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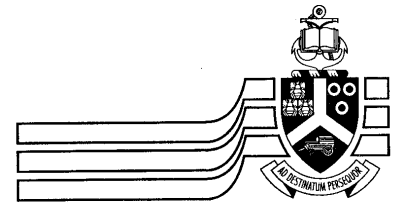
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APPENDIX A ETHICAL CLEARANCE CERTIFICATE



University of Pretoria

Faculty of Health Sciences Research Ethics Committee
University of Pretoria
Room 2 – 19 MRC-Building, Soutpansberg Road
Private Bag x 385
Pretoria 0001
Date: 27 / 07 / 2006

Number : 38/2006
Title : Factors influencing the rehabilitation outcome of clients disabled by spinal cord injury
Investigators: Mrs D J Mothabeng; Department of Physiotherapy; Pretoria Academic Hospital and Kalafong Hospital University of Pretoria ; Pretoria
joyce.mothabeng@up.ac.za T:012-354 1200 F: 012-354 1226 C: 0829565528
Sponsor : **None.**
VAT No : **None.**

Study Degree: **PhD Physiotherapy (Rehabilitation)**

This Protocol and Informed Consent have been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 26/07/2006 and found to be acceptable.

Mr P Behari B.Proc. KZN; LLM – Unisa; (Lay Member)
*Advocate AG Nienaber (female)BA(Hons) (Wits); LLB; LLM (UP); Dipl.Datometrics (UNISA)
*Prof V.O.L. Karusseit MBChB; MFGP (SA); M.Med (Chir); FCS (SA): Surgeon
Dr M E Kenoshi MB,CHB; DTM & H (Wits); C.E.O. of the Pretoria Academic Hospital
Prof M Kruger (female) MB.ChB.(Pret); Mmed.Paed.(Pret); PhD. (Leuven)
Dr N K Likibi MB.BCh.; Med.Adviser (Gauteng Dept.of Health)
*Dr F M Mulaudzi (female) Department of Nursing,
*Mrs E.L. Nombe (female) B.A. CUR Honours; MSC Nursing – UNISA (Lay Member)
+Snr Sr J. Phatoli (female) BCur (Et.AI) Senior Nursing-Sister
***Dr L Schoeman (female) Bpharm, BA Hons (Psy), PhD**
*Prof J.R. Snyman MBChB, M.Pharm.Med: MD: Pharmacologist
*Dr R Sommers (female) MBChB; M.Med (Int); MPhar.Med;
*Prof TJP Swart BChD, MSc (Odont), MChD (Oral Path) Senior Specialist; Oral Pathology
*Prof C W van Staden MBChB; Mmed (Psych); MD; FTCL; UPLM; Dept of Psychiatry

DR R SOMMERS; MBChB; M.Med (Int); MPhar.Med.
SECRETARIAT of the Faculty of Health Sciences Research Ethics Committee - University of Pretoria



Date: 20/11/2008

APPENDIXB: Approval of ammendment

The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- * **FWA** 00002567, Approved dd 22 May 2002 and Expires 24 Jan 2009.
- * **IRB** 0000 2235 IORG0001762 Approved dd Jan 2006 and Expires 13 Aug 2011.



AMENDMENT PROTOCOL NO.	Topic Change 38/2006
PROTOCOL TITLE	An assessment of factors influencing community integration for people living with Spinal cord injury
INVESTIGATOR DEPARTMENT	Mrs D J Mothabeng; joyce.mothabeng@up.ac.za T:012-354 1200 F: 012-354 1226 C: 0829565528 Department of Physiotherapy; Steve Biko Academic Hospital and Kalafong Hospital University of Pretoria ; Pretoria
STUDY DEGREE MEETING DATE	PhD Physiotherapy (Rehabilitation) 19/11/2008

This **Amendment** has been considered by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria on 19/11/2008 and found to be acceptable.

** Members attended & Feedback at the meeting .*

Dr A Nienaber (female) BA (Hons) (Wits); LLB; LLM (UP); Dipl.Datametrics (UNISA)
*Prof V.O.L. Karusseit MBChB; MFGP (SA); MMed (Chir); FCS (SA)
Prof M Kruger (female) MB.ChB. (Pta); MMed. Pead. (Pret); PhD.
(Leuven)

Dr N K Likibi MB.BCh; Med.Adviser (Gauteng Dept.of Health)
*Dr T S Marcus (female) BSc (LSE), PhD (University of Lodz, Poland)
*Mrs M C Nzeku (female) BSc (NUL); MSc Biochem (UCL, UK)
*Snr Sr J. Phatoli (female) BCur (Eet.A) BTec (Oncology Nursing Science) Snr Nursing-Sister
*Dr L Schoeman (female) BP harm, BA Hons (PSy), PhD
*Dr R Sommers (female) MBChB; MMed (Int); MPharMed;
*Mr Y Sikweyiya MPH; Master Level Fellowship in Research Ethics; BSC (Health Promotion)
Postgraduate Dip in Health Promotion

Prof TJP Swart BChD, MSc (Odont), MChD (Oral Path), **PGCHE**
*Dr A P van Der Walt BChD, DGA (Pret) Director: Clinical Services of the Pretoria Academic Hospital

*Prof C W van Staden MBChB; MMed (Psych); MD; FCPsych; FTCL; UPLM; Dept of Psychiatry

Dr R Sommers; MBChB; MMed (Int); MPhar.Med.

