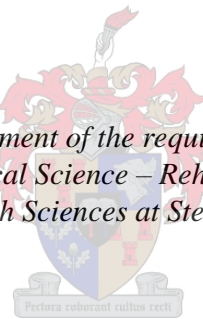


A study to investigate the functional rehabilitation outcomes of patients undergoing physical rehabilitation at Gugulethu Community Health Centre

by
Elizabeth Anne Pegram

(BSc Occupational Therapy: UWC)
(BA Honours Public Administration and Management: US)

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Master of Science in Medical Science – Rehabilitation in the Faculty of
Medicine and Health Sciences at Stellenbosch University*



Supervisor:
Ms S.B. Statham
(M.Sc Physiotherapy)

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Declaration

By submitting this thesis, 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.

Date: March 2016

ABSTRACT

There has been a significant shift in the focus of evidence-based health care internationally and within government in South Africa, specifically the Western Cape (The Lancet, 2009:1793; Cieza, et al. 205-207: 2002; Western Cape Government, xv: 2014). A need for improved evidence based information for disability and rehabilitation services has been identified at international level (WHA, 1-2; 2005). There is hence an opportunity to strengthen the development of rehabilitation services and with that concurrently, an evidence approach to this part of the public sector health services.

Aim: The aim of this study was to describe the functional rehabilitation outcomes of patients undergoing physical rehabilitation at the Gugulethu Community Health Centre.

Methodology:

This study employed a descriptive study design with pre-and post-rehabilitation test measuring changes in functional ability of clients. Quantitative methodology was followed. The study population included all patients who attended the Gugulethu Community Health Centre and who were referred to rehabilitation. The study sample included all patients who were admitted to the physiotherapy service at GCHC during the period February 2012 to September 2012. Patients with the five most prevalent conditions were included in the sample.

Self-developed outcome measures that used the ICF and CBR guidelines as conceptual models were used to determine what the participants' socio-economic and environmental facilitators and barriers were. Six, standardised outcome measures were applied, namely the EQ5D for the whole cohort; and the Barthel Index, DASH, AIMS, Clinical Mobility Scale and the Oswestry respectively to do determine the level of functioning at the onset of rehabilitation and again either at discharge or three months post cessation of rehabilitation for each of the five most prevalent conditions.

Results:

By applying a t-test for dependent samples (Pre-VAS: N = 58; Post-VAS: N =52) to the whole cohort a statistically significant difference ($p=0.03$) in the participants' self-assessment of their health status (VAS) is noted. No statistical difference was reported in the activity related domains as well as the impairment related domains.

Results for sub-sets of the cohort however indicated different results:

Participants with Lower Limb Injuries (N=40) showed an overall significant improvement in pre- and post-testing in the activity domain; walking ($p=0.02$), Gait ($p<0.3$), Stair Climbing ($p=0.01$), Hand-held appliances ($p=0.03$). There was no improvement in the participation domain.

Participants with Upper Limb Injuries (N=16) reported improvement in all three domains, namely impairment, activity limitations and participation restrictions. In terms of *activity* related elements, the following results indicated a significant improvement: Pushing a heavy door ($p=0.04$); Garden/yard work and making a bed ($p=0.03$) as well as pulling over a sweater ($p=0.04$). Impairment related element "tingling of the arm, shoulder or hand" showed a significant improvement ($p=0.02$). Participation related elements where participants indicated significant improvement includes recreational activities with "little effort" ($p=0.01$) and where the "arm can move freely" ($p<0.01$); "managing transportation needs" ($p=0.01$) and "sexual activities" ($p=0.01$).

Participants with Lower Back Pain (N=11) reported a statistically significant difference in pre- and post-test results for the participation restriction domain: Socialising and Travel ($p=0.04$). No statistically significant difference was reported in the activity and impairment domains in this sub-set.

Participants with Arthritis and Stokes reported no statistically significant difference between pre- and post-tests. This can be contributed to the low numbers of re-test that was present in these sub-sets.

Conclusion

The results indicate significant changes in patients attending physical rehabilitation as far as mobility is concerned for people with lower leg injuries and lower back pain. Positive shifts were noted in the activity levels for patients with upper limb injuries as well as those with mobility problems. Significant improvements were noted in pain levels as well as patients' mental health. Participation in life roles were improved. More in-depth studies regarding the rehabilitation process would be beneficial to establish which interventions yield the most positive outcomes.

Recommendations

The mainstreaming of outcome measures at primary health-care level for rehabilitation services is strongly recommended. This will strengthen the development and delivery of rehabilitation services at primary health-care level. Furthermore, recommendations will be used to inform management and policy makers to move towards a firm outcome-based approach. Other recommendations include areas of strengthening further research, based on limitations identified in this study.

