34.
- Nockels, R.P. 2001. Non-operative management of acute spinal cord injury. *Spine* 26(S24): S31-S37.
- Noreau, L., Dion, S., Vachon, J., Gervais, M. & Laramee, M. 1999. Productivity outcomes of individuals with spinal cord injury. *Spinal Cord* 37(10):730-736.
- Noreau, L. & Fougeyrollas, P. 2000. Long term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disability and Rehabilitation* 22(4):170-180.
- Noreau, L., Fougeyrollas, P., Post, M. & Asano, M. 2005. Participation after spinal cord injury: the evolution of conceptualization and measurement, *Journal of Neurologic Physical Therapy* 29(13):147-156.
- Noreau, L., Proulx, P., Gagnon, L., Drolet, M. & Laramée, M-T. 2000. Secondary impairments after spinal cord injury. A population-based study. *American Journal of Physical Medicine and Rehabilitation* 79(6):526-535.
- Northwest Regional Spinal Cord Injury System (NRSCIS). 2005. *Staying healthy after spinal cord injury: Pain after spinal cord injury. Information leaflet*. [Online]. Available: <http://www.sci.washington.edu> [2011, June 4].
- Pentland, W., Harvery, A.S., Smith, T. & Walker, J. 1999. The impact of spinal cord injury on men's time use. *Spinal Cord* 37:786-792.
- Pickett, G.E., Campos-Benitez, M., Keller, J.L. & Duggal, N. 2006. Epidemiology of traumatic spinal cord injury in Canada. *Spine* 31(7):799-805.
- Pierce, C.A., Richards, J.S., Gordon, W. & Tate, D. 1999. Life satisfaction following spinal cord injury and the WHO model of functioning and disability. *Spinal Cord Injury Psychosocial Process* 12:124-127.

Pope, A.M. & Tarlov, A.R. (eds.). 1991. *Disability in America: towards a national agenda for prevention*. Washington, DC: National Academy Press.

Post, M.W., van Dijk, A.J., van Asbeck, F.W. & Schrijvers, A.J. 1998. Life satisfaction of persons with spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 78:395-401.

Potter, P.J., Wolfe, D.L., Burkell, J.A. & Hayes, K.C. 2004. Challenges in educating individuals with SCI to reduce secondary conditions. *Topics in Spinal Cord Injury Rehabilitation* 10(1):30-40.

Priebe, M.M., Chiodo, A.E., Scelza, W.M., Kirshblum, S.C., Wuermsler, L-A. & Ho, C.H. 2007. Spinal Cord Injury Medicine. 6. Economic and societal issues in spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 88(3,S1):S84-S88.

Prysak, G.M., Andresen, E.M. & Meyers, A.R. 2000. Prevalence of secondary conditions in veterans with spinal cord injury and their interference with life activities. *Topics in Spinal Cord Injury Rehabilitation* 6(1):34-42.

Putzke, J.D., Hicken, B.L. & Richards, J.S. 2002. Race: predictor versus proxy variable after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 83:1603-1611.

Putzke, J.D. & Richards, J.S. 2001. Nursing home residence; quality of life among individuals with spinal cord injury. *American Journal of Physical Medicine and Rehabilitation* 80:404-409.

Ramutloa, L. 2010. *Sheltered employment factories*. [Online]. Available: <http://www.labour.gov.za> [2011, July 18].

Reed, G.M., Lux, J.B., Bufka, L.F., Peterson, D.B., Threats, T.T., Trask, C., Stark, S., Jacobson, J.W. & Hawley, J.A. 2005. Operationalizing the International Classification of Functioning, Disability and Health in clinical settings. *Rehabilitation Psychology* 50(2):122-131.

Rentsch, H.P., Bucher, P., Dommen Nyffeler, I., Wolf, C., Hefti, H., Fluri, E., Wenger, U., Wälti, C. & Boyer, I. 2003. The implementation of the International Classification of Functioning, Disability and Health (ICF) in daily practice of neurorehabilitation: an interdisciplinary project at the Kantonsspital of Lucerne, Switzerland. *Disability and Rehabilitation* 25(8):411-421.

- Rhodes, W.S. 2000. *Furthering the South African Housing Renaissance*. Presentation by William Stacy Rhodes, USAID/SA Mission Director, at the Institute Of Housing Conference October 13, 2000. [Online]. Available: <http://www.sa.usaid.gov/southafrica> [2011, July 17].
- Richards, J.S., Bombardier, C.H., Tate, D., Dijkers, M., Gordon, W. & Shewchuk, R. 1999. Access to the environment and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 80:1501-1506.
- Richards, J.S., Waites, K., Chen, Y.Y., Kogos, S. & Schmitt, M.M. 2004. The epidemiology of secondary conditions following spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 10(1):15-29.
- Roodt, D.W. 2011. Correspondence. 30 August, Mitchell's Plain.
- Rouillard, S. 2007. Pattern of recovery and outcome after stroke in patients accessing a Western Cape rehabilitation facility. Unpublished master's thesis. Cape Town: University of Cape Town.
- Salisbury, S.K., Choy, N.L. & Nitz, J. 2003. Shoulder pain, range of motion and functional motor skills after acute tetraplegia. *Archives of Physical Medicine and Rehabilitation* 84:1480-1485.
- Scelza, W.M., Kirshblum, S.C., Wuermsler, L-A., Ho, C.H., Priebe, M.M. & Chiodo, A.E. 2007. Spinal cord injury medicine. 4. Community reintegration after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 88(3,S1):S71-S75.
- Schneidert, M., Hurst, R., Miller, J. & Usten, B. 2003. The role of the environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation* 25(11-12):588-595.
- Schonherr, M.C., Groothoff, J.W., Mulder, A. & Eisma, W.H. 2005. Participation and satisfaction after spinal cord injury: results of a vocational and leisure outcome study. *Spinal Cord* 43:241-248.
- Sekhon, L.H.S. & Fehlings, M.G. 2001. Epidemiology, demographics and pathophysiology of acute spinal cord injury. *Spine* 26:S2-S12.

Siosteen, A., Lundqvist, C., Blomstrand, C., Sullivan, L. & Sullivan, M. 1990. The quality of life of three functional spinal cord injury subgroups in a Swedish community. *Paraplegia* 28: 476-488.

Sipski, M.L., Jackson, A.B., Gómez-Marín, O., Estores, I. & Stein, A. 2004. Effects of gender on neurological and functional recovery after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 85:1826-1836.

Slater, D. & Meade, M.A. 2004. Participation in recreation and sports for persons with spinal cord injury: review and recommendations. *NeuroRehabilitation* 19:121-129.

South African Government Services. 2011. *Disability grant*. [Online]. Available: <http://www.services.gov.za> [2011, June 21].

South African Human Rights Commission (SAHRC). 2002. *Towards a Barrier-Free Society*. [Online]. Available: <http://www.info.gov.za> [2010, April 16].

Spinal cord injury model systems consumer information. 2009: *Pain after spinal cord injury*. [Online]. Available: <http://www.upmc-sci.org> [2011, June 4].

Statistics South Africa (SSA). 2005. *Census 2001*. [Online]. Available: <http://www.stats.gov.za> [2010, June 2].

Stiens, S.A., Kirshblum, S.C., Groah, S.L., McKinley, W.O. & Gittler, M.S. 2002. Spinal Cord Injury Medicine. 4. Optimal participation in life after spinal cord injury. Physical, Psychosocial and economic reintegration into the environment. *Archives of Physical Medicine and Rehabilitation* 83(S1):S72-S82.

Stucki, G., Cieza, A. & Melvin, J. 2007. The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of the rehabilitation strategy. *Journal of Rehabilitation Medicine* 39:279-285.

Stucki, G., Ewert, T. & Cieza, A. 2002. Value and application of the ICF in rehabilitation medicine. *Disability and Rehabilitation* 24(17):932-938.

- Stucki, G. & Melvin, J. 2007. The ICF: a unifying model for the conceptual description of physical and rehabilitation medicine. *Journal of Rehabilitation Medicine* 39:286-291.
- Targett, P., Wehman, P. & Young, C. 2004. Returning to work for persons with spinal cord injury: designing work supports. *NeuroRehabilitation* 19:131-139.
- Taricco, M., Colombo, M.D., Adone, R., Chiesa, M.D., Di Carlo, S., Borsani, M., Castelnuovo, E., Ghirardi, G., Lascioli, R. & Liberati, A. 1992. The social and vocational outcome of spinal cord injury patients. *Paraplegia* 30:214-219.
- Tasiemski, T., Bergstrom, E., Savic, G. & Gardner, B.P. 2000. Sports, recreation and employment following spinal cord injury – a pilot study. *Spinal Cord* 38:173-184.
- Tonack, M., Hitzig, S.L., Craven, B.C., Campbell, K.A., Boschen, K.A. & McGillivray, C.F. 2008. Predicting life satisfaction after spinal cord injury in a Canadian sample. *Spinal Cord* 46:380-385.
- Townsend, E. & Ryan, B. 1991. Assessing independence in community living. *Canadian Journal of Public Health* 82:52-57.
- United States Census Bureau (USCB). 2010. *Census results*. [Online]. Available: <http://www.census.gov> [2011, July 25].
- Usten, T.B., Chatterji, S., Bickenbach, J., Kostanjsek, N. & Schneider, M. 2003. The International Classification of Functioning, Disability and Health: a new tool for understanding disability and health. *Disability and Rehabilitation* 25(11-12):565-571.
- Van Asbeck, F.W.A., Post, M.W.M. & Pangalila, R.F. 2000. An epidemiological description of spinal cord injuries in The Netherlands in 1994. *Spinal Cord* 38:420-424.
- Van den Berg, M.E.L., Castellote, J.M., Mahillo-Fernandez, I. & de Pedro-Cuesta, J. 2010. Incidence of spinal cord injury worldwide: a systematic review. *Neuroepidemiology* 34(3): 184-192.

Van den Berg-Emons, H.J.G., Bussmann, J.B.J., Sluis, T.A.R., Bergen, M.P., Van der Woude, L.H.V. & Stam, H.J. 2004. Restoration of the level of everyday physical activity during spinal cord rehabilitation: preliminary results. [Abstract]. *Journal of Rehabilitation Research and Development* 41:25

Visser, M., Van den Berg-Emons, R., Sluis, T., Bergen, M.B., Stam, H. & Bussmann, H. 2008. Barriers to and facilitators of everyday physical activity in persons with a spinal cord injury after discharge from the rehabilitation centre. *Journal of Rehabilitation Medicine* 40:461-467.

Wade, D.T. & de Jong, B.A. 2000. Recent advances in rehabilitation. *British Medical Journal* 320:1385-1388.

Welage, N. & Liu, K.P.Y. 2008. Review of a home and community integration programme for people with spinal cord injuries in Hong Kong and its relevance to Sri Lanka. *Hong Kong Journal of Occupational Therapy* 18(1):34-39.

Western Cape Rehabilitation Centre (WCRC). 2009. [S.a.] [Online]. Available: <http://www.capegateway.gov.za/eng/directories/projects/15020/76162> [2009, July 25]

Whiteneck, G., Meade, M.A., Dijkers, M., Tate, D.G., Bushnik, T. & Forchheimer, M.B. 2004. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 85:1793-803.

Whiteneck, G., Tate, D. & Charlifue, S. 1999. Predicting community re-integration after spinal cord injury from demographic and injury characteristics. *Archives of Physical Medicine and Rehabilitation* 80:1485-1491.

Widerström-Noga, E.G., Felipe-Cuervo, E. & Yezierski, R.P. 2001. Relationships among clinical characteristics of chronic pain after spinal cord injury. *Archives of Physical Medicine and Rehabilitation* 82:1191-1197.

Williams, V. 1996. *Welcome to the Cape Flats. A virtual journey*. [Online]. Available: <http://www.capeflats.org.za> [2011, June 10].

World Health Organization (WHO). 1980. *The International Classification of Impairments, Disabilities and Handicaps*. [Online]. Available: <http://www.who.int/classifications> [2008, October 18].

World Health Organization (WHO). 1981: *Disability Prevention and Rehabilitation. Report of the WHO Expert Committee on Disability Prevention and Rehabilitation. WHO Technical Report No. 668, Geneva*. [Online]. Available: http://whqlibdoc.who.int/trs/WHO_TRS_668.pdf [2011, November 7].

World Health Organization (WHO). 1993. *United Nations Standard Rules on the Equalization of Opportunities for Persons with Disability*. [Online]. Available: <http://www.un.org> [2010, April 22].

World Health Organization (WHO). 2001. *International Classification of Functioning, Disability and Health (ICF)*. Geneva, Switzerland, WHO.

World Health Organization (WHO). 2003. *ICF Checklist*. [Online]. Available: <http://www.who.int/classifications/icf/training/icfchecklist.pdf> [2007, September 18].

World Health Organization Family of International Classifications. [S.a.] [Online]. Available: <http://www.who.int/classifications/en/> [2008, October 18].

Wuermsler, L-A., Ho, C.H., Chiodo, A.E., Priebe, M.M., Kirshblum, S.C. & Scelza, W.M. 2007. Spinal cord injury medicine. 2. Acute management of traumatic and non-traumatic injury. *Archives of Physical Medicine and Rehabilitation* 88(S1):S55-S61.

Wyndaele, M. & Wyndaele, J-J. 2006. Incidence, prevalence and epidemiology of spinal cord injury: what learns a worldwide literature survey? *Spinal Cord* 44:523-529.

Yarkony, G.M., Roth, E.J., Heinemann, A.W., Lovell, L. & Wu, Y. 1988. Functional skills after spinal cord injury rehabilitation: three-year longitudinal follow-up. *Archives of Physical Medicine and Rehabilitation* 69:111-114.

Yasuda, S., Wehman, P., Targett, P., Cifu, D.X. & West, M. 2002. Return to work after spinal cord injury: a review of recent research. *NeuroRehabilitation* 17:177-186.

APPENDIX I

Description of codes attached to ASIA impairment scale (AIS) (Ditunno *et al.*, 1994)

ASIA IMPAIRMENT SCALE

A = Complete: No motor or sensory function is preserved in the sacral segments S4-S5.

B = Incomplete: Sensory but not motor function is preserved below the neurological level and extends through the sacral segments S4-S5.

C = Incomplete: Motor function is preserved below the neurological level, and the majority of the key muscles below the neurological level have a muscle grade less than 3.

D = Incomplete: Motor function is preserved below the neurological level and the majority of the key muscles below the neurological level have a muscle grade greater than or equal to 3.

E = Normal: Motor and sensory function is normal.

APPENDIX II

INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)

INTRODUCTION

The ICF is a classification of human functioning and disability (ICF: WHO, 2001). A variety of conceptual models has been proposed to understand and explain disability and functioning, such as the medical and social model (ICF: WHO, 2001). Historically disability assessment has been based on the premise that by assessing impairments in body structures and function, the person's ability to function in daily life can be determined. Therapy has therefore focused on addressing these person-level issues (impairments) in a clinical environment and it was assumed that improvement in body structures and function will improve functional ability in everyday situations. This approach of addressing the impairment directly caused by disease, trauma or other health conditions to decrease the disability reflects the medical model. Management of the disability therefore requires medical care provided by health professionals, or the individual's adjustment and behavior change (Reed *et al.*, 2005; WHO, 2001).

In contrast to the medical model, the social model of disability sees disability as a complex collection of conditions, many of which are created by the social environment, therefore the management of the problem requires social action to assure full participation of people with disabilities in all areas of social life (WHO, 2001).