SECRETARIAT of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria, Pretoria Academic Hospital

DEPARTMENT OF PHYSIOTHERAPHY

PARTICIPANT INFORMATION LEAFLET

(To be read to the participant in his or her own language)

TITLE OF THE STUDY

An Assessment of Factors Influencing the Community Integration of People Living With Spinal Cord Injury in the Tshwane Metropolitan Area

INTRODUCTION

My name is _____ and I am a Physiotherapy Assistant. I am working together with Joyce Mothabeng, the researcher for this study. Joyce is a PhD student at the University of Pretoria. You have been identified from the database of a Spinal Rehabilitation unit as someone who has been rehabilitated for a spinal cord injury. You are hereby invited to take part, as a volunteer, in this research study.

This information leaflet is to help you to decide if you would like to participate. By participate, we mean that we are asking you to agree to be interviewed. We will ask you some questions about your condition, how you find living with it and what you think needs to be done to improve life for people living with spinal cord injury.

Before you agree to be interviewed, you should fully understand what is involved. If you have any questions which are not fully explained, do not hesitate to ask me or Joyce. You should not agree to be interviewed unless you are completely happy to do so.

1) THE NATURE AND PURPOSE OF THIS STUDY

The aim of the study is to determine the things that affect people who are disabled by spinal cord injury to cope with functioning as members of society. The information that will be gained will assist the physiotherapists and other members of the rehabilitation team to plan the rehabilitation programs in a way that will better prepare future patients to cope in society. The information will also be used to lobby other

relevant people in positions of power to address issues that we as physiotherapists may not be able to address (e.g. transport, buildings etc).

2) EXPLANATION OF PROCEDURES TO BE FOLLOWED.

The researcher will visit you at your home (or other place of your choice) at a time convenient for you to conduct the study. The study will involve measurement of your ability to perform activities of daily living, and asking you questions (interview) regarding the following aspects of living with SCI:

- How you cope with it and what you think need to be done to help you cope better.
- How it influences your daily life (at home, work or school)

The people who take care of you may also be asked some questions concerning your condition, but only with your permission and if you feel that they might be able give us more information on some of the questions we might ask you.

A tape recorder will be used as we talk to you and ask you some questions. However, the information that will be recorded will only be used for the purpose of this study and not for anything else. The researcher will also be taking some notes by hand.

3) RISK AND DISCOMFORT INVOLVED.

The only problems and discomfort that you may experience during this study is that you will be visited at home by the researcher. You may feel uncomfortable with some of the questions asked. If at all you feel unhappy about some of the questions you will be asked, you are not obliged to answer those questions, and you are free to discontinue with the participation. Even if you decide to stop participating in the study, your current and future health care will not be affected in any way.

Taking part in the survey by agreeing to be interviewed will not cost you anything, just a few minutes of your time.

4) POSSIBLE BENEFITS OF THIS STUDY.

This study will highlight the issues that affect the functioning of people disabled by spinal cord injury. The information will be used by the physiotherapists and other health professionals to make sure that rehabilitation efforts are in line with the needs of the people in society, thus better preparing them for life out there.

The information will also be used to alert policy-makers and other relevant authorities to the needs of people with spinal cord injury, so they can put measures in place to address them.

5) CONFIDENTIALITY.

All the information that you will give us during this study shall not be given to any other person. It will only be used for the purpose of this study. If at all the results of the study gets published by the researcher, your name and identity will not be revealed. And no one will know where the information came from.

6) INFORMATION

If you have any questions about the interview, please contact the researcher, **Ms. Joyce Mothabeng**. Her telephone number is 012 354-1343 or 0829565528. You can also contact the study supervisor, Dr. Carina Eksteen at the Physiotherapy Department at the University of Pretoria. Her telephone number is 012 354-3718.

Thank- you very much for your help.

APPENDIX D: Consent form



CONSENT TO PARTICIPATE IN A STUDY

(Written consent by participant)

TITLE OF THE STUDY

An Assessment of Factors Influencing the Community Integration of People Living With Spinal Cord Injury in the Tshwane Metropolitan Area

Ihave read, and it has been read to me in a language that I understand, the above information before I signed this consent form. The meaning of this information has been explained to me. I have been given an opportunity to ask questions and I am happy that my questions have been answered very well. I therefore, volunteer to take part in this study.

I understand that even if I refuse to participate in this study, I will not be penalized in any way. I will still be able to receive any necessary health care including Physiotherapy whether I participate in the study or not. I also understand that I can withdraw from the study at any time.

I hereby freely consent to be interviewed by.....

I have been given a copy of the information leaflet and a signed copy of the consent form that indicates that I have given consent to participate in this study.

.....
Participant' signature Date

.....
Person obtaining informed consent Date

.....
Witness Date



APPENDIX E: PERMISSION TO USE THE CHIEF AND CHART

Subject: RE: Request for permission to use research instruments
Date : Tue, 16 Aug 2005 07:24:44 -0600
From : "Charlifue, Susie" <Susie@CraigHospital.org>
To : "Joyce Mothabeng" <mothadj@med.up.ac.za>

Dear Joyce,

Please feel free to use CHART and CHIEF for your studies. The training should be fairly clear from the manuals that can also be downloaded. We only ask that the appropriate citations be given when you are publishing your results. I look forward to meeting you at the SASCA conference.

Best wishes,

Susan Charlifue, PhD
Research Supervisor
Craig Hospital
3425 S. Clarkson St.
Englewood, CO 80113
Phone: 303/789-8306
Fax: 303/789-8441
e-mail: susie@craighospital.org

-----Original Message-----

From: Joyce Mothabeng [mailto:mothadj@med.up.ac.za]
Sent: Tuesday, 16 August, 2005 07:49
To: Charlifue, Susie
Subject: Request for permission to use research instruments

Dear Suzie Charlifue

My name is Joyce Mothabeng, a physiotherapy lecturer at the university of Pretoria in South Africa. I am also a member of SASCA. I am registered for Ph.D. studies, looking at SCI rehabilitation outcomes.