KEY TERMS: Disability, Rehabilitation, functional outcomes, standardised outcome measures

OPSOMMING

Daar is 'n merkwaardige verandering in fokus op meer uitkoms-gebaseerde gesondheidsorg op internasionale sowel as plaaslike vlak in Suid-Afrika en ook in die Wes-Kaap.(The Lancet, 2009:1793; Cieza, et al. 205-207: 2002; Western Cape Government, xv: 2014). Die behoefte om verbeterde uitkomste-gebaseerde inligting rondom gestremdheid en rehabilitasie te bekom, is reeds op internasionale vlak identifiseer en gedryf. (WHA, 1-2; 2005). Daar is dus 'n geleentheid om rehabilitasie dienste te verbeter en sodoende die fokus op meer uitkomste-gebaseerde benadering te vestig en te versterk.

Doelwit: Die doelwit van hierdie studie was om die funksionele rehabilitasie uitkomste van pasiente wat fisiese rehabilitasie dienste by Gugulethu Gemeenskap Gesondheidsentrum (GGGS) bywoon, te beskryf.

Metodologie:

Die studie het 'n beskrywende ontwerp met 'n voor- en na-rehabilitasie toets gebruik wat verandering in funksionering by kliente meet. 'n Kwantitatiewe metodologie was gevolg. Die studie populasie het alle pasiënte verwys was na rehabilitasie dienste by die GGGS. Die steekproef het pasiënte wat die vyf hoof diagnostiese groepe gesien by die sentrum ingesluit oor die periode van Februarie 2012 tot September 2012. Pasiënte met die vyf toestande wat die meeste voorgekom het, is ingesluit in die steekproef.

Self-ontwikkelde meetinstrumente wat die IKF en GGR riglyne as konseptuele modelle gebruik het, is aangewend. Ses gestandaardiseerde meetinstrumente was ook gebruik, naamlik die EQ5D wat aangewend was vir die hele streekproef; en die Barthel Indeks, DASH, AIMS, Clinical

Mobility Scale and the Oswestry was onderskeidelik aangewend ten einde uitkomst te meet in die vyf hoof diagnostiese groepe.

Results:

Die resultate van die EQ5D dui aan dat daar wel 'n statisties-beduidende verskil in die self-gerapporteerde gesondheidsevaluasie was. 'n T-toets is gedoen vir afhanklike steekproewe (Voor-toets: N=58; Na-Toets : N=52) en het 'n statisties-beduidende resultaat getoon met $p=0.03$.

Die resultate vir die onderskeie sub-groepe van die steekproef het wel ander resultate getoon:

Deelnemers met onderste ledemaat beserings (N=40) het 'n algemene statisties beduidende verbetering in getoon met die voor- en na-toetsing in die aktiwiteite naamlik: loop ($p=0.02$), Loopgang ($p<0.3$); Klim van trappe ($p=0.01$); Hantering van aparate wat met hand vasgehou word ($p=0.03$). Geen verbetering is gerapporteer in die deelname afdeling nie.

Deelnemers met boonste ledemaat beserings (N=16) het verbeteringe in al drie afdelings rapporteer naamlik aktiwiteit, fisiese inkorting en deelname. In terme van aktiwiteite, is die volgende statisties beduidende resultate verkry: *Stoot van swaar deur* ($p=0.04$); beide *Tuinwerk* en "*om bed op te maak*" ($p=0.03$) asook om 'n trui aan te trek ($p=0.04$). Afdelings wat "fisiese inkorting" insluit "tingling of the arm, shoulder or hand" het 'n statisties beduidende verbetering getoon ($p=0.02$). Elemente wat "Deelname" behels, sluit in 'n beduidende verskil in ontspannings aktiwiteite wat min inspanning verlang" ($p=0.01$); aktiwiteite waar die arm nie meer vrylik kan beweeg ($p<0.01$); die bestuur van vervoer behoeftes ("managing transportation needs") ($p=0.01$) en seksuele aktiwiteite ($p=0.01$).

Deelnemers met Lae Ruggyn (N=11) het 'n statisties beduidende verskil rapporteer in die voor-en na-toetse vir die deelname afdeling: "Socialising and Travel" ($p=0.04$). Geen beduide verskille is in die aktiwiteit en inkorting afdeling.

Deelnemers met Artritis en Beroertes het geen beduidende verskille rapporteer nie. Dit mag wel wees as gevolg van die lae aantal deelnemers wie teruggekom het vir die her-toetsing.

Terwyl daar was ook 'n statisties-beduidende verskil en voor-en na toetsing is vir pyn/ongemak sowel as angs/depressie was, was daar geen beduidende verbetering in aktiwiteite nie. Deelname is nie hier getoets nie. Die resultate vir diagnosties-spesifieke instrumente het eerder anders gewys.

Daar was ook 'n statisties beduidende verbetering in belangrike aktiwiteite wat mobiliteit en self-sorg ingesluit het. Deelnemers met boonste ledemaat beserings het 'n algemene statisties beduidende verbetering getoon. Deelnemers met lae ruggyn het 'n statisties beduidende verskil in voor-en na toete vir deelname rapporteur. Geen statisties beduidende verandering was rapporteur in die aktiwiteit en liggaamsfunksie en struktuur in hierdie groep nie.