The ICF is a classification of health and health-related domains and is based on the integration of two opposing models i.e. the medical and social models for the management of disability and functioning. These domains are classified by means of two lists: (1) Body Functions and Structures and (2) Activities and Participation. In contrast to the medical and social models a biopsychosocial approach is used in the ICF (WHO, 2001). The biopsychosocial approach allows users to assess and document the impact of health conditions on human functioning from a biological, individual and societal perspective (Reed *et al.*, 2005; WHO, 2001).

Since functioning and disability is a product of health characteristics and the context in which the individual functions a list of environmental factors is included in the ICF to assess the impact of the environment on the individual (WHO, 2001).

DEVELOPMENT OF THE ICF

The International Classification of Functioning, Disability and Health (ICF) belongs to the Family of International Classifications (WHO-FIC, 2008) developed by the World Health Organization (WHO) for application to various aspects of health. The purpose of the WHO-FIC is to promote the appropriate selection of classifications in settings in the health field across the world. Internationally endorsed classifications facilitate the storage, retrieval, analysis and interpretation of data. The ICF is the WHO's framework for measuring health and disability at both individual and population levels (WHO, 2001).

The ICF was developed from, and officially replaced the International Classification of Impairments, Disabilities and Handicaps (ICIDH) (WHO, 1980). The ICIDH was criticized for not allowing the measurement of environmental and social barriers and facilitators in the process of disablement (Bickenbach *et al.*, 1999). According to Stucki *et al.* (2002), the approval of the ICF by the World Health Assembly in May 2001 is an exiting landmark event for rehabilitation medicine. The purpose of the ICF is to provide a standard language and framework for description of human functioning and disability for common use in every day work by the multi-professional team (Rentsch *et al.*, 2003). The ICF defines components of health and health-related components of well-being. The health and health-related domains contained in the ICF are described from the perspective of the body, the individual and the society in two basic lists: (1) Body Functions and Structures; and (2) Activities and Participation. "Functioning" is a term encompassing all body functions, activities and participation and "disability" serves as an umbrella term for impairments, activity limitations and participation restrictions. The ICF actually describes what a person with a specific disease or disorder does do (performance) or can do (capacity), but in contrast with the ICIDH lists the environmental factors that interact with all these constructs (WHO, 2001).

Diseases, disorders and injuries are classified primarily in the International Classification of Disease, Tenth Revision (ICD-10) and together with the ICF provides a broader and more meaningful picture of the health of people or a population, which can be used for decision-making purposes (WHO, 2001).

The WHO family of international classifications provides a valuable tool to describe and compare the health of populations in an international context. The ICF has moved away from being a "consequences of disease" classification (1980 version) to a "components of health" classification (WHO, 2001).

The aims of the ICF are as follows:

- to provide a scientific basis for understanding and studying health and health-related states, outcomes and determinants;
- to establish a common language for describing health and health-related states in order to improve communication between different users;
- to permit comparison of data across countries, health care disciplines, services and time;
- to provide a systematic coding scheme for health information systems (WHO, 2001).

The ICF can and has been used since 1980 (then known as the ICIDH) for various purposes, for example:

- as a statistical tool – in the collection and recording of data;
- as a research tool – to measure health outcomes;
- as a clinical tool – in needs assessment and rehabilitation and outcome evaluation;
- as a social policy tool – in social security planning, compensation systems and policy design and implementation;
- as an educational tool – in curriculum design and to raise awareness and undertake social action (WHO, 2001).

DEVELOPMENT OF ICF CORE SETS FOR PERSONS WITH SPINAL CORD INJURY (SCI)

Spinal Cord Injury (SCI) is defined as an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory or autonomic function (Dawodu, 2007). Probably due to the increased survival after traumatic SCI the prevalence of SCI has increased over the last 2 decades (Biering-Sorensen, Scheuringer, Baumberger, Charlifue, Post, Montero, Kostanjsek & Stucki, 2006). The likely result of this increasing prevalence is an increase in the number of persons living with chronic disabling conditions (Biering-Sorensen *et al.*, 2006).

Long term functional outcomes for SCI are a result from acute neurological recovery and medical intervention, rehabilitation social participation (Biering-Sorensen *et al.*, 2006). To ensure optimal acute and long term management of SCI, an in-depth understanding, systematic consideration and sound measurement of its consequences at different levels is essential (Biering-Sorensen *et al.*, 2006). Persons with SCI may experience a wide range of activity limitations and participation restrictions relating to, amongst other, mobility, activities of daily living, employment, social relationships and being active members of the community. As activity limitations for SCI are a direct or indirect result from the SCI, participation restrictions a person with a SCI might experience

are dependant on environmental factors (Whiteneck *et al.*, 2004). A wide range of instruments are used in SCI research, but most of these measures were not developed for use in SCI populations and the validity for use in this group has not been established (Biering-Sorensen *et al.*, 2006). There was therefore a need for a measuring instrument specifically for use in SCI research and with the approval of the ICF by the World Health Assembly in May 2001 there is now a comprehensive and internationally accepted framework to assess functioning, disability and health in persons with all kinds of diseases and conditions, including SCI (Biering-Sorensen *et al.*, 2006). The plan to develop ICF Core Sets for SCI was derived in a meeting held in Switzerland on 14 and 15 January 2005. The ICF Core Sets will be defined at an ICF Core Set Consensus Conference which will integrate (1) evidence from an empirical study, (2) a systematic review of outcomes and measures used in SCI research, (3) an expert survey and (4) focus groups and semi-structured interviews with persons with SCI. As the development of ICF Core Sets for SCI must result in practical tools, the ICF Core Set Consensus Conference will primarily involve health care professionals from different parts of the world and different health professionals that will work together in the interdisciplinary approach that is typical in the care of persons with SCI (Biering-Sorensen *et al.*, 2006).

The aim of this study is to establish the degree to which activity limitations and participation restrictions exist six months after discharge from the WCRC and to identify the environmental barriers that are associated with these constructs. Body functions and structures will therefore not be assessed as this will provide information at impairment level which is not applicable for this study.

APPENDIX III

INCLUSION CRITERIA FOR ADMISSION TO THE STUDY

Does the patient meet the following criteria for admission to the study?

Reference number: _____ Ward: _____

- Traumatic Spinal Cord Injury (SCI) [YES] [NO]
- Discharge to the Metropolitan region of the Western Cape [YES] [NO]
- 18 years and older of age [YES] [NO]
- Able to speak Afrikaans, English or Xhosa [YES][NO]
- Some physical impairment after SCI [YES][NO]
- Cognitive ability to give independent and informed consent [YES] [NO]
and to respond to questionnaire and physical testing
- Informed, written consent from patient [YES] [NO]
- Admitted for rehabilitation for first time [YES][NO]

CONTACT DETAILS FOR SIX MONTH FOLLOW-UPContact 1 (patient)

Title: _____ First Name: _____ Surname: _____

Address discharged to: _____

_____ Postal Code: _____

Tel (h) _____ (c) _____ (w) _____

Contact 2

Name: _____ Relationship: _____

Tel (h) _____ (c) _____ (w) _____

Contact 3

Name: _____ Relationship: _____

Tel (h) _____ (c) _____ (w) _____

APPENDIX IV

Standard Neurological Classification of Spinal Cord Injury

Reference number: _____

Date: _____ (discharge /6 months)

STANDARD NEUROLOGICAL CLASSIFICATION OF SPINAL CORD INJURY

MOTOR

KEY MUSCLES

Spinal Level	R	L
C2		
C3		
C4		
C5		
C6		
C7		
C8		
T1		
T2		
T3		
T4		
T5		
T6		
T7		
T8		
T9		
T10		
T11		
T12		
L1		
L2		
L3		
L4		
L5		
S1		
S2		
S3		
S4-5		

Elbow flexors
Wrist extensors
Elbow extensors
Finger flexors (distal phalanx of middle finger)
Finger abductors (little finger)

0 = total paralysis
1 = palpable or visible contraction
2 = active movement, gravity eliminated
3 = active movement, against gravity
4 = active movement, against some resistance
5 = active movement, against full resistance
NT = not testable

Hip flexors
Knee extensors
Ankle dorsiflexors
Long toe extensors
Ankle plantar flexors

Voluntary anal contraction (Yes/No) Yes No

MOTOR SCORE = (100)

SENSORY

KEY SENSORY POINTS

0 = absent
1 = impaired
2 = normal
NT = not testable

Any anal sensation (Yes/No) Yes No

PIN PRICK SCORE = (max: 112)

LIGHT TOUCH SCORE = (max: 112)

TOTALS (MAXIMUM) (56) (56) (56) (56)

NEUROLOGICAL LEVEL
The most caudal segment with normal function

COMPLETE OR INCOMPLETE?

Incomplete = presence of any sensory or motor function in lowest sacral segment

ZONE OF PARTIAL PRESERVATION
Partially innervated segments

	R	L
SENSORY	<input type="text"/>	<input type="text"/>
MOTOR	<input type="text"/>	<input type="text"/>

Version 4d
CIC1997

This form may be copied freely but not altered without permission from the American Spinal Injury Association

APPENDIX V

American Spinal Injury Association Impairment Scale (AIS)

Reference number: _____

Date: _____ (discharge/6 months)

ASIA IMPAIRMENT SCALE

A = Complete: No motor or sensory function is preserved in the sacral segments S4-S5.

B = Incomplete: Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5.

C = Incomplete: Motor function is preserved below the neurological level, and more than half of key muscles below the neurological level have a muscle grade less than 3.

D = Incomplete: Motor function is preserved below the neurological level, and at least half of key muscles below the neurological level have a muscle grade of 3 or more.

E = Normal: motor and sensory function are normal

CLINICAL SYNDROMES

Central Cord

Brown-Sequard

Anterior Cord

Conus Medullaris

Cauda Equina

APPENDIX VI

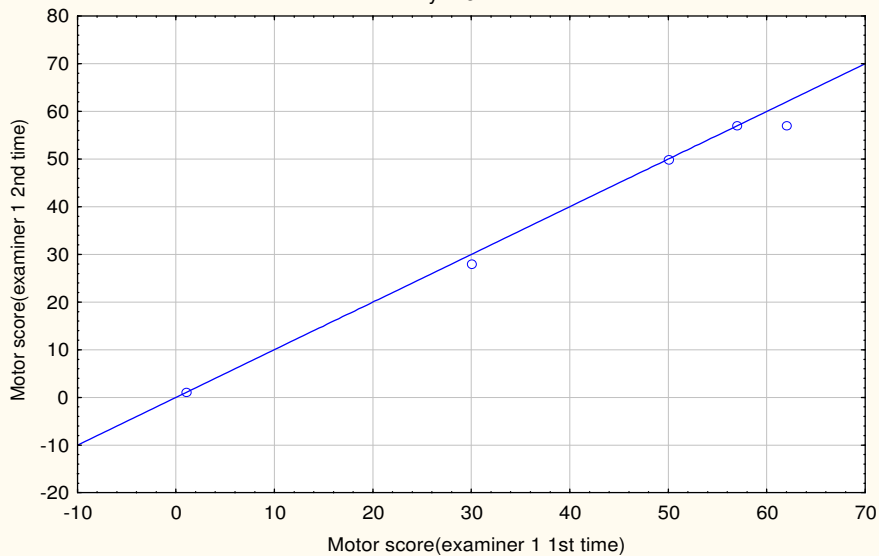
Statistical results for the inter- and intra-rater reliability study for the International Standards for the Classification of Spinal cord Injury

1 Kappa

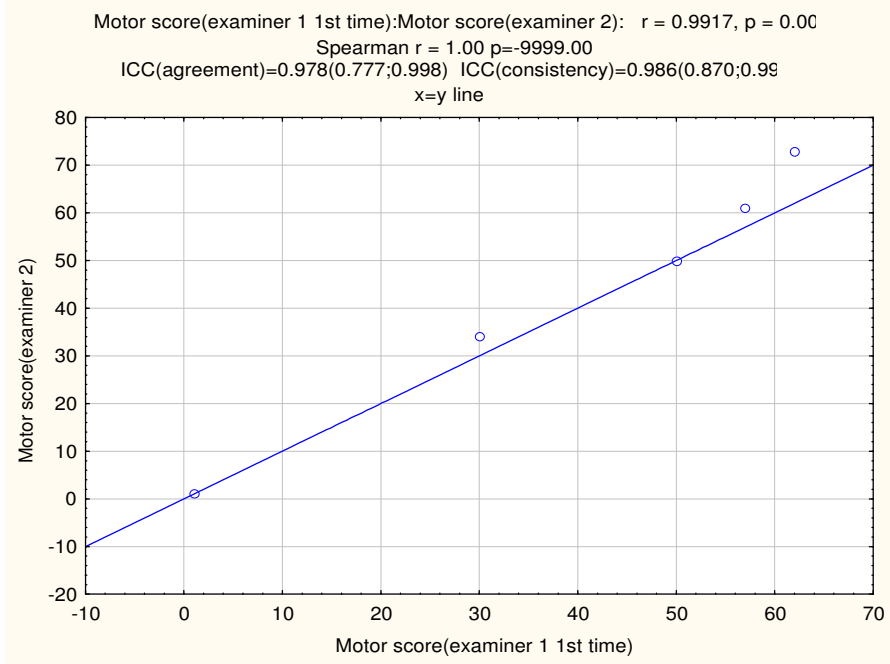
	1 rater1	2 rater2	3 Cohen Kappa	4 Lower 95%	5 Upper 95%
1	AIS(examiner 1 1st time)	AIS(examiner 1 2nd time)	1		
2	AIS(examiner 1 1st time)	AIS(examiner 2)	1		
3	AIS(examiner 1 2nd time)	AIS(examiner 2)	1		
4	C / I(examiner 1 1st time)	C / I(examiner 1 2nd time)	1		
5	C / I(examiner 1 1st time)	C / I(examiner 2)	1		
3	C / I(examiner 1 2nd time)	C / I(examiner 2)	1		

2 Motor score(examiner 1 1st time) vs Motor score(examiner 1 2nd time)

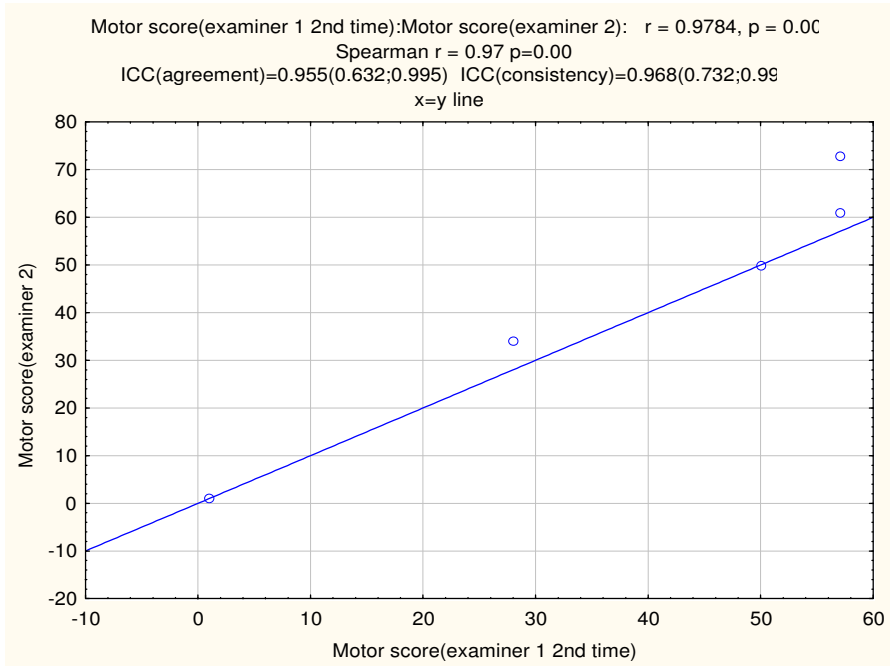
Motor score(examiner 1 1st time):Motor score(examiner 1 2nd time): $r = 0.9966, p = 0.00$
 Spearman $r = 0.97, p = 0.00$
 ICC(agreement)=0.995(0.961;0.999) ICC(consistency)=0.996(0.962;1.00)
 x=y line