I am interested in using instruments from your institution to evaluate outcome of patients post discharge (i.e. in the community). I am particularly interested in using the CHIEF and the CHART. I therefore request permission to download and use these instruments in my study. Kindly let me know if there are any licensing issued involved or training required.

I noticed you will also be one of the speakers at our SASCA congress later this month. I will also be delivering a paper and I hope it will be possible to meet and discuss my request and proposed study. Attached find a summary of the proposed study.

Thanking you in advance

Yours truly

Joyce Mothabeng
Tel: +2712 354-1200
Fax: +2712 354



**APPENDIX F: PERMISSION TO USE THE SCI DATABASE AT THETSHWANE
REHABILITATION CENTRE**

From: "Management" <management@muelmedrehab.co.za>
To: mothadj@med.up.ac.za
Date: 2009/03/12 01:18 PM
Subject: Dr Theron says ok

Hi joyce

Dr Theron says you can come use our Data base you will just have to
arrange with Nadia for suitable times her number is 012 3411909 or email
info@muelmedrehab.co.za

Melanie



APPENDIX G: PERMISSION TO USE THE SCI DATABASE AT TSHWANE REHABILITATION CENTRE



TSHWANE REHABILITATION CENTRE



Enquiries : Françoise Law
☎ : 012 354 6131
☎ : 012 354 6131
E-mail: Francoise.Law@gauteng.gov.za

Ms DJ Mothabeng
PhD Physiotherapy candidate

Dear Ms Mothabeng

RE: PERMISSION TO ACCESS PATIENT DETAILS IN THE SPINAL UNIT OF TSHWANE REHAB CENTRE

Thank you for your letter dated 6 March 2009. Having considered your application to conduct research on the patients who have been discharged at our institution, we have noted that you already have ethical clearance from the Faculty of Health Sciences Research Ethics Committee of the University of Pretoria and that you request permission to access the spinal ward's patient register.

Management hereby grants you permission to conduct your research as requested, by spending two hours per morning for one week in the spinal unit, obtaining the patient's contact details. Could you kindly inform this office or the Clinical Executive of your proposed dates so that the ward can be notified.

The Centre wishes you all of the best for your research and management would be very interested in your findings and kindly requests that you do a presentation and or provide a executive summary of your results so that the institution can utilize/ apply the findings that you may discover.

Please do not hesitate to contact myself or the Clinical Executive, Ms F Mokgokong should you have any queries.

Yours sincerely

Ms FK Mokgokong
Clinical Executive
Date: 26/03/2009

Ms Françoise Law
CEO: Tshwane Rehabilitation Centre
Date: 26/3/09



APPENDIX H: SOCIO-DEMOGRAPHIC AND INJURY PROFILE

STUDYNUMBER

Participant:.....

Date:.....

1. Age when injured:
1 = less than 18, 2= 18 – 29, 3 = 30 – 39, 4 = 40 – 49, 5 = 50 – 59, 6 = 60 and above
2. Gender 1 = Male 2 = Female
3. Years of schooling _____
4. Levell of schooling
1 = 0 school, 2= junior primary, 3 = senior primary, 4 = junior high, 5 = senior high, 6 = matriculated
5. Academic qualifications (degree, diploma)
1 = none 2 = Certificate 3 = Diploma 4 = Degree.
6. Home (preferred) language
1 = Zulu 2 = Sotho 3 = Xhosa 4 = Tsonga
5 = Pedi 6 = Tswana 7 = Afrikaans 8 = English
9 = Venda 10 = Ndebele 11 = Swazi
7. Marital status
1 = Single 2 = Married 3 = Widowed 4 = Separated/divorced 5 = living together
8. Residential area
1 = township 2 = suburb 3 = informal settlement
4 = Other – specify
9. How long have you lived here (years)? _____
10. Where did you live before the SCI?
1 = township 2 = suburb 3 = informal settlement
4 = Other – specify.....
11. How long did you live there (years)?

12. With whom do you live now?
1 = Own family ; 2 = Friends ; 3 = other (e.g. shelter/home) _____
13. Are you working? 1 = no; 2 = yes
14. If yes, what kind of work?

15. If no, how do you get money to live? _____



- 16 If no, are you looking for work?
1 = NO 2. YES
17. If yes, do you think you will find work?
1. NO ; 2. YES; 3 = don't know
18. Did you work before you got injured?
1. NO 2. YES
19. If yes, what kind of work?

- 20 Years living with SCI.....
14. Cause of SCI
1. MVA – passenger; 2. MVA – driver, 3 MVA – pedestrian, 4. ASSAULT – gunshot
5. Assault – stab, 6. Assault – other, 7. Sporting accident, 8. Tumour, 9. TB Spine
10. Other
- 21 Type of SCI
1. Paraplegia 2 = Quadriplegia
- 22 Level of SCI
1= Cervical (neck) 2 = thoracic (chest) 3 = lumbar (waist and below)
- 23 Completeness of lesion
1 = complete, 2 = incomplete 3 = don't know
24. Did you receive rehabilitation at a specialized Rehab centre?
0 = no centre; 1 = specialized rehab centre public; 2= specialized rehab centre private
- 25 CENTRE NAME:.....
- 26 Have you been hospitalised for any health problems after discharge?
1 Yes
2 No
27. 1 If yes, which health problem
1 = Pressure ulcers; 2 = UTI; 3 = Respiratory complications
4 = Pressure ulcers and UTI, 5 = Pressure ulcers and respiratory complications
6 = UTI and respiratory complications 7 = Pressure ulcers, UTI and respiratory complications
8 = OTHER _____ 9 = NONE
- 28 Tell me about any other health problems you have experienced.
- 29 In general, how would you rate your current state of health?
a. = Poor 2 = Fair = Good 4 = Excellent