Deelnemers met artritis en beroerte het geen statisties beduidende verskille in voor-en na-toetse gerapporteer nie. Dit kan moontlik toegeskryf word aan die beperkte getalle deelnemers wat her-toets is.

Afsluiting

Die resultate toon beduidende verandering in mobiliteit in pasiënte met onderste ledemaar beserings sowel as lae ruggyn wie fisiese rehabilitasie ondergaan. Positiewe veranderinge het gebeur in aktiwiteitsvlakke vir pasiënte met boonste ledemaat beserings sowel as diegene met lower limb injuries. Interessant is die beduidende veranderinge in pasiënte se se pynvlakke en

geestesgesondheid. Deelname in hul lewensrolle is verbeter. Meer in-diepte studies word aanbeveel om te bepaal watter behandeling die beste uitkomst bied.

Aanbevelings

Die algehele gebruik van uitkomst-gebaseerde instrument op primêre gesondheidsvlak word sterk aanbeveel. Dit sal die ontwikkeling en lewering van rehabilitasie dienste versterk. Aanbevelings sal verder gebruik word om bestuur in diegene verantwoordelik vir beleidformuleing in te lig rondom 'n uitkoms-gebaseerde diens. Die versterking van navorsing soon identifiseer in die beperkinge van die studie word ook aanbeveel.

CONTEXT OF THE STUDY

This study is part of a series of studies conducted by a research collaboration including the Centre for Rehabilitation studies at Stellenbosch University, the Physiotherapy Division at Stellenbosch University and the Physiotherapy Department of University of the Western Cape. This larger study was funded by the South African Netherlands Research Programme on Alternatives in Development (SANPAD)

The Main aim of the larger study was:

To critically assess the services rendered at four selected rehabilitation sites in the Western Cape. The objectives are to contribute towards problem-solving in service delivery, to facilitate livelihood strategies for persons with disabilities, and give feedback towards existing policies.

Each of the sites had two separate studies: one assessing the functional outcomes of patients presenting themselves for rehabilitation and one assessing the organisational structure of the services. This study focuses on the functional outcomes of rehabilitation.

The researcher of this study was part of the reference group that planned the methodology and developed some of the data collection tools for the series of studies.

This study was designed to reach the aims for this site and the researcher was responsible for this part of the overall study on this site.

The larger study is referred to as the SANPAD study.

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DEDICATION

I would like to dedicate this work to **my family** because one can never make up for lost time. The investment in time for intellectual purposes should never be underestimated as knowledge can never be taken from you.

To my mom, Creans, for taking care of my daughter Tarryn during my academic contact time and for always supporting and believing in my decisions;

Tarryn, even though it was difficult to understand what this means at your age, my hope is that you will be inspired to always believe in your dreams (thank you for my yellow star as a gesture of motivation);

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“Education is the most powerful weapon to change the world” – Nelson Mandela

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- B : SANPAD Questionnaire 2 [Post-Questionnaire]
- C : Medical Records Review Tool
- D : Barthel Index
- E : Oswestry Low Back Pain Disability Questionnaire
- F : Disabilities of the Arm, Shoulder and Hand Questionnaire (DASH)
- G : Clinical Mobility Scale
- H : EQ5D Health Questionnaire
- I : Department of Health Ethics Approval Letter
- J : U.S Ethics Committee Approval

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DEFINITIONS AND TERMS

Activity limitations

“...are difficulties in executing activities – for example, walking or eating.” (WHO, 2013:p6)

Activity

Activity is described as “the execution of a task or action by an individual”.

(WHO, 2013:p6)

A disabled person (Person with a disability)

A disabled person is the one who in his or her society is regarded or officially recognized as such, because of a difference in appearance and/or behaviour, in combination with a functional limitation or an activity restriction. (Helander, E.; 1999)

Community-based Rehabilitation:

“Community-based rehabilitation is a strategy for the equalization of opportunities and social integration of all children and adults with disabilities. It is implemented through the combined efforts of disabled people, their families and communities, and representatives of the appropriate health, education, vocational and social sectors” WHO; 2004

Disability

“...refers to difficulties encountered in any or all three areas of functioning namely impairments, activity limitations and participation restrictions.” (World Report on Disability, 2011)

Environmental factors

“The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person’s functioning.” (WHO, 2013: p6)

Functioning

The ICF conceptualizes functioning as a ‘dynamic interaction between a person’s health condition, environmental factors and personal factors.’ (WHO, 2013: p6)

Impairments

“...are problems in body function or alterations in body structure for example paralysis or blindness.”(WHO, 2013:p6)

International Classification of Function, Disability and Health (ICF)

A classification system as developed by the WHO to ensure comparability and providing a “unified and standard language and framework for the description of health and health-related states (WHO, 2001). This system was used as a framework in the study.