3 Motor score(examiner 1 1st time) vs Motor score(examiner 2)

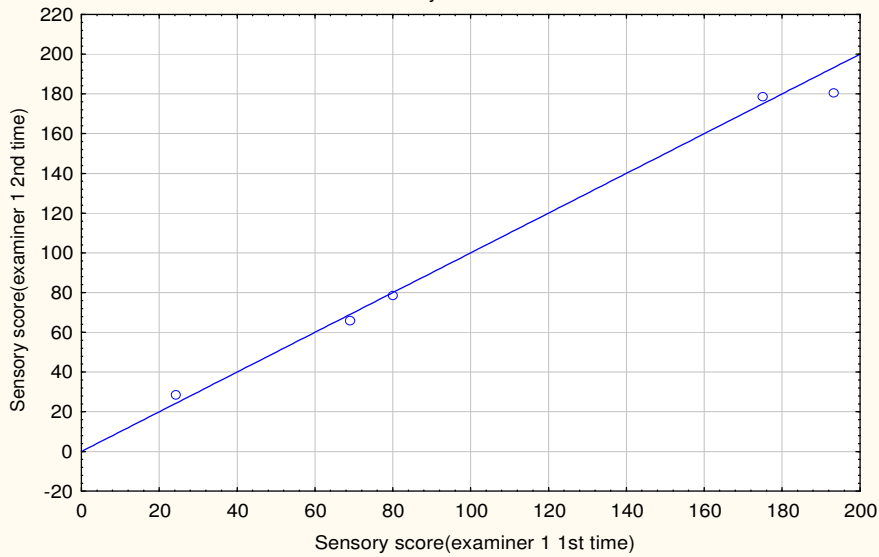


4 Motor score(examiner 1 2nd time) vs Motor score(examiner 2)



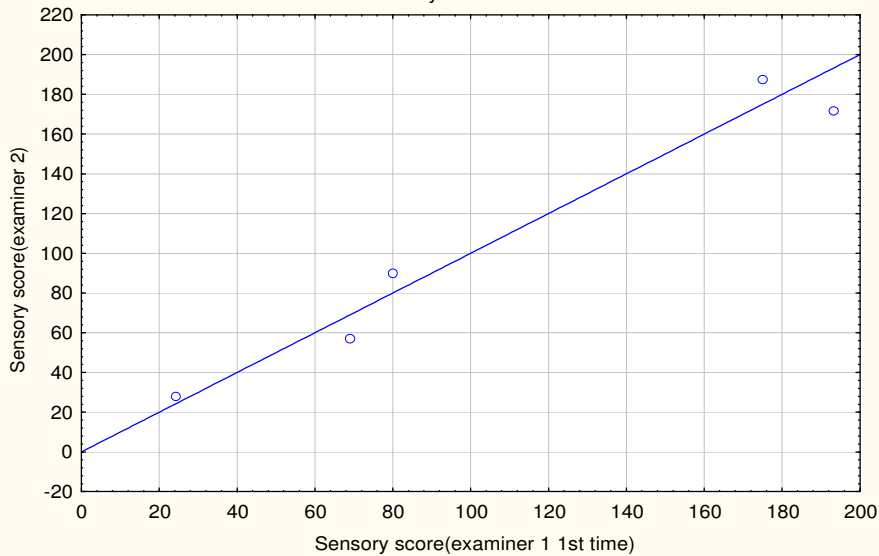
5 Sensory score(examiner 1 1st time) vs Sensory score(examiner 1 2nd time)

Sensory score(examiner 1 1st time):Sensory score(examiner 1 2nd time): $r = 0.9965$, $p = 0.00$
 Spearman $r = 1.00$ $p = -9999.00$
 ICC(agreement)=0.996(0.967;1.000) ICC(consistency)=0.995(0.957;1.00
 x=y line

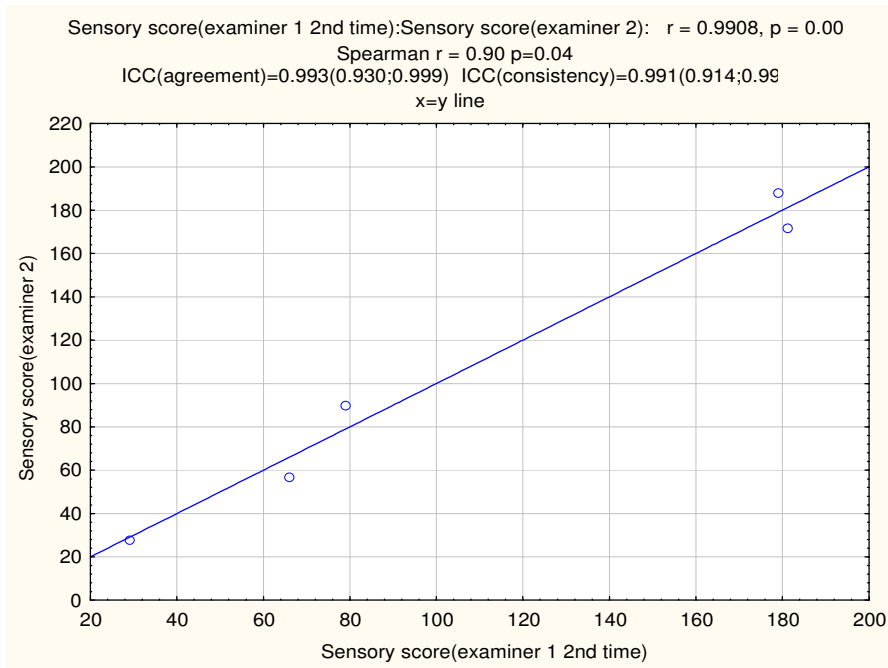


6 Sensory score(examiner 1 1st time) vs Sensory score(examiner 2)

Sensory score(examiner 1 1st time):Sensory score(examiner 2): $r = 0.9794$, $p = 0.00$
 Spearman $r = 0.90$ $p = 0.04$
 ICC(agreement)=0.983(0.848;0.998) ICC(consistency)=0.979(0.814;0.99
 x=y line



7 Sensory score(examiner 1 2nd time) vs Sensory score(examiner 2)



APPENDIX VII

QUESTIONNAIRE TO ESTABLISH DEMOGRAPHIC, MEDICAL AND SOCIO-ECONOMIC PROFILE

(All the information for this questionnaire will be provided by the subject unless stated otherwise. The questionnaire will be completed by the principle researcher at discharge and six months after discharge from the Western Cape Rehabilitation Centre)

Reference number: _____

SECTION ONE

(To be completed at discharge from WCRC)

1. INJURY-RELATED DETAILS (information from medical records and/or subject)

1.1 Date of injury: _____

1.2 Date of admission to WCRC: _____

1.3 Where referred from? _____

1.4 Time elapsed between injury and admission to WCRC: _____ days

1.5 Cause of injury: MVA GSW STAB RUGBY DIVING

FALL ASSAULT PVA MCA Other (specify): _____

1.6 Orthopedic lesion? Yes No

1.7 Orthopedic surgery? Yes No

1.8 ISCSI classification (at discharge from the WCRC)

Sensory level: _____

Sensory score: _____

Motor level: _____

Motor score: _____

Complete/incomplete: _____

ASIA Impairment Scale: _____

1.9 Health information: (on admission)

[1] Pneumonia or chest infection

[2] Urinary tract infection

[3] Pulmonary embolism

[4] Shoulder pain [R] [L]

[5] Back pain

[6] Elbow and wrist pain [R] [L]

[7] Spasticity limiting function

[8] Bowel problems

[17] No problems

[9] Pressure sores

[10] Deep vein thrombosis

[11] Neuralgia

[12] Neck pain

[13] Hip, knee and ankle pain

[14] Contracture(s) (specify): _____

[15] Depression

[16] Other (specify): _____

1.10 Date of discharge from WCRC: _____

1.11 Length of stay at WCRC: _____ days.

2. PERSONAL DETAILS

2.1 Age: _____

2.2 Gender: Male Female

2.3 Race (statistical purposes only): Asian Black Colored White

Other (specify): _____

2.4 In what language do you want me to conduct the interview?

Afrikaans English Xhosa

Other (specify): _____

2.5 Where do you reside (suburb only)? _____

3. HEALTH INFORMATION (at discharge from WCRC)

Do you currently have any of the following secondary complications?

- | | |
|----------------------------------|--------------------------------------|
| [1] Pneumonia or chest infection | [9] Pressure sores |
| [2] Urinary tract infection | [10] Deep vein thrombosis |
| [3] Pulmonary embolism | [11] Neuralgia |
| [4] Shoulder pain [R] [L] | [12] Neck pain |
| [5] Back pain | [13] Hip, knee and ankle pain |
| [6] Elbow and wrist pain [R] [L] | [14] Contracture(s) (specify): _____ |
| [7] Spasticity limiting function | [15] Depression |
| [8] Bowel problems | [16] Other (specify): _____ |

4. ASSISTIVE DEVICES

Do you currently use any assistive device(s) (at discharge from the WCRC)?

Yes No

If "yes" please specify:

- [1] Wheelchair (specify type): _____
- | | |
|----------------------------|---------------------|
| [2] 2 elbow crutches | [11] Walking frame |
| [3] 1 elbow crutch | [12] Caliper(s) |
| [4] Ordinary walking stick | [13] AFO |
| [5] Legbrace(s) | [14] Commode seat |
| [6] KAFO(s) | [15] Bath board |
| [7] Wheelchair cushion | [16] Eating strap |
| [8] Wheelchair table | [17] Transfer board |
| [9] Rollator | [18] Other: _____ |

[10] Walking stick with $\frac{3}{4}$ feet

5. SOCIO-ECONOMIC DETAILS

5.1 What is the highest level of schooling/education that you have completed? €

- 1= Pre-primary /no formal education
- 2= Gr. 1-3
- 3= Gr. 4-7
- 4= Gr. 8-10
- 5= Gr. 11-12
- 6= Gr. 10 or above with Diploma/Certificate
- 7= Gr. 12 with Diploma/Certificate (short course less than 2 years)
- 8= Tertiary education: non-degree /diploma (minimum of 2 years)
- 9= Tertiary education: degree
- 10= Other (specify): _____

5.2 How would you best describe your level of productive activity at the time of your injury (select the single best option)? €

- 1= Paid employment: Permanent
- 2= Paid employment: Probation period
- 3= Paid employment: Casual
- 4= Self employed
- 5= Work around the home such as cleaning, cooking, gardening or maintenance
- 6= Non-paid work helping in family business or volunteer/ charity work
- 7= School or study
- 8= Unemployed
- 9= Retired
- 10= Other (specify): _____

5.3 What was your gross monthly income at the time of your injury? €

- 1= R0
- 2= R1-R1 000
- 3= R1 001-R2 500
- 4= R2 501-R4 500
- 5= R4 501- R8 000
- 6= R8 001-R12 000
- 7= R12 001-R16 000
- 8= R16 001-R20 000
- 9= More than R20 000
- 10= Prefers not to answer or does not know

5.4 Do you currently have any income?

€Yes €No

If 'NO', proceed to QUESTION 5.6.

5.5 What is your main source of income?

€ € €

- 1= Disability grant
- 2= Unemployment benefits
- 3= Workman's compensation
- 4= Road Accident Fund Compensation
- 5= Monthly salary: Full
- 6= Monthly salary: Part
- 7= Family
- 8= Child support grant
- 9= No income
- 10= other (specify): _____

5.6 What is your current monthly income before tax?

€

- 1= R0
- 2= R1-R1 000
- 3= R1 001-R2 500
- 4= R2 501-R4 500
- 5= R4 501- R8 000
- 6= R8 001-R12 000
- 7= R12 001-R16 000
- 8= R16 001-R20 000
- 9= More than R20 000
- 10= Prefers not to answer or does not know

5.7 Does this income cover your expenses?

€Yes

€No

5.8 Does anybody else contribute to the household income?

€Yes

€No

If "yes", whom? _____

How much? _____

5.9 What is the reason for you not currently having an income?

€

- 1= Applied for DG but have not received any
 - 2= Have not applied for a DG
 - 3= Do not qualify for a DG
 - 4= Not receiving any benefits from employer
 - 5= Employment has been terminated
 - 6= Other (specify): _____
- If number 2, 3, 4 or 5 please specify reasons: _____
- _____

- 5.10 If you currently have no income who supports you financially? € €
- 1= Spouse
 - 2= Children
 - 3= Parents
 - 4= Siblings
 - 5= Extended family
 - 6= Friends
 - 7= Charity organizations
 - 8= Nobody
 - 9= Other (specify): _____

6. DETAILS ON DISCHARGE LIVING ENVIRONMENT

- 6.1 Will you be returning to the same residence as at the time of injury?

€Yes €No

If 'NO', what is the reason? €

- 1= House is unsuitable/inaccessible
- 2= No caregiver at home
- 3= Cannot afford rent or monthly payment
- 4= Other (specify): _____

- 6.2 How would you best describe the place that you will be discharged to? € € €

- 1= House
- 2= Block of flats
- 3= Wendy house /flat /room in back yard
- 4= Townhouse, cluster, semi-detached
- 5= Room, flat-let attached to a house
- 6= Retirement village / old age home
- 7= Informal dwelling / shack
- 8= Nursing care facility
- 9= Other (specify): _____

- 6.3 How many rooms do you have in your house (excluding bathroom)? _____

- 6.4 How many people are living at home including you? _____

- 6.5 Is there enough space for you to move around within your home?

€Yes €No €Unsure

If "no", please elaborate: _____

- 6.6 How do you access your home? €
- 1= Independently
2= Assistance of 1 person
3= Assistance of more than 1 person
4= Other (specify): _____
- 6.7 Where do you sleep? €
- 1= Bed
2= Mattress on the floor
3= Floor
4= Other (specify): _____
- 6.8 Where do you wash yourself? €
- 1= Bath
2= Shower
3= Both
4= Neither
5= Basin /tub
6= Other (specify): _____
- 6.9 Do you have a bathroom inside or outside? €
- 1= Inside
2= Outside
3= Neither
- 6.10 Do you have a toilet inside or outside? €
- 1= Inside
2= Outside
3= Neither
- 6.11 Can you use the toilet?
- €Yes €No
- 6.12 If “neither”, or if you cannot use your toilet, what do you use? €
- 1= Bed
2= Commode seat
3= Bush
4= Hole in the ground
5= Neighbor’s toilet
6= Other (specify): _____
- 6.13 Do you have electricity in your house?

Yes No

6.14 Do you have access to running water?

Yes No

6.15 Do you have access to a telephone?

Yes No

If "YES" please specify:

- 1= Inside your home
- 2= Neighbor's phone
- 3= Cell phone
- 4= Public phone within 50m
- 5= None of the above

6.16 Will there be someone available during the day should you need assistance?

Yes No

If not, how do you manage? _____

6.17 Have you been on a home visit with members of the rehabilitation team?

Yes No

If "yes" which member(s) of the rehabilitation team accompanied you?

6.18 Did your caregiver/ family receive training prior to discharge?

Yes No

6.19 If "NO" what is the reason?

- 1= No need/independent
- 2= D/C to care facility
- 3= Family training was not discussed/offered
- 4= Other (specify) _____

SECTION TWO

(To be completed at 6 months post discharge during interview with participant at WCRC)

7. HEALTH INFORMATION

Have you developed any of the following secondary complications since your discharge from the WCRC?