APPENDIX I: THE REINTEGRATION TO NORMAL LIVING INDEX (RNLI)

Please rate your satisfaction with your community participation, using the following, on a 1 -4 point scale where

- 1 = the statement does not describe my situation
- 2 = the statement describes my situation a little
- 3 = the statement describes my situation a lot
- 4 = the statement fully describes my situation

QUESTION	STATEMENT	SCORE
RNLI 1	I move around my living quarters as I feel necessary.	
RNLI 2	I move around my community as I feel necessary.	
RNLI 3	I am able to take trips out of town as I feel are necessary.	
RNLI 4	I am comfortable with how my self-care needs (dressing feeding toileting bathing) are met.	
RNLI 5	I spend most of my days occupied in work activity that is necessary or important to me.	
RNLI 6	I am able to participate in recreational activities (hobbies crafts sports reading television games computers etc.) as I want to.	
RNLI 7	I participate in social activities with family friends' and/or business acquaintances as is necessary or desirable to me.	
RNLI 8	I assume a role in my family which meets my needs and those of other family members.	
RNLI 9	In general I am comfortable with my personal relationships.	
RNLI 10	In general I am comfortable with myself when I am in the company of others.	
RNLI 11	I feel that I can deal with life events as they happen.	
RNLI TOT	TOTAL SCORE	/44
RNLI	ADJUSTED SCORE (AS A PERCENTAGE)	

total score = SUM (points for all 11 items)

adjusted score = (total score) /44 * 100

Comments on very high or very low scores

APPENDIX J: SPINAL CORD INDEPENDENCE MEASURE

PATIENT NAME: _____

ID: _____

Self-Care

1. Feeding (cutting, opening containers, bringing food to mouth holding cup with fluid)

- 0. Needs parenteral, gastrostomy or fully assisted oral feeding
- 1. Eats cut food using several adaptive devices for hand and dishes
- 2. Eats cut food using only one adaptive device for hand; unable to hold cup
- 3. Eats cut food with one adaptive device; holds cup
- 4. Eats cut food without adaptive devices; needs a little assistance (e.g., to open containers)
- 5. Independent in all tasks without any adaptive device

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2. Bathing (soaping, manipulating water tap, washing)

- 0. Requires total assistance
- 1. Soaps only small part of body with or without adaptive devices
- 2. Soaps with adaptive devices; cannot reach distant parts of the body or cannot operate a tap
- 3. Soaps without adaptive devices; needs a little assistance to reach distant parts of body
- 4. washes independently with adaptive devices or in specific environmental setting
- 5. Washes independently without adaptive devices

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3. Dressing (preparing clothes, dressing upper and lower body, undressing)

- 0. Requires total assistance
- 1. Dresses upper body partially (e.g. without buttoning) in special setting (e.g. back support)
- 2. Independent in dressing and undressing upper body. Needs much assistance for lower body
- 3. Requires little assistance in dressing upper or lower body
- 4. Dresses and undresses independently, but requires adaptive devices and/or special setting
- 5. Dresses and undresses independently, without adaptive devices

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4. Grooming (washing hands and face, brushing teeth, combing hair, shaving, applying makeup)

- 0. Requires total assistance
- 1. Performs some tasks using adaptive devices, needs help to put on/take off devices
- 3. Performs some tasks using adaptive devices; puts on/takes off devices independently
- 4. Performs all tasks with adaptive devices or most tasks without devices
- 5. Independent in all tasks without adaptive devices

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TOTAL SELFCARE=

Respiration and Sphincter Management

5. Respiration

- 0. Requires assisted ventilation
- 2. Requires tracheal tube and partially assisted ventilation
- 4. Breathes independently but requires much assistance in tracheal tube management
- 6. Breathes independently and requires little assistance in tracheal tube management
- 8. Breathes without tracheal tube, but sometimes requires mechanical assistance for breathing
- 10. Breathes independently without any device

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6. Sphincter management – Bladder

- 0. Indwelling catheter
- 5. Assisted intermittent catheterization or no catheterization, residual urine volume >100cc
- 10. Intermittent self-catheterization
- 15. No catheterization required, residual urine volume < 100cc

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7. Sphincter management – Bowel

- 0. Irregularity, improper timing or very low frequency (less than once in 3 days) of bowel movements
- 5. regular bowel movements, with proper timing, but with assistance (e.g. for applying suppository)
- 10. Regular bowel movements, with proper timing, without assistance

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8. Use of toilet (perineal hygiene, clothes adjustment before/after, use of napkins or diapers)

- 0. Requires total assistance
- 1. Undresses lower body. needs assistance in all the remaining tasks
- 2. Undresses lower body and partially cleans self (after); needs assistance in adjusting clothes and/or diapers
- 3. Undresses and cleans self (after); needs assistance in adjusting clothes and/or diapers
- 4. Independent in all tasks but needs adaptive devices or special setting (e.g. grab-bars)
- 5. Independent without adaptive devices or special setting

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TOTAL RESP AND BLADDR =

Mobility (room and toilet)