Outcome Measures:

An outcome measure is the result of a test that is used to objectively determine the baseline function of a patient at the beginning of treatment (http://www.physio-pedia.com/Outcome_Measures)

Participation and participation restriction

Participation is described as the involvement in a life situation whilst participation restriction is described as problems an individual may experience in involvement in life situations. (WHO, 2013:p6)

Primary Health Care

Primary health care (PHC) refers to "essential **health care**" that is based on scientifically sound and socially acceptable methods and technology, which make universal **health care** universally accessible to individuals and families in a community.” (https://en.wikipedia.org/wiki/Primary_health_care)

Rehabilitation

“...is a goal-orientated and time limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functional level, thus providing one with tools to change one’s life when and where necessary”. (DoH, 2001)

“...a set of measures that assists individuals who experience, or are likely to experience, disability to achieve and maintain optimal functioning in interaction with their environments”. (WHO; 2011)

ABBREVIATIONS

AIMS	:	Arthritis Impact Measure
CBR	:	Community-based Rehabilitation
CHC	:	Community Health Centre
CODESA	:	Commission for Development in South Africa
CSP	:	Comprehensive Service Plan
DASH	:	Disabilities of the Arms Shoulder and Hand
DHS	:	District Health Services
DoH	:	Department of Health
FIMS	:	Functional Independence Measure
ICF	:	International Classification of Function
ICU	:	Intensive Care Unit
LBP	:	Lower Back Pain
LLIs	:	Lower Limb Injuries
PHC	:	Primary Health Care
SANPAD	:	South African Netherlands Research Programme on Alternatives in Development
SINJANI	:	DoH Information Management System used in the Western Cape.
U.S.	:	University of Stellenbosch
ULIs	:	Upper Limb Injuries
WCDoH	:	Western Cape Department of Health
WHO	:	World Health Organisation

CHAPTER 1

1.2 Introduction

The implementation of the District Health System (DHS) has been legislated in the South African Health Act of 2003 (SA; 2003). This piece of legislation specifies the delivery of services at a level closest to the people, thereby ensuring increased access to healthcare services.

Rehabilitation services form a strong part of the Primary Health Care (PHC) Approach and also within the comprehensive district based primary healthcare services in South Africa (Kautzky & Tollman, 2008:18-19). Important to note is Kautzky and Tollman's focus on the delivery of a model where there is a more robust emphasis on community participation and empowerment. Rehabilitation service is one of the four pillars of primary health care. This service has generally have not been prioritized within the public health domain as can be seen through the allocation of human resources, technical devices and other therapeutic equipment (WCDoH, 2006; Rhoda et al; 2009).

The need to investigate, or to evaluate the rehabilitation services, either from a system's perspective or based on patients' experiences, has become pressing. Research in the rehabilitation setting, however, is complicated due to the number of differences and variables within the rehabilitation setting, including the rehabilitation providers, context and patient characteristics (Rhoda et al; 2009) . Historically, rehabilitation professionals have focused on their clinical work and limited research has been done to produce evidence with regard to rehabilitation outcomes within the rehabilitation field (Cole et al, 1995; Rhoda et al, 2009).

The PHC Approach, as described in the Alma Ata Declaration, identifies rehabilitation as one of four pillars of primary healthcare (WHO, 1978). The Declaration emphasizes the role of rehabilitation as well as prevention and health promotion interventions in a health setting. Whether this equal status has been acknowledged and/or considered in the South African context – and specifically in the Western Cape Department of Health's services - needs to be explored further.

The Comprehensive Service Plan of the Department of Health (DoH) in the Western Cape, has shown a significant decrease in the number of allied health professionals within the newer structures at district level (WCDoH; 2006). Health management has not been provided with sufficient evidence on the value of rehabilitation services to society as a whole but also at individual level (WCDoH, 2006; Kautzky & Tollman, 2008:18-19).

There has, however, been a change in the Western Cape DoH's strategic direction in the form of the Comprehensive Service Plan. No record of research commissioned by the National Department of Health has been found to determine the evidence around rehabilitation services (DoH, 2001). Whilst the Presidency's unit on government monitoring and impact evaluation has included the Department of Health as a priority, focus has been placed on survival indicators as well as adherence support (SA, 2007). Examples include the routine reporting on the child health indicators such as diarrhoeal disease management, immunisations as well as adherence support indicators on a national system to enable tracking of the HIV infected cohort on treatment.

1.2 Problem statement

Rehabilitation services are often restricted due to the limited number of rehabilitation professionals in the service. In terms of availability at all levels of care, there are often more therapists and supporting resources at tertiary level of care. This is due to the historical hospi-centric services that are based on the medical model. Whilst there is an acknowledgement of the specialisation of therapeutic interventions at higher levels of care, Kautzky and Tollman (2008) highlights the importance of prevention and primary level services in the South African Context.