[1] Pneumonia or chest infection

[9] Pressure sores

[2] Urinary tract infection

[10] Deep vein thrombosis

[3] Pulmonary embolism

[11] Neuralgia

- | | |
|----------------------------------|--------------------------------------|
| [4] Shoulder pain [R] [L] | [12] Neck pain |
| [5] Back pain | [13] Hip, knee and ankle pain |
| [6] Elbow and wrist pain [R] [L] | [14] Contracture(s) (specify): _____ |
| [7] Spasticity limiting function | [15] Depression |
| [8] Bowel obstruction | [16] Other (specify): _____ |

8. ASSISTIVE DEVICES

Do you currently use any assistive device(s)?

Yes No

If “yes” please specify:

- | | |
|--------------------------------------|---------------------|
| [1] Wheelchair (specify type): _____ | |
| [2] 2 elbow crutches | [11] Walking frame |
| [3] 1 elbow crutch | [12] Caliper(s) |
| [4] Ordinary walking stick | [13] AFO |
| [5] Legbrace(s) | [14] Commode seat |
| [6] KAFO(s) | [15] Bath board |
| [7] Wheelchair cushion | [16] Eating strap |
| [8] Wheelchair table | [17] Transfer board |
| [9] Rollator | [18] Other: _____ |
| [10] Walking stick with ¾ feet | |

9. SOCIO-ECONOMIC DETAILS

9.1 Do you currently have any income?

Yes No

If ‘NO’, proceed to QUESTION 12.8

9.2 What is your main source of income? €

- 1= Disability grant
- 2= Unemployment benefits
- 3= Workman’s compensation
- 4= Road Accident Fund Compensation
- 5= Monthly salary: Full
- 6= Monthly salary: Part
- 7= Family
- 8= Child support grant
- 9= No income

10= Other (specify): _____

9.3 How would you best describe your current level of productive activity? €

(select the single best option)

- 1= Paid employment: Permanent
- 2= Paid employment: Probation period
- 3= Paid employment: Casual
- 4= Self employed
- 5= Work around the home such as cleaning, cooking, gardening or maintenance
- 6= Non-paid work helping in family business or volunteer/ charity work
- 7= School or study
- 8= Unemployed
- 9= Retired
- 10= Other (specify): _____

9.4 What is your current monthly income before tax? €

- 1= R0
- 2= R1-R1 000
- 3= R1 001-R2 500
- 4= R2 501-R4 500
- 5= R4 501- R8 000
- 6= R8 001-R12 000
- 7= R12 001-R16 000
- 8= R16 001-R20 000
- 9= More than R20 000
- 10= Prefers not to answer or does not know

9.5 Does this income cover your expenses?

€Yes €No

9.6 Does anybody else contribute to the household income?

€Yes €No

If "yes", whom? _____

9.7 If you are not in paid employment, what best describes the reason for that? €

- 1= Unable to work due to illness and/or disability
- 2= Sought employment, but cannot find work
- 3= Have not sought employment, receiving a DG
- 4= Have not sought employment, not receiving a DG but financially supported
- 5= Retired, receiving a pension
- 6= Looking after the home without benefits
- 7= Care giver for another
- 8= Scholar or student
- 9= Doing volunteer work

10= Other (specify): _____

9.8 Why are you not currently receiving a disability grant (DG)?

€

1= Applied for DG but have not received any

2= Have not applied for a DG

3= Do not qualify for a DG

4= Other (specify): _____

9.9 If you currently have no income, who supports you financially? (Name main one)

€

1= Spouse

2= Children

3= Parents

4= Siblings

5= Extended family

6= Friends

7= Charity organizations

8= Nobody

9= Other (specify): _____

10. DETAILS ON LIVING ENVIRONMENT

10.1 How would you best describe where you are living now?

€

1= Home as at discharge

2= Alternative home

3= Nursing care facility/ institution

If not the same house as at discharge, give reason(s): _____

11. ISCSCI

▪ Sensory level: _____

▪ Sensory score: _____

▪ Motor level: _____

▪ Motor score: _____

▪ Complete/incomplete: _____

▪ ASIA Impairment Scale: _____

APPENDIX VIII

QUESTIONNAIRE TO ESTABLISH ACTIVITY AND PARTICIPATION PROFILE

COMPREHENSIVE ICF CORE SET FOR SPINAL CORD INJURY

PART 1: FUNCTIONING AND DISABILITY

COMPONENT: ACTIVITIES AND PARTICIPATION

CONSTRUCT: PERFORMANCE

Reference number: _____

Date d/c: _____

Date 6/12: _____

SCALE FOR CODING PERFORMANCE (P)

xxx.0 No difficulty	(none, absent)	0 – 4%
xxx.1 Mild difficulty	(slight, low)	5 – 24%
xxx.2 Moderate difficulty	(medium, fair)	25 – 49%
xxx.3 Severe difficulty	(high, extreme)	50 – 95%
xxx.4 Complete difficulty	(total)	96 – 100%
xxx.8 Not specified		
xxx.9 Not applicable		

SCALE FOR CODING THE AMOUNT AND TYPE OF ASSISTANCE NEEDED (A)

0: No assistance needed**1: Non-personal assistance/ adapted or specially designed tools and/or vehicle****2: Personal assistance of 1 or more persons****3: Both non-personal and personal assistance****4: Impossible even if assistance is provided****5: Level of assistance unknown****6: Not applicable**

ICF code	Title	P d/c	A d/c	P 6/12	A 6/12	Comment
d4100	Changing basic body position: Lying down					
d4101	Changing basic body position: Squatting					
d4102	Changing basic body position: Kneeling					
d4103	Changing basic body position: Sitting					

d4104	Changing basic body position: Standing					
d4105	Changing basic body position: Bending					
d4153	Maintaining a body position: Sitting					
d4154	Maintaining a body position: Standing					
d4200	Transferring oneself while sitting					
d430	Lifting and carrying objects					
d440	Fine hand use (unilateral)					
d445	Hand and arm use (unilateral)					
d4500	Walking short distances					
d4501	Walking long distances					
d4502	Walking on different surfaces					
d4503	Walking around obstacles					
d4600	Moving around within the home					
d4601	Moving around within buildings other than home					
d4602	Moving around outside the home and other buildings					
d465	Moving around using equipment					
d4701	Moving around using private					

	motorized transportation					
d4702	Moving around using public motorized transportation					
d475	Driving					
d510	Washing oneself					
d520	Caring for body parts					
d5300	Toileting: Regulating urination					
d5301	Toileting: Regulating defecation					
d5302	Toileting: Menstrual care					
d540	Dressing					
d550	Eating					
d560	Drinking					
d570	Looking after one's health					
d620	Acquisition of goods and services					
d630	Preparing meals					
d640	Doing housework					
d650	Caring for household objects					
d660	Assisting others					
d750	Informal social relationships					

d760	Family relationships					
d770	Intimate relationships					
d820	School education					
d850	Remunerative employment					
d855	Non-remunerative employment					
d870	Economic self-sufficiency					
d920	Recreation and leisure					
d930	Religion and spirituality					

APPENDIX IX

A DETAILED DESCRIPTION OF THE ACTIVITIES AND PARTICIPATION DOMAINS AND ITEMS INCLUDED IN THE QUESTIONNAIRE (WHO, 2001)

CHAPTER 4: MOBILITY

This chapter is about moving by changing body position or location or by transferring from one place to another, by carrying, moving or manipulating objects, by walking or running, or climbing and by using various forms of transportation.

CHANGING AND MAINTAINING BODY POSITION (d410 - d429)

d4100: Changing basic body position: Lying down

Getting into and out of a lying down position or changing body position from horizontal to any other position, such as standing up or sitting down.

Inclusions: Sitting to lying

d4101: Changing basic body position: Squatting

Getting into and out of the seated or crouched posture on one's haunches with knees closely drawn up or sitting on one's heels, such as may be necessary in toilets that are at floor level, or changing body position from squatting to any other position, such as standing up.

Inclusions: Standing to squatting to standing

d4102: Changing basic body position: Kneeling

Getting into and out of a position where the body is supported by the knees with legs bent, such as during prayers, or changing body position from kneeling to any other position, such as standing up.

Inclusions: Standing to kneeling to standing

d4103: Changing basic body position: Sitting

Getting into and out of a seated position and changing body position from sitting down to any other position, such as standing up or lying down.

Inclusions: Lying down to sitting up

d4104: Changing basic body position: Standing

Getting into and out of a standing position or changing body position from standing to any other position, such as lying down or sitting down.

Inclusions: Sitting to standing

Exclusions: Sitting to therapeutic standing

d4105: Changing basic body position: Bending

Tilting the back downwards or to the side, at the torso, such as in bowing or reaching down for an object.

Inclusions: Bending trunk sideways or forwards in sitting or standing

d4153: Maintaining a body position: Sitting

Staying in a seated position, on a seat or the floor, for some time as required, such as when sitting at a desk or table.

Inclusions: (1) Sitting in w/c or any other seat or surface

(2) If patient can only sit in a wheelchair or specially designed seat, a non-personal code will be awarded

d4154: Maintaining a body position: Standing

Staying in a standing position for some time as required, such as when standing in a queue.

Inclusions: Standing for a minimum period of at least 5 – 10 min such as when standing in a queue.

Exclusions: Therapeutic standing

d4200: Transferring oneself while sitting

Moving from a sitting position on one seat to another seat on the same or a different level, such as moving from a chair to a bed.

Inclusions: (1) W/C to plinth

(2) W/C is not seen as an assistive device

(3) Transfer board is seen as an assistive device

CARRYING, MOVING AND HANDLING OBJECTS (d430 – d449)**d430: Lifting and carrying objects**

Raising up an object or taking something from one place to another, such as when lifting a cup, or carrying a child from one room to another.

Inclusions: Moving objects in any possible way once the object has lifted off any surface, including carrying objects on lap.

d440: Find hand use

Performing the coordinated actions of handling objects, picking up, manipulating and releasing then using one's hand, fingers and thumb, such as required to lift coins off a table or turn a dial or knob.

Inclusions: Unilateral hand use

d445: Hand and arm use

Performing the coordinated actions required to move objects or to manipulate them by using hands and arms, such as when turning door handles or throwing or catching an object.

Inclusions: Unilateral arm use

WALKING AND MOVING (d450 – d469)**d4500: Walking short distances**

Walking for less than a kilometre, such as walking around rooms or hallways within a building or for short distances outside.

Exclusions: Therapeutic walking

d4501: Walking long distances

Walking for more than a kilometre, such as across a village or town, between villages or across open areas.

Excluding: Therapeutic gait

d4502: Walking on different surfaces

Walking on sloping, uneven, or moving surfaces, such as on grass, gravel or sand, or walking aboard a ship, train, or other vehicle.

Excluding: Therapeutic gait

d4503: Walking around obstacles

Walking in ways required to avoid moving and immobile objects, people, animals and vehicles, such as walking around a marketplace or shop, around or through traffic or other crowded areas.

Excluding: Therapeutic gait

d4600: Moving around within the home

Walking and moving around in one's home, within a room, between rooms, and around the whole residence or living area.

Inclusions: (1) Moving from floor to floor, on an attached balcony, courtyard, porch or garden.

(2) Any assistive device, including a wheelchair, is seen as non- personal assistance.

d4601: Moving around within buildings other than home

Walking and moving around buildings other than one's residence, such as moving around other people's homes, other private buildings, community and private or public buildings and enclosed areas.

Inclusions: (1) Moving throughout all parts of buildings and enclosed areas, between floors, inside, outside and around buildings, both public and private.

(2) Any assistive device, including a wheelchair, is seen as non- personal assistance.

d4602: Moving around outside the home and other buildings

Walking or moving around close to or far from one's home and other buildings, without the use of transportation, public or private, such as walking for short or long distances around a town or village.

Inclusions: (1) Walking or moving down streets in the neighbourhood, town, village or city, moving between cities and further distances, without using transportation.

(2) *Any assistive device, including a wheelchair, is seen as non- personal assistance.*

d465: Moving around using equipment

Moving the whole body from place to place, on any surface or space, by using specific devices designed to facilitate moving or create other ways of moving around, such as with skates, skis, or scuba equipment, or moving down the street in a wheelchair or walker.

MOVING AROUND USING TRANSPORTATION (d470 –d489)

d4701: Using private motorized transportation

Being transported as a passenger by private motorized vehicle over land, sea or air, such as by a privately-owned taxi, aircraft or boat.

Inclusions: (1) Getting into and out of vehicle.

(2) *Securing wheelchair or other assistive devices in or on vehicle.*

d4702: Using public motorized transportation

Being transported as a passenger by private motorized vehicle over land, sea or air designed for public transportation, such as being a passenger on a minibus taxi, bus, train, subway or aircraft.

Inclusions: (1) Getting into and out of vehicle.

(2) *Securing wheelchair or other assistive devices in or on vehicle.*

d475: Driving

Being in control of and moving a vehicle or the animal that draws it, travelling under one's own direction or having at one's disposal any form of transportation, such as by car, bicycle, boat or animal-powered vehicle.

Inclusions: Driving human-powered transportation, motorized vehicles, animal-powered vehicles.

CHAPTER 5: SELF-CARE

This chapter is about caring for oneself, washing and drying oneself, caring for one's body and body parts, dressing, eating and drinking, and looking after one's health.

d510: Washing oneself

Washing and drying one's whole body, or body parts, using water and appropriate cleaning and drying materials or methods, such as bathing, showering, washing hands and feet, face and hair, and drying with a towel.

Inclusions: Washing body parts, the whole body and drying oneself.

d520: Caring for body parts

Looking after those parts of the body, such as skin, face, teeth, scalp, nails and genitals, that require more than washing and drying.

Inclusions: Caring for skin, teeth, hair, finger and toe nails.

d5300: Toileting: Regulating urination

Coordinating and managing urination, such as by indicating need, getting into proper position, choosing and getting to an appropriate place for urination, manipulating clothing before and after urination, and cleaning oneself after urination.

Inclusions: Inserting/changing catheter and emptying bag.

d5301: Toileting: Regulating defecation

Coordinating and managing defecation, such as by indicating need, getting into proper position, choosing and getting to an appropriate place for defecation, manipulating clothing before and after defecation, and cleaning oneself after defecation.

d5302: Toileting: Menstrual care

Coordinating, planning and caring for menstruation, such as by anticipating menstruation and using sanitary towels and napkins.

d540: Dressing

Carrying out the coordinated actions and tasks of putting on and taking off clothes and footwear in sequence and in keeping with climate and social conditions, such as by putting on, adjusting and removing shirts, skirts, blouses, pants, undergarments, saris, kimono, tights, hats, gloves, coats, shoes, boots, sandals and slippers.

Inclusions: Upper and lower body

d550: Eating

Carrying out the coordinated tasks and actions of eating food that has been served, bringing it to the mouth and consuming it in culturally acceptable ways, cutting or breaking food into pieces, opening bottles and cans, using eating implements, having meals, feasting or dining.

d560: Drinking

Taking hold of a drink, bringing it to the mouth and consuming the drink in aculturally acceptable ways, mixing, stirring and pouring liquids for drinking, opening bottles and cans, drinking through a straw or drinking running water such as from a tap or a spring.

d570: Looking after one's health

Ensuring physical comfort, health and physical and mental well-being, such as by maintaining a balanced diet, and an appropriate level of physical activity, keeping warm or cool, avoiding harms to health, following safe sex practices, including using condoms, getting immunizations and regular physical examinations.

Inclusions: Knowledge on deep vein thrombosis, blocked catheter, bladder infection and pressure sores.

CHAPTER 6: DOMESTIC LIFE

This chapter is about carrying out domestic and everyday actions and tasks. Areas of domestic life include acquiring a place to live, food, clothing and other necessities, household cleaning and repairing, caring for personal and other household objects and assisting others.