9. Mobility in bed and action to prevent pressure sores

- 0. Requires total assistance
- 1. Partial mobility (turns in bed to one side only)
- 2. Turns to both sides in bed but does not fully release pressure
- 3. Release pressure when lying only
- 4. Turns in bed and sits up without assistance
- 5. Independent in bed mobility; performs push-ups in sitting position without full body elevation
- 6. Performs push-ups in sitting position

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10. Transfers: bed-wheelchair (locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision
- 2. Independent

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11. Transfers: wheelchair-toilet-tub (if uses toilet wheelchair – transfers to and from; if uses regular wheelchair – locking wheelchair, lifting footrests, removing and adjusting arm rests, transferring, lifting feet)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, or adaptive device (e.g. grab-bars)
- 2. Independent

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Mobility (indoors and outdoors)

12. Mobility indoors (short distances)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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13. Mobility for moderate distances (10 – 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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14. Mobility outdoors (more than 100 meters)

- 0. Requires total assistance
- 1. Needs electric wheelchair or partial assistance to operate manual wheelchair
- 2. Moves independently in manual wheelchair
- 3. Walks with a walking frame
- 4. Walks with crutches
- 5. Walks with two canes
- 6. Walks with one cane
- 7. Needs leg orthosis only
- 8. Walks without aids

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15. Stair management

- 0. Unable to climb or descend stairs
- 1. Climbs 1 or 2 steps only, in a training setup
- 2. Climbs and descends at least 3 steps with support or supervision of another person
- 3. Climbs and descends at least 3 steps with support of handrail and/or crutch and/or cane
- 4. Climbs and descends at least 3 steps without any support or supervision

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16. Transfers: wheelchair-car (approaching car, locking wheelchair, removing arm and foot rests, transferring to and from car, bringing wheelchair into and out of car)

- 0. Requires total assistance
- 1. Needs partial assistance and/or supervision, and/or adaptive devices
- 2. Independent without adaptive devices

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MOBILITY subtotal /40

TOTAL SCIM SCORE/ 100

APPENDIX K: THE CRAIG HOSPITAL INVENTORY OF ENVIRONMENTAL FACTORS – Short form

Item	RESPONSE								IMPACT
	Frequency						Magnitude		Frequency X Magnitude
	4 = Daily	3 = Weekly	2 = less than monthly	1 = Monthly	0 = Never	N/A	2 = Big problem	1 = Little problem	
1. How often has the availability of transport been a problem to you?									
2. How often has the natural environment – temperature, terrain, and climate – made it difficult to do what you want or need to do?									
3. How often have other aspects of your surroundings – light, noise, crowding etc. – made it difficult to do what you want or need to do?									
4. How often has information that you wanted or needed not been available in the format you use or understand?									
5. How often has the availability of health care services and medical care been a problem to you?									
6. How often did you need someone else's help in your home and could not get it easily?									
7. How often did you need someone else's help at work or school and could not get it easily?									
8. How often has other people's attitudes towards you been a problem at home?									
9. How often has other people's attitudes towards you been a problem at school or work?									
10. How often did you experience prejudice or discrimination?									
11. How often did policies and rules of businesses and organizations make problems for you?									
12. How often did policies and rules of government make problems for you?									

Thank you for participating in this phase of the study. Would you be willing to be interviewed in the next phase of the study

APPENDIX M: THEMES AND SUB-THEMES GENERATED

THEME 1: PERSONAL INFLUENCES

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
Coping skills	Acceptance of condition	But I have accepted my disability. (Thabo)
	Positive outlook on life	<p>There is a life to live even when you are in a wheelchair. (Thabang)</p> <p>Who knows, a miracle might happen and I walk one day – ha-ha (laughs). (Tumelo)</p> <p>I always say to myself, when I can do something, I better do it myself, when I know I need help, I better get help from anybody who is offering I don't mind. (Thabang)</p> <p>Now I am ready to face life with a future job. A partner is not one of my immediate plans right now. I want to work for people with disabilities and make sure things happen like jobs, transport etc. (Selina)</p>
	Spirituality	<p>I mean I am glad I am alive. Since I became para, ---there are many things that I have noticed and I am grateful for in my life, because, eh, god saved my life for a reason you know. (Tumelo)</p> <p>Sometimes I ask why God did not take my life during the accident; I would not be facing [silence]. But you know, God knows everything, and I must not give up, yeah but it is hard.</p> <p>Eish my sister – it is life. What can I say? It is not okay but it is okay you know – thank God I am alive. One day things will get better. (Thabo)</p>

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
Rehabilitation experience	Positive experience	<p>I would not have survived without rehab. I was so up and down- I don't know how they put up with me- but then I was a child – the youngest person in the unit. I guess they felt sorry for me. They must keep up the good work. Thanks to the rehab, I got placed in a special school for my entire high school. It was easier, and the school was in my town, so I had had my family- that helped. Now I am fine, I am studying computers and next year I'll be working (if I pass). (Selina)</p> <p>I am very happy with the training of the physio and occupational therapy. It helped me a bit, now I can do something like walk a bit.</p> <p>Maybe they must check on people in the home after discharge- some people they just sit and don't train and they get sick. The physio -they must come and check. (Sipho)</p> <p>Rehabilitation helped me a lot – I am thankful. Even though I am like this, at least I can do things for myself.....(George)</p> <p>Because my parents had medical aid, I had the best rehab – I think, because it was in the private hospital. (Selina)</p> <p>I think the training was good and must stay like that. It helped me get strong and I can use the wheelchair now. (Tumelo)</p> <p>Physio helped me a lot- I will always be grateful to them. They must keep on helping the</p>