With the devolvement of services to lower levels of care, such as district hospitals and Community Health Centres (CHC) and underpinned by the health legislation, the spread of rehabilitation services has been limited compared to resource injections in other services such as nursing (WCDoH, 2006) An example would be surgical procedures being devolved to district hospitals (Level 1), resulting in discharge happening much sooner. This often leads to more acute and complicated cases being seen at primary level. With the availability of rehabilitation professionals being limited, a patient who had an amputation or spinal fusion may be discharged without being seen by the physiotherapist or occupational therapist. This may also result in non-referral to rehabilitation services or being waitlisted at CHC-level. Patients like this are often discharged without an appropriate assistive device that may improve their level of function in the home or community.

Referrals from Level 1 hospitals to physiotherapy services at CHC level may also have other environmental factors, such as availability of accessible transport, limiting attendance at rehabilitation or outpatient services on a regular basis.

The information management system of the Department of Health does not make provision for the measurement of rehabilitation outcomes. Information regarding rehabilitation services includes headcounts at the various levels of care for the various allied health professionals. At PHC level, the only additional measure that is being used is the number of assistive devices (limited to wheelchairs and crutches) that are being issued on a monthly basis. There is also no recording of monthly statistical reports regarding the number of new patients who have been waitlisted during a particular month. As a result, rehabilitation managers and facility managers are unable to record the impact rehabilitation services have made in the quality of life of individuals attending rehabilitation services at PHC level. (SINJANI, 2011)

In addition to the lack of information management systems, most rehabilitation professionals have not initiated an evidence approach to their work as this has not been included as a systems approach to rehabilitation services.

Due to the limited empirical evidence available on the impact that rehabilitation has on individuals, families and society, rehabilitation managers and professionals have been unable to make a business case regarding the rehabilitation services' value-add component. Hence the aim of this study is **“to describe the rehabilitation outcomes of physical rehabilitation patients at the Gugulethu Community Health Centre”**.

1.3 Motivation for the study

Rehabilitation services have remained at the periphery when planning, delivery and monitoring and evaluating primary health care services. There are no rehabilitation-specific indicators in the Annual Operational Plans of the WCG Department of Health (2011, 2012) The Western Cape Department of Health (WCDoH) service model has

historically been hospi-centric, with the majority of resources being placed at tertiary levels of care. Being cognizant of this misdistribution of services and resources, there has been a systematic shift in health service legislation and strategy to ensure availability of services at a decentralized level (SA, 2001; WCDoH, 2002). This included the availability of rehabilitation services; hence the inclusion of rehabilitation services in the WCDoH strategy documents namely the Comprehensive Service Plan (CSP) and Health Care 2010.

The planning around the establishment of rehabilitation centres at a district level started in the late 1990's. This included the decommissioning of Conradie Hospital to establish the Western Cape Rehabilitation Centre, Elangeni Outpatient Rehabilitation Centre in Paarl as well as a feasibility study around the decentralization of orthotic and prosthetic services in the Western Cape (WCGHealth, 1999; WCG Health, 2000; WCGHealth, 2006).

All of the planning around decentralization also resulted in patients being decanted from tertiary level of service to more local settings, for example district level hospitals and Community Health Centres (CHC's). This policy and service shift resulted in large volumes of patients being seen at primary healthcare settings resulting in long waiting times and congestion at these facilities. For rehabilitation services, this shift resulted in increased patient numbers with no corresponding increase in staff and allocation of other resources such as assistive devices.

Service delivery has also historically been profession-specific with tertiary services varying from specialized services such as Burns Rehabilitation, Work Rehabilitation, and ICU interventions to a more developmental approach where community rehabilitation

services were available. Some examples of multidisciplinary and interdisciplinary work included the Centre for Care and Rehabilitation which was initiated in partnership with the University of Stellenbosch and the Department of Health. This was however an inpatient facility with limited accessibility for those residing in districts further away from the Metropole.

The use of an outcomes-based approach to rehabilitation services has been limited to individual work innovation and has not been systemized. An example of a service using an outcomes-based approach was the Centre for Care and Rehabilitation that implemented the Functional Independence Measure (FIMS) at facility level. The outcomes-based approach to rehabilitation was taken further when the old Conradie Hospital and the Centre for Care and Rehabilitation were decommissioned to establish the new Western Cape Rehabilitation Centre. Outcome measurement at primary healthcare level has not been implemented as a norm and as mentioned earlier may only be due to individual innovation.

An objective assessment of rehabilitation service outcomes for patients using an outcomes-based approach at one site may provide some insights into the value of this approach. This may further strengthen debates and solutions around the service platform service description, the distribution of resources, both human and other, as well as the implementation of an outcomes-based approach to rehabilitation at primary level of care.

1.4 Aim of the study

To describe the rehabilitation outcomes of physical rehabilitation patients at the Gugulethu Community Health Centre.

1.5 Research questions

What is the demographic profile of patients attending Gugulethu Community Health Centre?

What are the types of conditions that people have who are referred to rehabilitation at the centre?