ACQUISITION OF NECESSITIES (d610 – d629)

d620: Acquisition of goods and services

Selecting, procuring and transporting all goods and services required for daily living, such as selecting, procuring, transporting and storing food, drink, clothing, cleaning material, fuel, household items, utensils, cooking ware, domestic appliances and tools, procuring utilities and other household services.

Inclusions: Shopping and gathering necessities.

HOUSEHOLD TASKS (d630 – d649)

d630: Preparing meals

Planning, organizing, cooking and serving simple and complex meals for oneself and others, such as by making a menu, selecting edible food and drink, getting together ingredients for preparing meals, cooking with heat and preparing cold food and drinks, and serving the food.

d640: Doing housework

Managing a household by cleaning the house, washing clothes, using household appliances, storing food and disposing of garbage, such as by sweeping, mopping, washing counters, walls and other surfaces; collecting and disposing of household garbage, tidying rooms, closets and drawers; collecting, washing, drying, folding and ironing clothes; cleaning footwear, using brooms, brushes and vacuum cleaners, using washing machines, driers and irons.

CARING FOR HOUSEHOLD OBJECTS AND ASSISTING OTHERS (d650 – d669)

d650: Caring for household objects

Maintaining and repairing household and other personal objects, including house and contents, clothes, vehicles and assistive devices, and caring for plants and animals, such as painting or wallpapering, rooms, fixing furniture, repairing plumbing, ensuring the proper working order of vehicles, watering plants, grooming and feeding pets and domestic animals.

d660: Assisting others

Assisting household members and others with their learning, communicating, self-care, movement, within the house or outside; being concerned about the well-being of household members and others.

CHAPTER 7: INTERPERSONAL INTERACTIONS AND RELATIONSHIPS

PARTICULAR INTERPERSONAL RELATIONSHIPS (d730 – d779)

d750: Informal social relationships

Entering into relationships with others, such as casual relationships with people living in the same community or residence, or with co-workers, students, playmates or people with similar backgrounds or professions.

d760: Family relationships

Creating and maintaining kinship relationships, such as with members of the nuclear family, extended family, foster and adopted family and step-relationships, more distant relationships such as second cousins, or legal guardians.

d770: Intimate relationships

Creating and maintaining close or romantic relationships between individuals, such as husband and wife, lovers or sexual partners.

CHAPTER 8: MAJOR LIFE AREAS

EDUCATION (d810 – d839)

d820: School education

Gaining admission to school, education, engaging in all school-related responsibilities and privileges, and learning the course material, subjects and other curriculum requirements in a primary or secondary education programme, including attending school regularly, working cooperatively with other students, taking direction from teachers, organizing, studying and completing assigned tasks and projects and advancing to other stages of education.

WORK AND EMPLOYMENT (d840 – d859)

d850: Remunerative employment

Engaging in all aspects of work, as an occupation, trade, profession or other form of employment, for payment, as an employee, full or part time, or self-employed, such as seeking employment and getting a job, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups.

d855: Non-remunerative employment

Engaging in all aspects of work in which pay is not provided, full-time or part-time, including organized work activities, doing the required tasks of the job, attending work on time as required, supervising other workers or being supervised, and performing required tasks alone or in groups

such as volunteer work, charity work, working for a community or religious group without remuneration, working around the home without remuneration.

Exclusion: Chapter 6 Domestic Life

ECONOMIC LIFE (d860 – d879)

d870: Economic self-sufficiency

Having command over economic resources, from private or public sources, in order to ensure economic security for future and present needs.

CHAPTER 9: COMMUNITY, SOCIAL AND CIVIC LIFE

This chapter is about the actions and tasks required to engage in organized social life outside the family, in community, social and civic areas of life.

d920: Recreation and leisure

Engaging in any form of play, recreational or leisure activity, such as informal or organized play and sports, programmes of physical fitness, relaxation, amusement or diversion, going to art galleries, museums, cinemas or theatres; engaging in crafts or hobbies, reading for enjoyment, playing musical instruments; sightseeing, tourism and travelling for pleasure.

d930: Religion and spirituality

Engaging in religious or spiritual activities, organizations and practices for self-fulfilment, finding meaning, religious or spiritual value and establishing connection with a divine power, such as is involving in attending a church, temple, mosque or synagogue, praying or chanting for a religious purpose and spiritual contemplation.

APPENDIX X

QUESTIONNAIRE TO ESTABLISH ENVIRONMENTAL BARRIERS

COMPREHENSIVE ICF CORE SET FOR SPINAL CORD INJURY

PART 2: CONTEXTUAL FACTORS

COMPONENT: ENVIRONMENTAL FACTORS

CONSTRUCT: BARRIERS AND FACILITATORS

Barriers and facilitators will be coded in accordance with the following scale:

xxx.0	NO barrier	(none, absent, negligible,)	0 - 4%
xxx.1	MILD barrier	(slight, low,)	5 - 24%
xxx.2	MODERATE barrier	(medium fair,)	25% - 49%
xxx.3	SEVERE barrier	(high, extreme,)	50 - 95%
xxx.4	COMPLETE barrier	(total,...)	96 - 100%
xxx.8	Barrier, not specified		
xxx.9	Not applicable		

ICF code	Title	Code 6/12	Comment
e110	Products or substances for personal consumption		
e115	Products and technology for personal use in daily living		
e120	Products and technology for personal indoor and outdoor mobility and transportation		
e125	Products and technology for communication		
e130	Products and technology for education		
e135	Products and technology for employment		
e140	Products and technology for culture, recreation and sport		
e145	Products and technology for the practice of religion and spirituality		
e150	Design, construction and building products and technology of buildings for public use		

e155	Design, construction and building products and technology of buildings for private use		
e160	Products and technology of land development		
e310	Immediate family		
e315	Extended family		
e320	Friends		
e325	Acquaintances, peers, colleagues, neighbours and community members		
e330	People in positions of authority		
e340	Personal care providers and personal assistants		
e355	Health professionals		
e410	Individual attitudes of immediate family members		
e415	Individual attitudes of extended family members		
e420	Individual attitudes of friends		
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members		
e430	Individual attitudes of people in positions of authority		
e440	Individual attitudes of personal care providers and personal assistants		
e450	Individual attitudes of health professionals		

e460	Societal attitudes		
e5250	Housing services		
e5300	Utilities services		
e5350	Communication services		
e5400	Transportation services		
e5450	Civil protection services		
e5550	Associations and organizational services		
e5700	Social security services		
e5750	General social support services		
e5800	Health services		
e5850	Education and training services		
e5900	Labor and employment services		

APPENDIX XI

A DETAILED DESCRIPTION OF THE ENVIRONMENTAL FACTORS INCLUDED IN THE QUESTIONNAIRE (WHO, 2001)

CHAPTER 1: PRODUCTS AND TECHNOLOGY

This chapter is about the natural or human-made products or systems of products, equipment and technology in an individual's immediate environment that are gathered, created, produced or manufactured.

e110: Products or substances for personal consumption

Any natural or human-made object or substance gathered, processed or manufactured for ingestion.

Inclusions: food and drugs

e115: Products and technology for personal use in daily living

Equipment, products and technologies used by people in daily activities, including those adapted or specially designed, located in, on or near the person using them.

Inclusions: general and assistive products and technology for personal use

e120: Products and technology for personal indoor and outdoor mobility and transportation.

Equipment, products and technologies used by people in activities of moving inside and outside buildings, including those adapted or specially designed, located in, on or near the person using them.

Inclusions: general and assistive products and technology for personal indoor and outdoor mobility and transportation

e125: Products and technology for communication

Equipment, products and technologies used by people in activities of sending and receiving information, including those adapted or specially designed, located in, on or near the person using them.

Inclusions: general and assistive products for communication

e130: Products and technology for education

Equipment, products and technologies used for acquisition of knowledge, expertise or skill, including those adapted or specially designed.

Inclusions: general and assistive products for education

e135: Products and technology for employment

Equipment, products and technology used for employment to facilitate work activities.

Inclusions: general and assistive products for employment

e140: Products and technology for culture, recreation and sport

Equipment, products and technologies used for the conduct and enhancement, of cultural, recreational and sporting activities, including those adapted or specially designed.

Inclusions: general and assistive products for culture, recreation and sport

e145: Products and technology for the practice of religion and spirituality

Products and technology, unique or mass-produced, which are given or take on a symbolic meaning in the context of the practice of religion or spirituality, including those adapted or specially designed.

Inclusions: general and assistive products and technology for the practice of religion and spirituality

e150: Design, construction and building products and technology of buildings for public use

Products and technology that constitute an individual's indoor and outdoor human-made environment that is planned, designed and constructed for public use, including those adapted or specially designed.

Inclusions: design, construction and building products and technology of entrances and exits, facilities and routing

e155: Design, construction and building products and technology of buildings for private use

Products and technology that constitute an individual's indoor and outdoor human-made environment that is planned, designed and constructed for private use, including those adapted or specially designed.

Inclusions: design, construction and building products and technology of entrances and exits, facilities and routing

e160: Products and technology of land development

Products and technology of land areas, as they affect an individual's outdoor environment through the implementation of land policies, design, planning and development of space, including those adapted or specially designed.

Inclusions: products and technology of land areas that have been organized by the implementation of land use policies, such as rural areas, suburban areas, urban areas, parks, conservation areas and wildlife reserves.

CHAPTER 3: SUPPORT AND RELATIONSHIPS

This chapter is about people or animals that provide practical, physical or emotional support, nurturing, protection, assistance and relationships to other persons, in their home, place of work, school or at play or in other aspects of their daily activities. The chapter does not encompass the

attitudes of the person or people that are providing the support. The environmental factor is not the person or animal, but the amount of physical and emotional support the person or animal provides.

e310: Immediate family

Individuals related by birth, marriage or other relationships recognized by the culture as immediate family, such as spouses, partners, parents, siblings, children, foster parents, adoptive parents and grandparents.

Exclusions: extended family, personal care providers and personal assistance

e315: Extended family

Individuals related through family or marriage or other relationships recognized by the culture as extended family, such as aunts, uncles, nephews and nieces.

e320: Friends

Individuals who are close and ongoing participants in relationships characterized by trust and mutual support.

e325: Acquaintances, peers, colleagues, neighbors and community members

Individuals who are familiar to each other as acquaintances, peers, colleagues, neighbors and community members, in situations of work, school, recreation or other aspects of life, and who share demographic features such as age, gender, religious creed or ethnicity or pursue common interests.

e330: People in positions of authority

Individuals who have decision-making responsibilities for others and who have socially defined influence or power based on their social, economic, cultural or religious roles in society, such as teachers, employers, supervisors, religious leaders, substitute decision-makers, guardians or trustees.

e340: Personal care providers and personal assistants

Individuals who provide services as required to support individuals in their daily activities and maintenance of performance at work, education or other life situation, provided either through public or private funds, or else on a voluntary basis, such as providers of support for home-making and maintenance, personal assistants, paid help, nannies and others who function as primary caregivers.

e355: Health professionals

All service providers working within the context of the health system, such as doctors, nurses, physiotherapists, occupational therapists, speech therapists, audiologists, orthotist-prosthetists, medical social workers.

CHAPTER 4: ATTITUDES

This chapter is about the attitudes that are the observable consequences of customs, practices, ideologies, values, norms, factual beliefs and religious beliefs. These attitudes influence individual behavior and social life at all levels. The attitudes classified are those of the people external to the person whose situation is being described. They are not those of the person themselves.

e410: Individual attitudes of immediate family members

General or specific opinions and beliefs of immediate family members about the person or about other matters (e.g. social, political and economic issues), that influence individual behavior and actions.

e415: Individual attitudes of extended family members

General or specific opinions and beliefs of extended family members about the person or about other matters (e.g. social, political and economic issues), that influence individual behavior and actions.

e420: Individual attitudes of friends

General or specific opinions and beliefs of friends about the person or about other matters (e.g. social, political and economic issues), that influence individual behavior and actions.

e425: Individual attitudes of acquaintances, peers, colleagues, neighbors and community members

General or specific opinions and beliefs of acquaintances, peers, colleagues, neighbors and community members about the person or about other matters (e.g. social, political and economic issues), that influence individual behavior and actions.

e430: Individual attitudes of people in positions of authority

General or specific opinions and beliefs of people in positions of authority about the person or about matters (e.g. social, political and economic issues), that influence individual behavior and actions.

e440: Individual attitudes of personal care providers and personal assistants

General or specific opinions and beliefs of personal care providers and personal assistants about the person or about other matters (e.g. social, political and economic issues), that influence individual behaviour and actions.

e450: Individual attitudes of health professionals

General or specific opinions and beliefs of health professionals about the person or about other matters (e.g. social, political and economic issues), that influence individual behaviour and actions.

e460: Societal attitudes

General or specific opinions and beliefs generally held by people of a culture, society, sub cultural or other social group about other social, political and economic issues, that influence group or individual behavior and actions.

CHAPTER 5: SERVICES, SYSTEMS AND POLICIES

This chapter is about:

1. *Services* that provide benefits, structured programmes and operations in various sectors of society, designed to meet the needs of individuals. (Included in services are the people who provide them.) Services may be public, private or voluntary and may be established at a local, community, regional, state, provincial, national or international level by individuals, associations, organizations, agencies or governments. The goods provided by these services may be general or adapted or specially designed.
2. *Systems* that are administrative control and organizational mechanisms, and are established by governments at the local, regional, national and international levels, or by other recognized authorities. These systems are designed to organize, control and monitor services that provide benefits, structured programmes and operations in various sectors of the society.
3. *Policies* constituted by rules, regulations, conventions and standards established by governments at the local, regional, national and international levels, or by other recognized authorities. Policies govern and regulate the systems that organize, control and monitor services, structured programmes and operations in various sectors of the society.

e5250: Housing services

Services and programmes aimed at locating, providing and maintaining houses or shelters for persons to live in, such as estate agencies, housing organizations, and shelters for homeless people, including those who provide these services.

e5300: Utility services

Services and programmes supplying the population as a whole with utilities such as water, fuel, electricity, sanitation, public transportation and essential services (e.g. emergency repair services) for residential and commercial consumers, including those who provide these services.

Exclusion: civil protection services, systems and policies

e5350: Communication services

Services and programmes aimed at transmitting information by a variety of methods such as telephone, fax, surface and air mail, electronic mail and other computer-based systems (e.g. internet services), including those who provide these services.

e5400: Transportation services

Services and programmes aimed at moving persons or goods by road, paths, rail, air or water by public (including the provision and access to public transportation) or private transport, including those who provided these services.

e5450: Civil protection services

Services and programmes organized by the community and aimed at safeguarding people, property, such as fire, police, emergency and ambulance services, including those who provide these services.

e5550: Associations and organizational services

Services and programmes provided by people who have joined together in the pursuit of common, non-commercial interests with people who have the same interests, where the provision of such services may be tied to membership, such as associations and organizations providing recreation and leisure, sporting, cultural, religious and mutual aid services.

e5700: Social security services

Services and programmes aimed at providing income support to people who, because of age, poverty, unemployment, health condition or disability, require public assistance that is funded either by general tax revenues or contributory schemes, including those who provide these services.

e5750: General social support services

Services and programmes aimed at providing social support to people who, because of age, poverty, unemployment, health condition or disability, require public assistance in the areas of shopping, housework, transport, self-care and care of others, in order to function more fully in society.