		paralysed people – what they do is great. (Tumelo)
	Negative	<p>I would like to ask the nurses to treat us (PLWSCI) well please. You know, when a patient calls a nurse and says “nurse I am not okay (like soiled himself) and the nurse replies “you are not my husband”, that is not nice. I am not saying all nurses were like that, most of them are good. I just ask that they should feel for us – we did not choose to be like this. (George)</p> <p>The problem was some nurses in the ward – many of them are nice but some yo-yo, they really talk bad to us my sister. You find a man crying and that is not nice. Some nurses must try and be kind to us – when you are like that, you need people to treat you nice. (Tumelo)</p> <p>Some nurses must try and be kind to us – when you are like that, you need people to treat you nice.(Tumelo)</p> <p>The physios – eish, they push us very hard. We know that they are help us but they must not be so pushy. Especially early in rehab, when one is still trying to understand what is happening with his body...(George)</p> <p>.... I did not speak any English so I did not understand a lot of things. They tell me things, they write me things on paper but I did not experience a great deal of what’s going on. It was very hard and painful. I just focused myself on getting better and do what I can do and what I can’t, I can’t. That was my experience but in the long run I think they (therapists) do quiet well. With the pain I was in I just wanted to get out of the hospital and-oh well yeah-to adapt to my condition and all that. At that time I was also very angry. (Thabang)</p>

Future hopes	Find life partner	<p>No, but I am planning to (marry). That subject needs somebody who will understand who I am... I used to have a girlfriend but not at the moment...(Thabang)</p> <p>....may be get married one day....but who knows. (Thabo)</p> <p>A partner is not one of my immediate plans right now..... (Selina)</p>
	Walk again	I hope to walk but they say I am complete- so they did their best. At least I can move in the wheelchair. (Sifiso)
Personal needs	Study	Yes, everyday I think about studying. Now becomes the problem of funds and things like that. I lack that and I really want to study.... I'd really love to study again. (Thabang)
	Exercise	<p>I'd really like to be part of sport, I did play basketball at the time of my rehabilitation and even now, I still wanna hold the ball. I try to join the sports team in Pretoria academic but due to lack of transport I can't go so I am not part of any sport now. (Thabang)</p> <p>I always want to involve myself with sport. I love sport but I don't find club and don't even have one due to lack of transport. (Thabang)</p>
	Independence	<p>If you can't do things for yourself it is really tough especially for a man my sister- you understand. I mean no girl wants a man who cant ... (indicating sexual performance) you know. ...Well, my girlfriend she likes me but I have no job. If I marry her on the disability grant, what is the life going to be like.... (Sipho)</p> <p>I just wish I can find a job and stop being a burden to my parents. The disability grant helps, but it is not enough! What happens to me when they (parents) die? (Thabo)</p>

		<p>I just need to find something to do and continue living (Tumelo)</p>
	<p>Employment</p>	<p>Of course I wish I was working so I can look after myself better. I've never really worked even before...you know. I only have std 4. Who will give me job? What job can they give me - I don't know any job. Only selling fruits on the street – now I don't have money to buy. (Sifiso)</p> <p>Job is the big problem my sister. We all want the job. It is more difficult for us with the spinal cord to get job. Eish, I don't know, maybe if the government can help somehow. (Sipho)</p> <p>I think if I get a job and look better after myself I will be happier (Thabo)</p> <p>.....so we can start some business like making things and sell them to make money. But we need money to start, we need help. Maybe you can talk to somebody to help us my sister –he-he... you rich friends? (laughs). (Tumelo)</p> <p>I wish they (therapist) could help me get some job. Yeah, the job is the big problem my sister. Even before I was para I did not have a real job, just piece jobs We all want the job. It is more difficult for us who are para to get job. Eish, I don't know, maybe if the government can help somehow. The disability grant is too little- very little. Maybe some spare jobs must be reserved or the wheelchair people. (Tumelo)</p>

	Follow up after discharge	<p>Maybe they must check on people in the home after discharge- some people they just sit and don't train and they get sick. The physio -they must come and check. (Sipho)</p> <p>Thanks for checking on people like us – it is nice to see that people care you know. God bless you sister. (Thabo)</p> <p>I think you people must keep on checking people like us, especially poor people in shacks and rural areas – those people struggle. You know when you meet them at check up you can tell by the smell that someone has not had a bath in a long time – they are really suffering. It is hard to be disabled and poor – I am lucky, I have my 'sick pension, my wife is working – we are doing fine. But some people are struggling out there – they need your help...(George)</p> <p>When you check us, you can see for yourself our circumstances and how some of us are doing, some abused by their own people. The government must send more people to check on us(Tumelo)</p> <p>....if they (therapists) can go to there areas and help the person in the community and just encourage them to do things and help where they can help(Thabang)</p>
Psycho-emotional issues	Anger	I hate that taxi man who was driving us but I hear he died in the accident. (Selina)
	Sadness	<p>Other people see you first time and they cry – that makes you cry.</p> <p>I try to live normal, but people they see you as abnormal and it's not nice. Some look at you and say shame and you feel sad sometimes you ignore them. (Thabo)</p>
Use of free time	Positive	I read books and newspapers, I watch TV when I am tired of reading. I chat with my visitors –

		I have many friends – you can see this one here (he points at a visitor waiting outside) (George)
	Negativebut when everyone is at work or school, it is just me and my wheelchair- I wish I could do something during the day. (Sifiso) Otherwise I always go to the shops and hang out with the other guys – there so many guys who are not working here my sister. We talk, share some smoke and drink and just hang out.(Tumelo) My friends sometimes visit, but most of the time I am just in the house- it's easier that way..... When I am alone at home – I don't bother anyone you know – asking for this or for help with that. (Thabo)