How can one measure the rehabilitation service outcomes to ensure improved evidence of the role that rehabilitation plays at primary healthcare level?

What is the difference between patients' functional ability at the onset of rehabilitation compared to the functional ability at discharge or follow-up three months after participating in a rehabilitation programme?

1.6 Specific Objectives

To determine the demographic profile of the rehabilitation clients attending Gugulethu Community Health Centre

To identify the five most prevalent conditions referred to rehabilitation services at Gugulethu Community Health Centre;

To identify standardised outcome measures relevant to measuring the rehabilitation outcomes of the five most prevalent conditions in Gugulethu Community Health Centre;

To determine the functional status (activity limitations and participation restrictions) of clients on entry to rehabilitation services ;

To determine the rehabilitation outcomes of the patients on discharge in terms of activity limitations and participation restrictions.

1.7 Conceptual Framework and Significance of the Study

At health management level, this study will provide the various role-players such as the rehabilitation professionals in the facility, the facility manager, the primary healthcare manager as well as the Director within the Klipfontein/Mitchell's Plain district within the Metro District Health Services, with important evidence of the potential influence of rehabilitation services on the individual patient's level of functioning. This will assist management to make informed decisions regarding the package of rehabilitation services, the approach to rehabilitation and disability management in the broader sense as well as resource distribution, thereby ensuring improved patient-centred experiences.

At a service provider (therapist) level, it highlights the potential influence of their work on their patient population hence their ability to report on more indicators such as improvements in functioning as it pertains to mobility, self-care activities as well as some community participation activities. This may also be a prompt to revisit appropriateness of interventions at this level of care. In addition, the development and implementation of uniform tools and guidelines for rehabilitation services presents an excellent opportunity.

The following main concepts constitute the conceptual framework that has been applied throughout the study:

Outcomes based measurement in rehabilitation including the utilization of the International Classification of Function (ICF) (WHO, 2001);

Community Based Rehabilitation (CBR), including the World Health Organisation (WHO) CBR Matrix as well as the WHO CBR guidelines (UNSECO, 2004; WHO, 2010)

These concepts will be explored in detail in Chapter 2.

The International Classification of Function (ICF) is a tool developed by the WHO to enable measurement of disability as impairment (bodily function and structure), activity limitations and participation restrictions (WHO, 2001; Ustún et al. 2003). It enables one to assess the patients level of functioning at the start of a goal-oriented rehabilitation process (Rauch et al, 2008) whilst taking external factors and the complexities of the interactions between individuals and their environment into account (Wang, 2006). By using the ICF as a framework in this study, one would be able to gauge outcomes at individual level whilst also taking environmental factors into account ((Ustún et al. 2003). At a patient level, this detail of outcome measurement will enable the therapist and patient to measure objectively against the activity and participation goals (Kloppers, 2013; Felix, 2014). It will also keep patients motivated to attend rehabilitation services until such time that discharge is agreed upon.

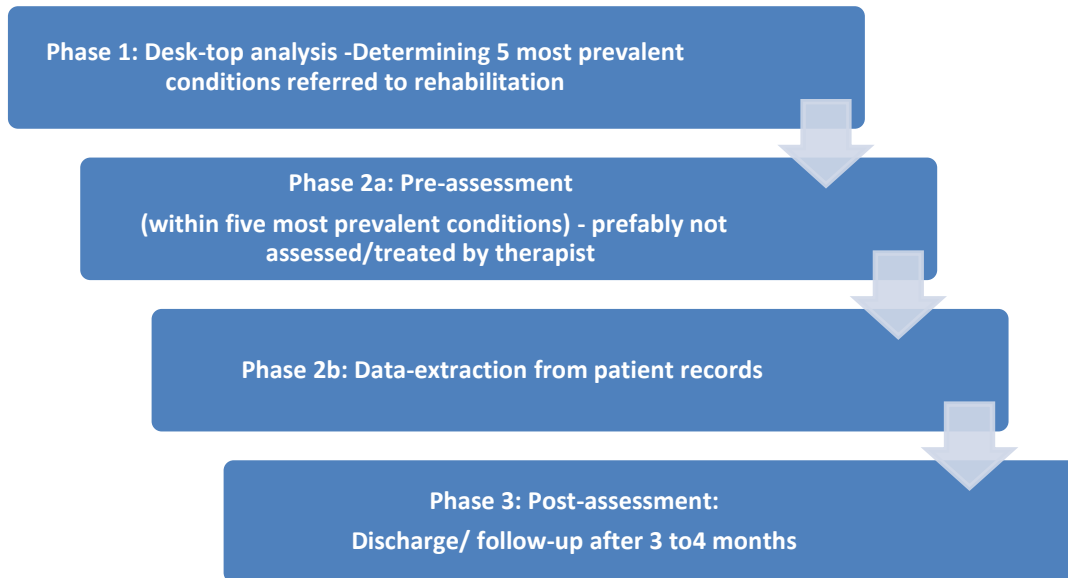
The Community Based Rehabilitation (CBR) approach (ILO, UNESCO, WHO; 2004) and the CBR Matrix has also been applied as an integral part of the conceptual framework thereby ensuring alignment to WHO standards for disability management and rehabilitation.