Exclusion: social security services, personal care providers and personal assistants, health services

e5800: Health services

Services and programmes at a local, community, regional, state or national level, aimed at delivering interventions to individuals for their physical, psychological and social well-being, such as health promotion and disease prevention services, primary care services, acute care, rehabilitation and long-term care services, services that are publicly or privately funded, delivered on a short-term, long-term, periodic or one-time basis, in a variety of service settings, such as community, home-based, school and work settings, general hospitals, specialty hospitals, clinics, and residential and non-residential care facilities, including those who provide the services.

e5850: Education and training services

Services and programmes concerned with education and the acquisition, maintenance and improvement of knowledge, expertise and vocational or artistic skills, such as those provided for different levels of education (e.g. secondary school, post-secondary institutions, professional programmes, training and skills programmes, apprenticeships and continuing education), including those who provide these services.

e5900: Labor and employment services

Services and programmes provided by local, regional or national governments, or private organizations to find suitable work for persons who are unemployed or looking for different work, or to support individuals already employed, such as services of employment search and preparation,

reemployment, job placement, outplacement, vocational follow-up, occupational health and safety services and work environment services, including those who provide these services.

APPENDIX XII

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM**TITLE OF THE RESEARCH PROJECT:**

The activity and participation profile of persons with traumatic spinal cord injury in the Cape Metropole: A prospective, descriptive study.

REFERENCE NUMBER:

PRINCIPLE INVESTIGATOR:

Mirda Maclachlan

ADDRESS:

c/o Physiotherapy Division
University of Stellenbosch
PO Box 19063
Tygerberg 7505
South Africa

CONTACT NUMBERS:

(w): 021-938 9300
(cell): 072 225 8825

Dear Participant

You are being invited to take part in a research project to investigate the level of functioning of persons that sustained an injury to the spinal cord due to an accident (also known as a traumatic spinal cord injury) after discharge from the Western Cape Rehabilitation Centre (WCRC). Please take some time to read the information presented here, which will explain the details of the project. Your participation is **entirely voluntary**. You have the right to decline to participate in the study and you have the right to withdraw from the study at any time even if you do agree to take part. If you decide not to participate or to withdraw from the study at any time, this will not affect you negatively in any way whatsoever. All the information collected will be handled in a confidential manner and participant privacy will be ensured throughout the study. Subjects will be allocated a number and the code to the names will be kept separately and in a secure place.

This study has been approved by the **Committee for Human Research at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is the aim of this research study?

The aim of the study is to establish whether persons with a traumatic spinal cord injury (SCI) maintain their level of functioning after discharge from the WCRC and to identify factors that can influence functioning after discharge. The aim of the rehabilitation that you receive as an inpatient at the WCRC is to fully reintegrate you into your discharge environment (home and community). To achieve this aim we, as health workers, need to know which factors can contribute to the maintenance or not of function after discharge from the WCRC.

Where and how will the study be conducted?

The study will be conducted at the WCRC. All patients that are discharged during a predetermined period and are eligible for the study will be invited to participate in the study. Patients will be invited to participate in the study until the required number of patients necessary for the study has been included (i.e. 50 patients).

Persons that are included in the study will be assessed by the principle researcher during the last 2 weeks of their stay at the WCRC and, if necessary, again at 6 months after discharge from the WCRC. On both occasions a questionnaire will be completed by the principal researcher and two (2) tests will be performed on you to establish the level of the spinal cord injury, and your level of functioning.

Why have you been invited to participate in the study?

According to the inclusion criteria of the study you are eligible to participate in the study. The inclusion criteria are as follows:

- Traumatic SCI.
- Age 18 years and older at time of injury.
- Males and females.
- Discharge to the Cape Metropolitan region of the Western Cape.

What will your responsibilities be?

It will be expected of you to assist the researcher in completing a questionnaire on details regarding your home, community and socio-economic circumstances. You are urged to answer all questions truthfully. Furthermore you will have to assist the researcher with tests that will be done to establish your level of functioning and to classify your SCI. These tests will not be harmful to you in any

way. It will also be expected of you to return to the WCRC 6 months after discharge from the WCRC for a once-off visit as an outpatient. There are no risks involved in the study.

Will you benefit from taking part in the study?

You will not benefit directly from taking part in the study, but any information you provide that need follow-up, will be addressed appropriately. Future patients admitted to the WCRC for rehabilitation after SCI will benefit from the results of the study.

Who will have access to your medical records?

Only the principal researcher will have access to your medical records. All information collected will be treated as confidential and will be protected. Participants will remain anonymous throughout the study.

Will you be paid to take part in this study and are there any costs involved?

No, you will not be paid to take part in the study, but your transport will be subsidized with a once-off payment of R30 (thirty rand) for your 6 month follow-up visit. You will only receive this payment after your 6 month assessment has been completed. You will therefore be responsible for your own transport to get to the WCRC for your 6 month appointment. There will be no other costs involved for you, if you do take part.

Thank you for your time and for agreeing to participate in the study. The study consists of 2 parts i.e. the assessment at discharge from the WCRC and again at 6 months after discharge. Even though you agree to participate in both parts of the study, but it might not be necessary for you to participate in the second part of the study. Participants that return to the WCRC for the 6 month follow-up assessment will be informed at least 2 weeks prior to the appointment. Feel free to contact the principal researcher at any time should you need further information and/or to request a copy of the results once the study is completed. You can contact the Committee for Human Research at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by the researcher.

You will receive a copy of this information and consent form for your own records.

Yours sincerely,

Mirda Maclachlan

Principal researcher

Declaration by participant

By signing below, I agree to take part in a generic research study entitled “The activity and participation profile of persons with traumatic spinal cord injury in the Cape Metropole: A prospective, descriptive study“.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurized to take part.
- I may choose to leave the study at any time and will not be penalized or prejudiced in any way.
- I may be asked to leave the study before it is finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (place) on (date)

.....

Signature of participant

Signature of witness

Declaration by investigator

I (name)..... declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above.
- I did/did not use a translator.

Signed at (place)..... on (date)

.....

Signature of investigator

Signature of witness

Declaration by translator

I (name) declare that:

- I assisted the investigator (name) to explain the information in this document to (name of participant)

..... Using the language medium of Afrikaans/Xhosa.

- We encourage him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her questions satisfactorily answered.

Signed at (place) on (date)

.....

.....

Signature of translator

Signature of witness

APPENDIX XIII

DEELNEMERINLIGTINGSBLAD EN TOESTEMMINGSVORM**TITEL VAN DIE NAVORSINGSPROJEK:**

Die aktiwiteit en deelname profiel van persone met 'n traumatiese spinaalkoordbesering (SKB) in die Kaapse Metropol: 'n vooruitwerkende, beskrywende studie.

VERWYSINGSNOMMER:

HOOFNAVORSER:

Mirda Maclachlan

ADRES:

P/a Fisioterapie Afdeling

Stellenbosch Universiteit

Posbus 19063

Tygerberg 7505

Suid-Afrika

KONTAKNOMMERS:

(W): 021-938 9300

(Sel): 072 225 8825

Geagte Deelnemer

U word uitgenooi om deel te neem aan 'n navorsingsprojek om die vlak van aktiwiteit en deelname te ondersoek van persone wat n besering van die spinaalkoord opgedoen het as gevolg van n ongeluk (ook genoem traumatiese spinaalkoordbesering (SKB)) na ontslag van die Wes-Kaapse Rehabilitasie Sentrum(WKRS). Lees asseblief hierdie inligtingsblad op u tyd deur, aangesien detail van die navorsingsprojek daarin verduidelik word. U deelname is **volkome vrywillig** Dit staan u vry om deelname aan die projek te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word, indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u

ingestem om deel te neem. Alle inligting wat ingesamel word, sal vertroulik hanteer word en elke deelnemer se privaatheid sal ten alle tye verseker word. Elke deelnemer sal 'n nommer ontvang en die kode tot die naam word apart in 'n veilige plek bewaar.

Hierdie navorsingsprojek is deur die Komitee vir Mensnavorsing van die Universiteit Stellenbosch **goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die**

Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).

Wat is die doel van die navorsingsprojek?

Die doel van die projek is om te bepaal of persone met traumatiese spinaalkoordbesering (SKB) hul funksie behou na ontslag van die WKRS en om faktore te identifiseer wat 'n invloed mag he op funksie na ontslag. Die doel van die rehabilitasie wat u ontvang by die rehabilitasie sentrum is om u ten volle te reintegreer in die omgewing waarin u ontslaan word nl. u huis en die gemeenskap. Om hierdie doel te bereik, is dit belangrik vir ons, as gesondheidswerkers, om te weet watter faktore moontlik 'n invloed kan he op die behoud van funksie, al dan nie, na ontslag van die WKRS.

Waar en hoe word die navorsingsprojek uitgevoer?

Die studie sal uitgevoer word by die WKRS. Alle persone wat ontslaan word vanaf en insluitend 1 Augustus 2008 en wat geskik is vir die studie sal uitgenooi word om aan die studie deel te neem. Persone sal ingesluit word in die studie tot die aangewese getal van 50 deelnemers bereik is. Persone wat in die studie ingesluit word, sal gedurende die laaste 2 weke van sy/haar verblyf by die rehabilitasie sentrum deur die navorser geevalueer word en weer op 6 maande na ontslag.

Tydens beide geleenthede sal n vraelys deur die navorser met u samewerking voltooi word en twee (2) toetse sal uitgevoer word om die vlak van u SKB en u funksie te bepaal.

Waarom is u genooi om deel te neem aan die navorsingsprojek?

U voldoen aan die insluitingsvereistes vir die studie, daarom is u geskik om deel te neem aan die studie.

Die insluitingsvereistes is die volgende:

- Traumatiese SKB.
- Ouderdom 18 jaar en ouer.
- Mans en vrouens.
- Ontslaan word na die Kaapse Metropool-streek van die Wes-Kaap.

Wat sal u verantwoordelikhede wees?

Dit sal van u verwag word om die navorser se vrae t.o.v. u huis, gemeenskap en sosio-ekonomiese omstandighede eerlik te beantwoord. U sal ook u samewerking moet gee tydens toetse wat uitgevoer word om u vlak van funksie te bepaal en u SKB te klassifiseer. Hierdie toetse kan op geen manier enige skade aan u as persoon aanrig nie. Dit sal ook van u verwag word om vir n eenmalige

opvolgbesoek 6 maande na ontslag terug te keer as n buitepasient na die WKRS. Daar is geen risikos verbonde aan die studie nie.

Sal u enige voordeel trek uit u deelname aan die navorsingsprojek?

U sal nie direk voordeel trek uit u deelname aan die studie nie, maar sou enige inligting na vore kom wat opgevolg moet word, sal dit op n toepaslike wyse hanteer word. Die resultate van die studies sal wel tot voordeel wees van persone wat in die toekoms tot die WKRS toegelaat word vir rehabilitasie.

Wie sal toegang hê tot u mediese rekords?

Slegs die hoofnavorser sal toegang tot u mediese rekords he. Alle inligting sal as vertroulik hanteer word en u identiteit sal deurentyd beskerm word.

Sal u betaal word vir u deelname aan die studie en is daar enige kostes verbonde aan deelname?

Nee, u sal nie betaal word om deel te neem aan die studie nie, maar die vervoer vir u 6 maande opvolgbesoek sal met n eenmalige bedrag van R30 (dertig rand) gesubsidieer word. U sal die betaling ontvang na afloop van die evaluering tydens die opvolgbesoek. U sal dus self verantwoordelik wees vir u vervoer tot by die WKRS vir die 6 maande opvolgbesoek. Deelname aan die navorsingsprojek sal u niks kos nie.

Dankie vir u tyd en dat u bereid is om deel te neem aan die navorsingsprojek. Die studie bestaan uit 2 dele nl. die evaluering met ontslag van die WKRS en weer op 6 maande na ontslag van die WKRS. Alhoewel u toestemming verleen om deel te neem aan beide dele van die navorsingsprojek, sal dit dalk nie nodig wees om aan die tweede gedeelte van die studie deel te neem nie. Sodra die verlangde getal van 50 persone op 6 maande na ontslag bereik is, sal die invordering van data gestaak word. U sal ten minste 2 weke voor die datum vir die opvolgbesoek in kennis gestel word of u moet terugkeer vir die 6 maande evaluering. U is welkom om die hoofnavorser enige tyd te kontak , sou u meer inligting oor die studie verlang of indien u sou belangstel in n afskrif van die resultate na afloop van die studie. U kan die Komitee vir Mensnavorsing by 021-938 9207 kontak indien u bekommerd is oor enige aspek van die studie of as u voel dat alle aspekte nie ten volle aangespreek is deur die navorser nie.

U sal n afskrif van die inligting en die toestemmingsvorm ontvang vir u eie rekords.

Die uwe.

Mirda Maclachlan

Hoofnavorser

Verklaring deur deelnemer

Met die ondertekening van hierdie dokument onderneem ek,, om deel te neem aan n navorsingsprojek getiteld “Die vlak van aktiwiteit en deelname van persone met ‘n traumatiese spinaalkoordbesering (SKB) in die Kaapse Metropol: ‘n Vooruitwerkende, beskrywende studie”.

Ek verklaar dat:

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in taal geskryf is waarin ek vaardig is en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te (plek) op (datum)

.....

Handtekening van deelnemer

Handtekening van getuie

Verklaring deur navorser

Ek, verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan
- Ek hom/ haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/ sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek n tolk gebruik het/ nie gebruik het nie.

Geteken te (plek) op (datum)

APPENDIX XIV

INCWADANA ENGOLWAZI NGOMTHATHI-NXAXHEBA KUNYE NEFOMU**YEMVUMELWANO****ISIHLOKO SEPROJEKTHI YOPHANDO**

Ukubuyisela umzimba kwiintshukumo zesiqhelo nokubonisa inxaxheba ethathwa ngabantu abakhathazwa kukonzakala komnqonqo kwezi ntshukumo e*Cape Metropole*: Isifundo esichaza ngendlela enika ithemba.

INOMBOLO YONXULUMANO:

UMPHANDI OYINTLOKO:

Mirda Maclachlan

IDILESI:

c/o ICandelo loKolulwa nokuthanjiswa kwamalungu omazimba (Physiotherapy Division)

University of Stellenbosch

PO Box 19063

Tygerberg 7505

South Africa

INOMBOLO YOQHAGAMSHELWANO:

(emsebenzini): 021-938 9300

(iselula): 072 225 8825

Mthathi-nxaxheba obekekileyo

Uyamenywa ukuba athathe inxaxheba kwiprojekthi yophando. You are being invited to take part in a research project. Nceda thatha ixesha lokufunda ulwazi oluvezwe apha, oluzakuthi luchaze iinkcukacha zale projekthi. Nceda buza nayiphina imibuzo emalunga nayiphina indawo ongayiqondiyo ngokupheleleyo kubasebenzi besi sifundo okanye kugqirha. Kubaluleke kakhulu ukuba waniliseke ngokupheleleyo yinto yokuba ucacelwe kakuhle ukuba yintoni ebangwa sesi sifundo kwaye ungabandakanyeka njani. Kwakhona, ukuthatha kwakho inxaxheba **kungentando yakho ngokupheleleyo** kwaye ukhululekile ukuba ungarhoxa ekuthatheni inxaxheba. Ukuba uthi hayi, oku akusayi kuchaphazela ukungavumi kwakho nangayiphina indlela. Ukwakhululekile ukuba uyeke kwesi sifundo naninina, nkqu nokokuba uyavuma ukuthatha inxaxheba ekuqaleni.

Olu phando luvunywe ziinqobo ezisesikweni zeKomiti yoPhando Lomntu kwiYunivesithi yaseStellenbosch kwaye luzakwenziwa ngokwemigaqo esesikweni loPhando elamkelekileyo kwiSaziso sehlabathi sika-Helsinki, iMigaqo eLungileyo yoMzantsi Afrika yokuSebenza eKliniki kunye neBhunga lezoPhando ngamaYeza (MRC) iMigaqo yeNqobo yezoPhando.