THEME 2: ENVIRONMENTAL INFLUENCES

SUBTHEME	CATEGORIES	SUPPORTING STATEMENTS
ATTITUDE OF OTHERS	OTHER PLWSCI	Most of the time I see the patients they need to be pushed they need to be feed even when their hands are working. They are just lazy (sounds angry) and they just make everybody to feel pity and that makes me angry.... that's what makes everybody think that when you are in a wheelchair you can't do anything for yourself. They can't even hire you for job because you will be relying on them for things (Thabang)
	MEMBERS OF THE	Other people see you first time and they cry – that makes you cry. (Thabo)

	COMMUNITY	<p>I try to live normal, but people they see you as abnormal and it's not nice. Some look at you and say shame and you feel sad sometimes you ignore them. (Thabo)</p> <p>I don't like it when people go "ag shame". It irritates me that kind of attitude, but I understand I would probably do the same if I was able bodied too- I don't know, maybe. It is okay at school and around home – everyone knows me and they are fine. I guess when you meet new people, they react differently, and you can feel that – I suppose it is human but... I don't know. (Selina)</p>
SOCIAL SUPPORT	POSITIVE	<p>Life is okay auntie Joyce. I just feel sorry for my wife because I don't satisfy her sexual needs. But she supports me well.(George)</p> <p>My neighbour comes and then prays for me. My family is very much helping (Sififso)</p> <p>Having parents who were both working and could afford some thing (like my computer studies) really helps. I can't imagine being poor and disabled- it must be really tough. I really thank God for my parents. Not everyone is as lucky as me – I have everything I need. (Selina)</p>
	NEGATIVE	<p>The problem is that some people in the families they take the money for themselves. They use the money to buy alcohol and stuff, and the paralysed person does not get his money. They eat his money and don't even buy him healthy food (voice loud –</p>

		<p>looks angry). That is a huge problem. (Tumelo)</p> <p>The guy from the other block, his mother is too old to help him, shame. I visit him sometimes but I cannot help too much as I am also paralysed (paraplegic).</p> <p>I also don't have many people who visit me. (Sifiso)</p> <p>.... I always go to the shops and hang out with the other guys – there so many guys who are not working here my sister. We talk, share some smoke and drink and just hang out. (Tumelo)</p>
TRANSPORTATION	AVAILABILITY AND COST	<p>When I want to go somewhere, first you struggle to get to the taxi, then you pay more; or else you must hire a car and it is too much.... The money gets finished on transport if you go to Academic for check up. The taxis charge you a special. (Sifiso)</p> <p>Transport is also a problem for many people. Someone in the government must do something for those who are suffering. (Selina)</p> <p>I think that "Maspala" (the municipality) must help us- yes the government must do something. Like special transport because it is expensive to hire transport to go to clinic. (Tumelo)</p>

ACCESS	AT HOME	<p>That is another problem my sister---the wheelchair can not get in the house easy because it is big for the door. You see my shack is small. I do not have a good place to live. Some people who are quadras (quadruplegic) never get out because of the steps at the door. (Tumelo)</p> <p>Well people need jobs, better houses – you know some people live in zozo’s with wheelchairs.</p>
	AROUND THE COMMUNITY	<p>You see the way coming here, the high hill...it is heavy. You can go down but coming up it is heavy (too steep). You can ask people to push you but as I told you I like doing things for myself but its heavy. (Thabang)</p> <p>Where I live it is difficult for the wheelchair. There are big holes on the road, see my wheelchair is broken. I don’t go out a lot, I live only with my family. (Sififso)</p> <p>Hm... and the township – the roads can be bad for wheelchairs – they must all be tarred. (Selina)</p> <p>.... when it rains the streets are not okay with the mud for the wheelchair. (Tumelo)</p>
	TO FACILITIES	I have to pay R150 just to go and come back from hospital. That is the most



		<p>challenging part of my life. The little bit I have is for transport and food. (Thabang)</p> <p>I don't go to physio because of transport now I am forced to exercise here by myself.</p> <p>I have all the exercise things; I know exercise is healthy for me so I do all the movements. Let me show you my 'home gym' (shows me the equipment he has for exercising – weights and an abdominal exerciser) (Thabang)</p> <p>I need transport to go to check up.(Tumelo)</p>
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APPENDIX N: TRANSCRIBED AND TRANSLATED INTERVIEW

- I: Ke lebogela nako ye le mphileng yona go tlo boledishana le lena ka bophelo bja lena e sale le gobala ka 'spinal cord injury' Ke rata go 'cheka' gore bjale ka ga le 'kreile' rehabilitation, le phela bjang mo gae. E kaba go na le mathata ao le kopanang le ona, and le a bereka bjang. Gape ke rata go tseba gore e kaba go na le eng se re ka se dirang during rehabilitation go thusa gore batho ba phele betere magang ge ba na le SCI.
Thank you for giving me this time to come and talk to you about how your life has been since you sustained a spinal cord injury. I would like to find out now that you have been through rehabilitation, how do find life out here at home? Are there any problems that you encounter and how do you cope with them? I also wish to find out if there is anything you can be done during rehabilitation to better prepare people with SCI for life in the community
- P: Okay...
- I: Ge eba go na le potso e o sa e thlaologanyeng, kgotsa o sa rateng go e araba, o lokologile gore o re bjalo.
If there is any question that you do not understand or don't feel like answering, you are free to say so.
- P: Gape le g eke sa tsebe karabo ke re bjalo:
Also if I don't know the answer I must tell you?
- I: Nods
- P: Okay - gone ga go na bothata
Okay then, no problem.
- I: Mpoelle gore o fumana bophelo bo le bjang ga o na le SCI?
Tell me, how are you coping with living with SCI:
- P: Ah.. mmane Joyce, nna ke a iphelela waitisi, ga ken a bothata ga kalo.
Ah.. auntie Joyce, I am living okay. I have no problems really.
- I: So mo gae, o kgona go itirela dilo tsohle?
So you are able to do everything for yourself here at home?