1.8 Study Process Outline

The flow diagram (Figure 1.1) depicts the process that was followed with regard to data collection for the study, with phase 1 being the desk-top analysis to determine the five most prevalent conditions referred to the rehabilitation service; phase 2(a) being the pre-assessment of patients after being referred for therapy but not yet assessed by the therapist; phase 2(b) being data extraction from the patient records and lastly, phase 3

being the post-assessment of patients either at discharge or three- to four-months after attending therapy.

Figure 1.1 Study Process Outline



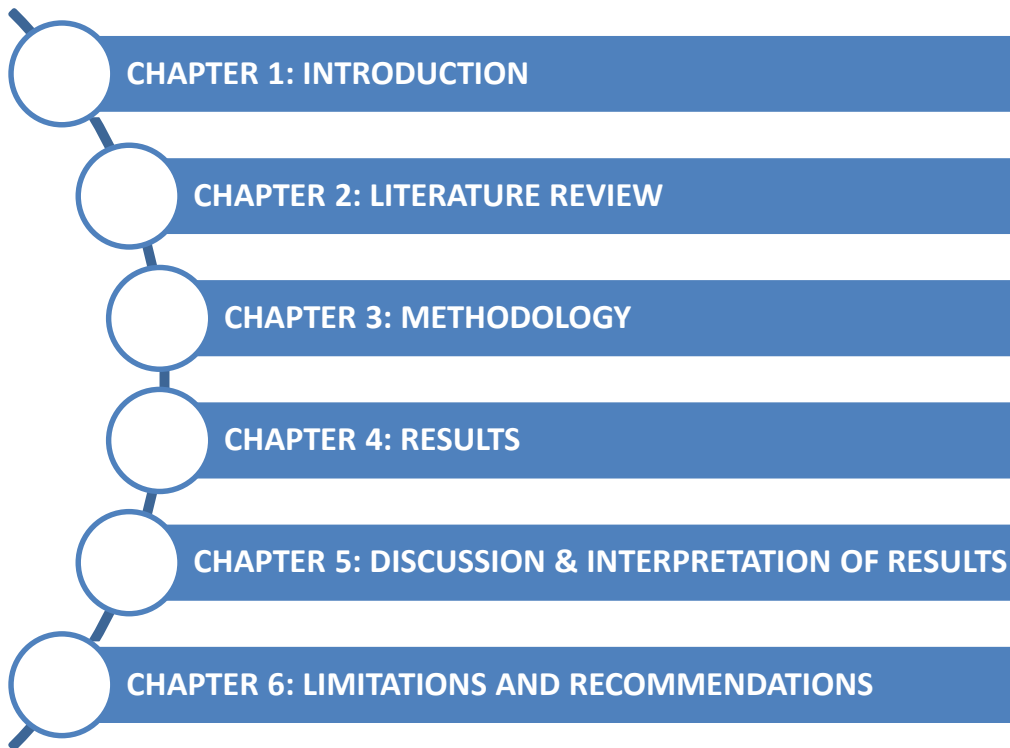
1.9 Thesis report outline

The study report will adhere to the flow that is depicted in Figure 1.2: Chapter 1: Introduction; Chapter 2: Literature Review; Chapter 3: Methodology; Chapter 4: Results; Chapter 5: Discussion and Interpretation of the results; and lastly, Chapter 6 which discusses the limitations of the study.

It is important to note that Chapter 4 will only depict the reporting of the results: no interpretation will be done in this chapter. Chapter 5 will include the interpretation of the results and relevance to international and national literature.

Figure 1.2 depicts the report outline and what will be covered in each chapter.

FIGURE 1.2: DESCRIPTION OF OUTLINE OF REPORT



CHAPTER 2

LITERATURE REVIEW

This chapter will provide an overview of the policy context of disability and rehabilitation in South Africa and also explores some of the human rights aspects of disability in the South African Context. The chapter furthermore explores how rehabilitation services fits into the primary health care platform as the burden of disease is explored and specifically the potential role that rehabilitation services could play. The complexity of measurement in disability is explored.

2.1 The Policy Context of Disability and Rehabilitation

“Disability tends to be couched within a medical and welfare framework, identifying people with disabilities as ill, different from their non-disabled peers, and in need of care. Because the emphasis is on the medical needs of people with disabilities, there is a corresponding neglect of their wider social needs. This has resulted in severe isolation for people with disabilities and their families.” (SA, 1997)

This view, as part of the introduction to the National Integrated Disability Strategy (1997), encapsulates the realities of persons with disabilities. It also puts forward in a very direct way, the challenge of moving away from working in a very medical and welfarist manner. The South African Government, with its strong human-rights base, has spear-headed the conceptualization and development of an Integrated National Disability Strategy (INDS) (SA, 1997).