Yintoni iinjongo zesi sifundo sophando?

Iinjongo zesi sifundo kukuqonda ukuba abantu abakhathazwa kukonzakala komnqonqo (SCI) babuyela kwiintshukumo zabo zesiqhelo na kakade emva kokuba bephumile eWCRC kunye nokuqaphela iimeko ezinokuba nempembelelo kwiintshukumo zomzimba emva kokuphuma esibhedlele apho. Injongo yokuba ubekwe kwiimeko zokuchacha njengesigulane esinyangelwa ngaphandle kukuba uqhelaniswe ngokupheleleyo neemeko zakho zokuhlala (ekhaya nasekuhlaleni). Ukufezekisa ezi njongo thina singabasebenzi kwimeko zonyango, sifuna ukuqonda ukuba ziziphi iimeko ezinokunceda ekubuyiseleni iintshukuno zakho zesiqhelo okanye ezinokuba ngumqobo emva kokuba uphumile eWCRC.

Esi sifundo siza kwenziwa njani, sisenzelwa phi?

Esi sifundo siza kuqhutyelwa eWCRC. Zonke izigulane esele kugqityiwe ngexesha eziza kuphuma ngalo kunjalo nje ziselungelweni ngokweemfuno zesifundo ukuba zingabandakanyeka ziza kucelwa ukuba zithathe inxaxheba. Izigulane ziza kucelwa ukuba zifake izicelo zokuthabatha inxaxheba lingakafiki inani lama-50 ezigulane ezifunekayo.

Abantu abaza kubandakanyeka kwesi sifundo baza kuvavanywa ngumphandi oyintloko ngexesha lokuchitha kwabo iiveki ezi-2 beseWCRC kwaye baza kuphinda bavavanywe emva kweenyanga ezi-6 bephumile eWCRC ukuba imfuneko ikhona. Kwezi zihlandlo zozibini umphandi ophambili uza kugcwalisa iphepha lemibuzo enze uvavanyo lokuqala nolwesibini kuwe apha ukuze aqonde ubungakanani bokonzakala komnqonqo.

Kutheni umenyiwe ukuba uthathe inxaxheba?

Ngokweemfuno zesifundo unazo izinto eziyimiqathango yokuba ungabandakanyeka. Ukuze ubandakanyeke kufuneka wanelise iimfuno zesifundo nezime ngolu hlobo lulandelayo:

- Umnqonqo owonzakele ngendlela ekhathazayo (Traumatic SCI).
- Kufuneka ube neminyaka eli-18 nangaphezulu ubudala.
- Amadoda nabaseThyini.
- Ube ngumhlali kwingingqi ye *Cape Metropolitan* eNtshona Koloni.

Yintoni eza kuba luxanduva lwakho?

Kuza kufuneka uncedisane nomphandi ekugcwaliseni iphepha lemibuzo ngokubhekisele kwiinkcukacha ngekhyaya, uluntu nemeko yentlalo noqoqosho. Uyabongozwa ukuba uphendule yonke imibuzo ngendlela enyanisekileyo. Ngaphaya koko kuza kufuneka uncedise umphandi

ekwenzeni uvavanyo lokuqonda iqondo lokumisa kweentshuko zomzimba nokukhetha isigaba okuso umonzakalo wonqonqo. Uvavanyo oluza kwenziwa kuwe alunabungozi. Emva kweenyanga ezi-6 uphumile WCRC kulindeleke ukuba ubuyele kwakhona apho ukuze ungeniswe isihlandlo sibe sinye njengesigulane esinyangelwa ngaphandle. Akukho ngozi unokuzifumana ukuyo kwesi sifundo.

Ingaba uza kuzuzisa ekuthatheni inxaxheba kolu phando?

Akukho mbuyekezo ithe nqo uza kuyifumana ngokuthabatha inxaxheba kwesi sifundo kodwa siyakulandela naluphi na ulwazi olusinika umkhondo. Izigulane ezichacha eWCRC ngenxa yomonzakalo womnqonqo ziya kuxhamla kwixesha eliya kuthi lilandele iziphumo.

Ngubani uza kufumana ingxelo yakho yamayeza?

Ngumphandi ophambili kuphela oya kuba nolwazi ngeenkukacha ezigciniweyo zonyango lwakho. Zonke iinkukacha eziqokelelweyo ziya kuba yimfihlo ekhuselekileyo. Amagama abo bathabatha inxaxheba aya kugcinwa eyimfihlo ngalo lonke ixesha kusenziwa uphando.

Ingaba uza kuhlulwa ngokuthatha inxaxheba kwesi sifundo kwaye ingaba kukho iindleko ezibandakanyekayo?

Hayi, akuzi kuhlulwa ngokuthatha kwakho inxaxheba kwezi zifundo, kodwa uza kufumana inkxaso-mali yesambuku sama R30 eziindleko zeenyanga ezi-6 zotyalelo ukuze kukhangelwe inkqubela. Le ntlawulo uza kuyifumana lusakuba lugqityiwe uvavanyo lweenyanga ezi-6. Ngoko ke kuza kufuneka uzifunele isithuthi sokuza kutyalelo lwakho lweenyanga ezi-6 eWCRC. Akube kuphinde kubekho zindleko zizezinye.

Enkosi kakhulu ngexesha lakho nokuba uvume ukuthabatha inxaxheba kwesi sifundo. Esi sifundo sinamacandelo amabini (okt.) uvavanyo olwenziwayo xa uphuma eWCRC nolo lwenziwa emva kweenyanga ezi-6 uphumile eWCRC. Nangona uvumile ukuthabatha inxaxheba kuwo omabini amacandelo, ise nokungabikho imfuneko yokuba uthabathe inxaxheba kwicandelo lesibini lesifundo. Abathathi inxaxheba abaza kuchitha iinyanga ezi-6 besiza kuvavanyo lokujonga inkqubela eWCRC baza kwaziswa kwisithuba seeveki ezimbini phambi kokuba luqalise utyalelo lwabo lokuqala. Xa kunokwenzeka ufune iinkukacha ezongezelekileyo kunye/okanye ufune ikopi yeziphumo emva kokugqitywa kwesifundo kufuneka uqhagamshelane nomphandi oyintloko. Ungaqhagamshelana neKomiti yoPhando ngoMntu kule nombolo 021-938 9207 ukuba unezinto ezikuxhalabisayo okanye izikhalazo ezingakhange ziphendulwe ngendlela eyanelisayo ngumphandi.

Uza kufumana ikopi ngezi nkukacha nefomu yokunika imvume yakho uzigcinele ekhaya.

Ndim ngenene.
 Mirda Maclachlan
 UMphandi oPhambili

Isifungo somthathi-nxaxheba

Ngokutyikitya ngezantsi apha, Mna ndinika imvume yokuthabatha inxaxheba kwisifundo sophando esinesihloko “Ukubuyisela umzimba kwiintshukumo zesiqhelo nokubonisa inxaxheba ethathwa ngabantu abakhathazwa kukonzakala komqonqo kwezi ntshukumo e*Cape Metropole*: Isifundo esichaza ngendlela enika ithemba”.

Ndenza isifungo sokuba:

- Ndilufundile okanye ndalufunda olu lwazi kunye nefomu yemvumelwano kwaye ibhalwe ngolwimi endiliciko nendikhululekileyo kulo
- Bendinalo ithuba lokuba ndibuze imibuzo kwaye yonke imibuzo yam iphendulwe ngokwanelisayo.
- Ndiyakuqonda ukuba ukuthatha inxaxheba kolu phando kube **kukuzithandela kwam** kwaye andikxange ndinyanzelwe ukuba ndithathe inxaxheba.
- Ndingakhetha ukusishiya isifundo naninina kwaye andisayi kohlwaywa okanye uqal’ ugwetywe nangayiphi indlela.
- Usenokucelwa ukuba usishiye isifundo phambi kokuba siphele, ukuba ugqirha wesifundo okanye umphandi ukubona kuyinzuzo kuwe, okanye ukuba andisilandeli isicwangciso sesifundo, ekuvunyelenwe ngaso.

Kutyikitywe e-(indawo) ngo-(usuku)

.....

Umtyikityo womthathi-nxaxheba

Umtyikityo wengqina

Isifungo somphandi

Mna (*igama*) ndiyafunga ukuba:

- Ndilucacisile ulwazi olu kweli xwebhu ku-.....
- Ndimkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.

- Ndiyaneliseka kukuba uyakuqonda ngokwanelisayo konke okumalunga nophando okuxoxwe ngasentla.
- Ndisebenzise/andisebenzisanga toliki. (*Ukuba itoliki isetyenzisiwe kumele ityikitye isaziso ngezantsi.*)

Kutyikitywe e-(indawo) ngo-(usuku)

.....
Umtyikityo womphandi

.....
Umtyikityo wengqina

Isifungo setoliki

Mna (*igama*) ndazisa ukuba:

- Ndicende umphandi (*igama*) Ekucaciseni ulwazi olu lapha kweli xwebhu ku-(*igama lomthathi-nxaxheba*) ndisebenzisa ulwimi lwesiAfrikaans/lwesiXhosa.
- Simkhuthazile ukuba abuze imibuzo kwaye athathe ixesha elifanelekileyo ukuba ayiphendule.
- Ndimxelele eyona nto iyiyo malunga nokunxulumene nam.
- Ndiyaneliseka kukuba umthathinxaxheba ukuqonda ngokupheleleyo okuqulathwe loluxwebhu lwemvumelwano eyazisiweyo kwaye nemibuzo yakhe yonke iphendulwe ngokwanelisayo.

Kutyikitywe e-(indawo) ngo-(usuku)

.....
Umtyikityo wetoliki

.....
Umtyikityo wengqina

APPENDIX XV

Complete results for activity and participation at discharge from the WCRC

Table 4.9: Activity and participation at discharge

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
Mobility								
d4100	Changing basic body position: Lying down	45	1	1	0	0	0	0
d4101	Changing basic body position: Squatting	3	9	2	3	30	0	0
d4102	Changing basic body position: Kneeling	3	6	4	3	31	0	0
d4103	Changing basic body position: Sitting	45	0	1	1	0	0	0
d4104	Changing basic body position: Standing	14	2	4	1	26	0	0
d4105	Changing basic body position: Bending	35	1	2	1	8	0	0
d4153	Maintaining a body position: Sitting	44	3	0	0	0	0	0
d4154	Maintaining a body position: Standing	12	5	3	1	26	0	0
d4200	Transferring oneself while sitting	37	5	4	1	0	0	0
d430	Lifting and carrying objects	33	7	4	3	0	0	0
d440	Unilateral fine hand use	34	1	3	2	7	0	0
d445	Unilateral hand and arm use	35	4	3	2	3	0	0
d4500	Walking short distances	10	2	5	3	27	0	0
d4501	Walking long distances	5	1	3	0	38	0	0
d4502	Walking on different surfaces	7	4	2	0	34	0	0
d4503	Walking around obstacles	8	4	2	0	33	0	0

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
d4600	Moving around within the home	34	1	4	5	3	0	0
d4601	Moving around buildings other than home	16	5	1	0	25	0	0
d4602	Moving around outside the home and other buildings	24	8	6	6	3	0	0
d465	Moving around using equipment	21	6	8	2	0	0	10
d4701	Moving around using private motorized transportation	24	6	9	4	4	0	0
d4702	Moving around using public motorized transportation	3	1	3	3	33	0	4
d475	Driving	0	0	0	1	16	0	30
Self-care								
d510	Washing oneself	37	4	6	0	0	0	0
d520	Caring for body parts	40	4	2	1	0	0	0
d5300	Toileting: Regulating urination	42	2	3	0	0	0	0
d5301	Toileting: Regulating defecation	44	1	1	1	0	0	0
d5302	Toileting: Menstrual care	2	0	0	1	0	0	44
d540	Dressing	35	6	6	0	0	0	0
d550	Eating	42	3	2	0	0	0	0
d560	Drinking	44	2	0	1	0	0	0
d570	Looking after one's health	32	3	6	5	1	0	0
Domestic life								
d620	Acquisition of goods and services	11	0	2	0	34	0	0

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
d630	Preparing meals	17	0	1	1	17	0	11
d640	Doing housework	10	0	4	1	16	0	16
d650	Caring for household objects	11	2	1	0	20	0	13
d660	Assisting others	5	1	0	0	14	0	27
Interpersonal interactions and relationships								
d750	Informal social relationships	28	5	3	6	5	0	0
d760	Family relationships	42	0	1	3	1	0	0
d770	Intimate relationships	21	0	2	3	21	0	0
Major life areas								
d820	School education	0	0	0	0	2	0	45
d850	Remunerative employment	2	0	0	0	45	0	0
d855	Non-remunerative employment	0	0	0	0	5	0	42
d870	Economic self-sufficiency	6	0	0	2	39	0	0
Community, social and civic life								
d920	Recreation and leisure	2	1	3	4	37	0	0
d930	Religion and spirituality	8	1	0	1	23	0	14

APPENDIX XVI

Complete results for activity and participation at six months after discharge from the WCRC

Table 4.14 Activity and participation profile at six months

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
Mobility								
d4100	Changing basic body position: Lying down	26	1	0	0	0	0	0
d4101	Changing basic body position: Squatting	3	5	3	2	14	0	0
d4102	Changing basic body position: Kneeling	2	7	2	2	14	0	0
d4103	Changing basic body position: Sitting	24	2	0	1	0	0	0
d4104	Changing basic body position: Standing	10	2	2	0	13	0	0
d4105	Changing basic body position: Bending	22	1	0	0	4	0	0
d4153	Maintaining a body position: Sitting	26	1	0	0	0	0	0
d4154	Maintaining a body position: Standing	11	2	1	0	13	0	0
d4200	Transferring oneself while sitting	24	1	1	1	0	0	0
d430	Lifting and carrying objects	22	4	1	0	0	0	0
d440	Unilateral fine hand use	20	2	1	1	3	0	0
d445	Unilateral hand and arm use	23	2	1	0	1	0	0
d4500	Walking short distances	9	2	0	3	13	0	0
d4501	Walking long distances	4	4	1	1	17	0	0
d4502	Walking on different surfaces	8	2	1	2	14	0	0
d4503	Walking around obstacles	8	2	1	2	14	0	0
d4600	Moving around within the home	22	2	2	1	0	0	0

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
d4601	Moving around within buildings other than home	23	3	1	0	0	0	0
d4602	Moving around outside the home and other buildings	16	7	3	1	0	0	0
d465	Moving around using equipment	13	3	1	0	0	0	10
d4701	Moving around using private motorized transportation	21	0	3	2	1	0	0
d4702	Moving around using public motorized transportation	7	1	2	2	12	0	3
d475	Driving	1	0	0	0	10	0	16
Self-care								
d510	Washing oneself	23	2	2	0	0	0	0
d520	Caring for body parts	23	3	1	0	0	0	0
d5300	Toileting: Regulating urination	26	1	0	0	0	0	0
d5301	Toileting: Regulating defecation	26	1	0	0	0	0	0
d5302	Toileting: Menstrual care	0	1	0	0	0	0	26
d540	Dressing	23	3	1	0	0	0	0
d550	Eating	25	1	0	1	0	0	0
d560	Drinking	27	0	0	0	0	0	0
d570	Looking after one's health	18	2	5	1	1	0	0
Domestic life								
d620	Acquisition of goods and services	25	0	2	0	0	0	0
d630	Preparing meals	21	1	1	0	0	0	4
d640	Doing housework	14	1	3	0	3	0	9