P: Ee, ke a kgona.

Yes, I can

I: Ke ra gore o kgona go itérela dijo, go ithlapisa, go ya toilet, le dilo tse bjalo?

I mean can you make your own food, bath yourself, go to the toilet etc?

P: Ee ke a kgona...ts tsohle. Go ya toilet ke ne ke dirisa 'gloving' Jaanong ke tsaya dipilisi, ka be ke ya toilet ka nako e rileng.

Yes, I can do them all. For the toilet I was using the glove, now I use the timing method with tablets

I: Ga o na bothata go 'tsamaya' around mo ntlung le ka fo ntle?

Don't you have any problems moving in and around the house?

P: Nyaya – bothata fela ke steps se ka mo pele

No problem except for the step at the entrance

I: Go tsamaya mo motseng gone – ga a na bothata?

Any problem moving around the neighbourhood

P: Ga go bothatha – ke ya le ko 'complexeng' ntle le bothata – ene wa e bona tsela e ya namella.

No problem – I even go to the shopping complex without any problem – and you can see the road is a bit steep

I: O dira eng letsatsi lohle:

How do you spend your days?

P: Ke bala dibuka le di-newspaper, ke sheba TV ga ke lapile go bala. Ke tlotla le baeti bame – ke na le dichomi tse dintsi – o a mmona le yena o (o supa moeti o letileng ko ntle)

I read books and newspapers, I watch TV when I am tired of reading. I chat with my visitors – I have many friends – you can see this one here (he points at a visitor waiting outside)

- I: O bona bothselo bo le jwang ka mo gae
How do you find life with the family
- P: Botshelo bo tamaya pila mmane Joyce, Ke utlwela mofumagadi bothloko
gonne ga ke mo kgotsofatse dikobong. Empa yema o nsapota pila.
*Life is okay auntie Joyce. I just feel sorry for my wife because I don't satisfy
her sexual needs. But she supports me well.*
- I: Mpolelle ka rehabilitation ya gago – e ne e le bjang
Tell me about your rehabilitation experience
- P: Rehabilitation e nthusitse thata – ke a le leboga. Le fa ke le jana, at least ke
kgona go itirela tsohle.
*Rehabilitation helped me a lot – I am thankful. Even though I am like this, at
least I can do things for myself*
- I: (NODS)
- P: Ke rata fela go ikopela gore ma-nurse a re treate pila. Waitsi ga molwetsi a
bitsa nurse a mmolella gore 'nurse ga ke alright (gongwe o itshinyeditse)',
ya ba nurse e mo araba ka gore "ga o monna wame"... - ga go pila waitsi.
Ga kere bohle ba bjalo, bontsi bo lokile. Re kopa gore ba re naganele, ga
rea itira gore re nne bjana.
*I would like to ask the nurses to treat us (PLWSCI) well please. You know,
when a patient calls a nurse and says "nurse I am not okay (like soiled
himself) and the nurse replies "you are not my husband", that is not nice. I
am not saying all nurses were like that, most of them are good. I just ask
that they should feel for us – we did not choose to be like this.*
- I: Training yona ene e le bjang ko rehabilitation?
What about the training at rehab – how was it?
- P: Maphysio – eish, ba trainana thata – ba a go pusha! Re a itse gore ba a re
thusa empa ba tshwanetse go leka go se be so pushy. Segolothata kwa

tshimologong, ga motho a sa leka go thlaologanya gore go irega eng ka mmele wa gagwe...

The physios – eish, they push us very hard. We know that they are help us but they must not be so pushy. Especially early in rehab, when one is still trying to understand what is happening with his body...

I: A go na le sengwe se o ratang re ka bua ka sona:
Anything else you would like to say

P: Ke nagana gore go ka nna pila ga le ka etela batho ba ja ka rona, thata ba nnamg mo mekhukhung le ko magaeng – batho bao ba a sotlega. Waitsi ga o kopana le bona ko ‘check-up’ o utlwa fela ka monkgo gore ke kgale mothe a sa thlape – ba sotlega e le tota. Go boima go golofala o le modidi. Nna ke lehlogonolo gone ken a le ‘sick pension’, mofumagadi o na le tiro – re phela sentle. Fela batho ba bang ba a sotlega – ba hloka thuso ya lona.
I think you people must keep on checking peple like us, especially poor people in shacks and rural areas – those people struggle. You know when you meet them at check up you can tell by the smell that someone has not had a bath in a long time – they are really suffering. It is hard to be disabled and poor – I am lucky, I have my ‘sick pension, my wife is working – we are doing fine. But some people are struggling out there – they need your help...



APPENDIX O: DECLARATION BY LANGUAGE EDITOR

Ruth Scheepers

Language Specialist

30 November 2010

To whom it may concern

This is to confirm that I, Ruth Angela Scheepers, edited Joyce Mothabeng's doctoral dissertation for language and style. The onus is, however, on the student to implement the changes that I suggested.

RA Scheepers

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