ICF code	Activity	No difficulty	Mild difficulty	Moderate difficulty	Severe difficulty	Complete difficulty	Not specified	Not applicable
		0	1	2	3	4	8	9
d650	Caring for household objects	19	1	1	2	0	0	4
d660	Assisting others	13	2	0	0	0	0	12
Interpersonal interactions and relationships								
d750	Informal social relationships	16	4	1	3	3	0	0
d760	Family relationships	22	0	1	3	1	0	0
d770	Intimate relationships	16	0	0	0	11	0	0
Major life areas								
d820	School education	1	0	0	0	0	0	26
d850	Remunerative employment	2	1	0	0	24	0	0
d855	Non-remunerative employment	0	0	0	0	3	0	24
d870	Economic self-sufficiency	19	0	0	1	7	0	0
Community, social and civic life								
d920	Recreation and leisure	7	2	4	4	10	0	0
d930	Religion and spirituality	15	0	0	0	5	0	7

APPENDIX XVII

Complete results for amount and type of assistance utilized at discharge from the WCRC

Table 4.10: Amount and type of assistance needed at discharge ($n = 47$)

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
Mobility								
d4100	Changing basic body position: Lying down	41	0	6	0	0	0	0
d4101	Changing basic body position: Squatting	9	8	0	0	30	0	0
d4102	Changing basic body position: Kneeling	6	10	0	0	30	1	0
d4103	Changing basic body position: Sitting	40	0	7	0	0	0	0
d4104	Changing basic body position: Standing	13	8	0	0	26	0	0
d4105	Changing basic body position: Bending	37	2	0	0	8	0	0
d4153	Maintaining a body position: Sitting	39	8	0	0	0	0	0
d4154	Maintaining a body position: Standing	12	9	0	0	26	0	0
d4200	Transferring oneself while sitting	35	3	6	3	0	0	0
d430	Lifting and carrying objects	11	1	35	0	0	0	0
d440	Unilateral fine hand use	40	0	0	0	7	0	0
d445	Unilateral hand and arm use	44	0	0	0	3	0	0
d4500	Walking short distances	8	12	0	0	27	0	0
d4501	Walking long distances	6	2	1	0	27	11	0
d4502	Walking on different surfaces	7	5	1	0	27	7	0
d4503	Walking around obstacles	7	6	1	0	27	6	0
d4600	Moving around within the home	8	32	0	4	1	2	0

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
d4601	Moving around buildings other than home	6	15	0	1	0	25	0
d4602	Moving around outside the home and other buildings	7	21	1	15	0	3	0
d465	Moving around using equipment	18	0	19	0	0	0	10
d4701	Moving around using private motorized transportation	10	0	30	3	0	4	0
d4702	Moving around using public motorized transportation	2	3	5	0	0	33	4
d475	Driving	0	1	0	0	3	13	30
Self-care								
d510	Washing oneself	34	0	13	0	0	0	0
d520	Caring for body parts	28	0	19	0	0	0	0
d5300	Toileting: Regulating urination	37	0	10	0	0	0	0
d5301	Toileting: Regulating defecation	35	0	12	0	0	0	0
d5302	Toileting: Menstrual care	0	0	3	0	0	0	44
d540	Dressing	36	0	11	0	0	0	0
d550	Eating	36	0	8	3	0	0	0
d560	Drinking	41	0	6	0	0	0	0
d570	Looking after one's health	34	0	12	0	0	1	0
Domestic life								
d620	Acquisition of goods and services	4	0	9	0	0	34	0
d630	Preparing meals	11	0	8	0	0	17	11
d640	Doing housework	5	0	10	0	0	16	16
d650	Caring for household objects	2	0	12	0	0	20	13

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
d660	Assisting others	3	0	3	0	0	14	27
Interpersonal interactions and relationships								
d750	Informal social relationships	42	0	0	0	0	5	0
d760	Family relationships	46	0	0	0	0	1	0
d770	Intimate relationships	24	0	2	0	0	21	0
Major life areas								
d820	School education	0	0	0	0	0	2	45
d850	Remunerative employment	2	0	0	0	1	44	0
d855	Non-remunerative employment	0	0	0	0	0	5	42
d870	Economic self-sufficiency	6	0	2	0	39	0	0
Community, social and civic life								
d920	Recreation and leisure	4	0	6	0	0	37	0
d930	Religion and spirituality	6	0	4	0	0	23	14

APPENDIX XVIII

Complete results for amount and type of assistance utilized at six months after discharge from the WCRC

Table 4.15 Amount and type of assistance needed at six months (n=27)

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
Mobility								
d4100	Changing basic body position: Lying down	24	0	3	0	0	0	0
d4101	Changing basic body position: Squatting	9	4	0	0	14	0	0
d4102	Changing basic body position: Kneeling	5	8	0	0	14	0	0
d4103	Changing basic body position: Sitting	22	0	5	0	0	0	0
d4104	Changing basic body position: Standing	10	4	0	0	13	0	0
d4105	Changing basic body position: Bending	23	0	0	0	3	1	0
d4153	Maintaining a body position: Sitting	25	2	0	0	0	0	0
d4154	Maintaining a body position: Standing	11	3	0	0	13	0	0
d4200	Transferring oneself while sitting	22	1	3	1	0	0	0
d430	Lifting and carrying objects	6	0	21	0	0	0	0
d440	Unilateral fine hand use	24	0	0	0	3	0	0
d445	Unilateral hand and arm use	26	0	0	0	1	0	0
d4500	Walking short distances	9	5	0	0	13	0	0
d4501	Walking long distances	8	1	1	0	14	3	0
d4502	Walking on different surfaces	8	4	1	0	13	1	0
d4503	Walking around obstacles	8	4	1	0	13	1	0
d4600	Moving around within the home	10	16	0	1	0	0	0

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
d4601	Moving around buildings other than home	8	14	0	5	0	0	0
d4602	Moving around outside the home and other buildings	8	11	1	7	0	0	0
d465	Moving around using equipment	7	0	10	0	0	0	10
d4701	Moving around using private motorized transportation	9	0	17	0	0	1	0
d4702	Moving around using public motorized transportation	5	3	4	0	0	12	3
d475	Driving	0	1	0	0	3	7	16
Self-care								
d510	Washing oneself	19	0	8	0	0	0	0
d520	Caring for body parts	18	0	9	0	0	0	0
d5300	Toileting: Regulating urination	23	0	4	0	0	0	0
d5301	Toileting: Regulating defecation	22	0	5	0	0	0	0
d5302	Toileting: Menstrual care	0	0	1	0	0	0	26
d540	Dressing	20	0	7	0	0	0	0
d550	Eating	23	0	2	2	0	0	0
d560	Drinking	25	0	2	0	0	0	0
d570	Looking after one's health	19	0	7	0	0	1	0
Domestic life								
d620	Acquisition of goods and services	9	0	17	0	0	1	0
d630	Preparing meals	16	0	7	0	0	0	4
d640	Doing housework	8	0	10	0	0	0	9
d650	Caring for household objects	6	0	17	0	0	0	4

ICF code	Activity	No assistance needed	Non-personal assistance	Personal assistance	Non-personal and personal assistance	Impossible even if assistance is provided	Level of assistance unknown	Not applicable
d660	Assisting others	5	0	9	0	0	1	12
Interpersonal interactions and relationships								
d750	Informal social relationships	24	0	0	0	0	3	0
d760	Family relationships	26	0	0	0	0	1	0
d770	Intimate relationships	16	0	0	0	0	11	0
Major life areas								
d820	School education	1	0	0	0	0	0	26
d850	Remunerative employment	3	0	0	0	1	23	0
d855	Non-remunerative employment	0	0	0	0	0	3	24
d870	Economic self-sufficiency	20	0	0	0	7	0	0
Community, social and civic life								
d920	Recreation and leisure	9	0	8	0	0	10	0
d930	Religion and spirituality	10	0	5	0	0	5	7

APPENDIX XIX

Complete results for environmental barriers at six months after discharge from the WCRC

Table 4.16 Environmental barriers at six months

ICF code	Environmental factor	No barrier	Mild barrier	Moderate barrier	Severe barrier	Some barrier	Complete barrier	Not applicable
		0	1	2	3	1+2+3	4	9
Products and technology								
e110	Products or substances for personal consumption	22	1	1	3	5	0	0
e115	Products and technology for personal use in daily living	26	0	0	0	0	1	0
e120	Products and technology for personal indoor and outdoor mobility and transportation	21	2	1	2	5	1	0
e125	Products and technology for communication	25	0	1	0	1	1	0
e130	Products and technology for education	1	0	0	0	0	0	26
e135	Products and technology for employment	3	0	1	5	6	0	18
e140	Products and technology for culture, recreation and sport	14	0	1	0	1	2	10
e145	Products and technology for the practice of religion and spirituality	14	1	0	0	1	0	12
e150	Design, construction and building products and technology of buildings for public use	18	6	2	0	8	0	1
e155	Design, construction and building products and technology of buildings for private use	23	2	1	1	4	0	0
e160	Products and technology of land development	18	3	2	1	6	2	1
e165	Assets	6	1	0	0	1	1	19
Support and relationships								
e310	Immediate family	25	0	1	0	1	1	0

ICF code	Environmental factor	No barrier	Mild barrier	Moderate barrier	Severe barrier	Some barrier	Complete barrier	Not applicable
		0	1	2	3	1+2+3	4	9
e315	Extended family	15	0	0	0	0	4	8
e320	Friends	17	0	1	4	5	5	0
e325	Acquaintances, peers, colleagues, neighbors and community members	22	0	0	1	1	1	3
e330	People in positions of authority	7	0	0	0	0	1	19
e340	Personal care providers and personal assistants	3	0	0	0	0	0	24
e355	Health professionals	27	0	0	0	0	0	0
Attitudes								
e410	Individual attitudes of immediate family members	24	1	1	0	2	1	0
e415	Individual attitudes of extended family members	15	0	0	0	0	4	8
e420	Individual attitudes of friends	16	1	2	2	5	6	0
e425	Individual attitudes of acquaintances, peers, colleagues, neighbors and community members	21	0	1	1	2	0	4
e430	Individual attitudes of people in positions of authority	7	0	0	0	0	1	19
e440	Individual attitudes of personal care providers and personal assistants	3	0	0	0	0	0	24
e450	Individual attitudes of health professionals	22	2	1	2	5	0	0
e460	Societal attitudes	18	4	5	0	9	0	0
Services, systems and policies								
e5250	Housing services	4	0	0	0	0	2	21
e5300	Utilities services	26	0	0	0	0	1	0

ICF code	Environmental factor	No barrier	Mild barrier	Moderate barrier	Severe barrier	Some barrier	Complete barrier	Not applicable
		0	1	2	3	1+2+3	4	9
e5350	Communication services	26	0	0	1	1	0	0
e5400	Transportation services	13	0	1	2	3	10	1
e5450	Civil protection services	2	0	1	0	1	1	23
e5550	Associations and organizational services	0	0	0	0	0	0	27
e5700	Social security services	17	0	0	2	2	2	6
e5750	General social support services	1	0	0	0	0	0	26
e5800	Health services	24	0	2	1	3	0	0
e5850	Education and training services	1	0	0	0	0	0	26
e5900	Labor and employment services	2	0	0	0	0	3	22

APPENDIX XX

Letters of permission:

- (i) Letter of permission by the Committee for Human Research at Stellenbosch University to conduct the realibility, pilot and main studies
- (ii) Letter to the Institutional Head of the WCRC to request permission to conduct the study at the WCRC.

APPENDIX XX(i)

12 September 2007

Mrs M Maclachlan
Division of Physiotherapy
Dept of Interdisciplinary Health Sciences

Dear Mrs Maclachlan

RESEARCH PROJECT: "THE FUNCTIONAL ABILITY OF PERSONS WITH TRAUMATIC SPINAL CORD INJURY IN THE CAPE METROPOLE: A PROSPECTIVE, DESCRIPTIVE STUDY"
PROJECT NUMBER : N07/07/155

At a meeting of the Committee for Human Research that was held on 1 August 2007 the above project was approved on condition that further information that was required, be submitted.

This information was supplied and the project was finally approved on 11 September 2007 for a period of one year from this date. This project is therefore now registered and you can proceed with the work. Please quote the above-mentioned project number in all further correspondence.

Please note that a progress report (obtainable on the website of our Division) should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.

Patients participating in a research project in Tygerberg Hospital will not be treated free of charge as the Provincial Government of the Western Cape does not support research financially.

Due to heavy workload the nursing corps of the Tygerberg Hospital cannot offer comprehensive nursing care in research projects. It may therefore be expected of a research worker to arrange for private nursing care.

Yours faithfully



CJ VAN TONDER
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)
Tel: +27 21 938 9207 / E-mail: cjvt@sun.ac.za
CJVT/pm

APPENDIX XX(ii)

10 October 2007

Ms J. Henry
Head of Institution
Western Cape Rehabilitation Centre
Mitchell's Plain

Dear Ms Henry

PERMISSION TO CONDUCT RESEARCH AT THE WESTERN CAPE REHABILITATION CENTRE (WCRC)

I am currently doing a Masters Degree in Physiotherapy at the Stellenbosch University. The title of the research project is: “**The functional ability of persons with traumatic spinal cord injuries in the Cape Metropole: A prospective, descriptive study.** The project has been approved by the Committee for Human Research (project number: N07/07/155).

The study consists of a reliability study, a pilot study and a main study. The primary **aim** of the study is to establish whether functional ability of persons with traumatic spinal cord injury is maintained after discharge from inpatient rehabilitation and to identify factors that can influence maintenance of functional ability after discharge. Subjects will be assessed at discharge from the WCRC and again during a follow-up session at the WCRC. The population for this study will include adults with traumatic spinal cord injuries (SCI) admitted for rehabilitation to the WCRC. Consecutive sampling will be used and all patients that meet the inclusion criteria will be included in the study. Power calculation was done to determine sample size and it was found that with a population correlation (Rho) of 0.4, significant results will be obtained with a sample size of 50 at follow-up.

Data will be collected by means of a self-developed questionnaire and three (3) outcome measure instruments i.e. the South African Database for Functional Medicine (SADFM) Beta Scale (February 2005, Version 6) (SADFM Beta Scale), the Modified Ashworth Scale (MAS) and the International Standards for Neurological and Functional Classification of SCI (ISCSICI).

I will not require any assistance from the staff of the WCRC as all the data will be collected by myself.

I will however need the assistance of a suitable person(s) to inform me of all the patients with traumatic spinal cord injuries that are for discharge within two (2) weeks of their proposed discharge date.

I will also need the assistance of a medical officer to assist me with the inter- and intra-reliability study. Although reliability has been established for the International Standards for Neurological and Functional Classification of SCI (ISCSCI) it is essential to conduct a reliability study to assure inter- and intra-tester reliability for the ISCSCI as applied by the researcher. In preliminary discussions with Dr Ernst Scriba, he has indicated his willingness to assist in this regard.

As there is no need for the subjects to draw their medical folders for the follow-up session at 6 months post discharge, I therefore assume that no costs will be involved.

The plan is to conduct the pilot - and reliability studies this year and to start with the data collection for the main study in January 2008.

The results of the research project will be made available to the WCRC.

I will appreciate you considering granting me permission to conduct the above-mentioned study at the WCRC as data collected for this study will reveal information on the profile of persons with SCI receiving rehabilitation in the Cape Metropole and more specifically at the WCRC. This information will give insight into factors that can influence functional ability post discharge, resource allocation and motivation thereof, education on prevention of SCI and hopefully set a platform for further research in the field of SCI, not only in the Western Cape, but nationally.

Included are the questionnaire and examination sheets that will be used for data collection. Should you require more information on the project you are welcome to contact me.

I thank you in advance.

Yours faithfully.

Ms Mirda Maclachlan.

Contact details:

Cell: 072 225 8825

Home: 021 939 3520