Due to the concept of disability often being described as complex, the Office of the Deputy President took a very comprehensive view to acknowledge both the medical and social models. The INDS stipulated, at the stage of circulation for implementation, a strong inter-sectoral focus including the inclusion and empowerment of persons with disabilities (PWDs). (SA, 1997)

Defining disability has been seen as a complex matter in the sense that there have been various models that has been described (Mitra. et al., 2009). The medical model is described as the model where professionals and service providers prescribe what services and or intervention is required (SA,1997; WHO, 2011) with very little regard of what the person with disability requires from the process or what the environment is like to which the person with disability will have to return (Wang, 2006; Schneider, 2011). The social model on disability has been seen to be more acceptable to the disability sector; one that looks at the environment and society's view thereby focusing in particular on those barriers as opposed to the individual impairment (Helander, 2009; SA, 1997; Schneider, et al; 2009; WHO, 2011).

The National Department of Health published the National Rehabilitation Policy (NRP) in 2000 (DoH, 2000). It refers to disability as "... any restriction or lack of ability to perform an activity in the manner or in the range considered normal for a human being for example difficulty in speaking, hearing or walking." (DoH, 2000) Whilst this definition focuses on the loss of function of the individual, there is no mention of the role that environmental factors play in the life of a person with impaired function (Marks, 1997). There is a need to address disability from a human rights perspective as well. (SA, 1997; Helander, 2009)

2.2 The Human Rights Context of Disability

The South African constitution recognizes the protection of human rights as a strong basis for service delivery and an ethos of creating and sustaining the human rights philosophy (SA, 1996). In 2008, SA ratified the UN Convention on the Rights of People with Disabilities (UNCRPD) and therefore the country subscribes to various United Nations (UN) treaties on human rights (UN, 2006). The purpose of this Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity (UN; 2006)

Post-democracy pressure from the disability sector in South Africa facilitated a process for move towards the Community-based Rehabilitation philosophy (Howell, et al, 2006: 50-51). The organization and formalization of the disability sector on various platforms became evident in the new democracy. The formation of CODESA, the Convention for Democratic South Africa, in December 1991 brought together various political, civil, religious and community organizations to develop a new roadmap for the new democratic South Africa (www.sahistory.co.za).

These platforms signified the acknowledgement of the inclusion of persons with disabilities in the government of the new South Africa and included the Office of the Status of Disabled People in the Presidency that was established on 1 May 1997.

“We felt there was a need to create a voice of our own, where we would, for the first time, be able to advocate for our own rights without having to depend on professionals to speak on our behalf...” (Howell, Chalken & Alberts, 2006:50-51)

Self-representation and advocacy is seen as integral in the Community-based Rehabilitation philosophy (Helander, 2009). These views are shared by Kautzky and Tollman in their perspective of Primary Health Care in South Africa of which rehabilitation forms an integral part of.

2.3 Rehabilitation within the context of Primary Health Care

The World Health Organisation (WHO) together with the United Nations Children's Fund co-founded the First International Conference on Primary Health Care in Alma Ata in 1978. It was at this conference that the member countries "...express[ed] the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all the people of the world..." (WHO, 1978).

According to the World Health Organisation, "the ultimate goal of primary healthcare is better health for all." (http://www.who.int/topics/primary_health_care/en/) . As support to implementing this approach, the WHO has identified five key elements that would give effect to and support the achievement of better health for all. These elements include:

- reducing exclusion and social disparities in health (universal coverage reforms);
 - organizing health services around people's needs and expectations (service delivery reforms);
 - integrating health into all sectors (public policy reforms);
 - pursuing collaborative models of policy dialogue (leadership reforms);
- and,

- increasing stakeholder participation.

(http://www.who.int/topics/primary_health_care/en/)

The Declaration of Alma Ata looked at the importance of primary healthcare, lobbying and declaring the need to establish public health systems that would be accessible and subsequently lead to a philosophy and mandate of healthcare for all (WHO; 1978). Article vii of the Declaration (WHO, 1978) stipulates that primary healthcare “...addresses health problems in the community providing promotive, preventive, curative and rehabilitative services...” Whilst article vii speaks to the comprehensive nature of the package of services that ought to be provided, article xii provides a directive to governments with regard to their legislative mandate thereby ensuring the availability of resources to implement the primary healthcare approach. (WHO, 1978)

The Department of Health has, since the new democracy, been tasked to operationalize international treaties and directives. An example of this would be the National Health Act of 2003 (SA; 2003). It stipulates the establishment of the District Health System, with specific focus on the decentralization of services from more specialized levels of care and the subsequent cascading of relevant services to facilities that should be more accessible to people living in communities (SA; 2003). The Health Act stipulates the establishment of various health authorities, their roles and functions as well as the classification of health facilities based on various factors such as size, location and the nature of the services that is provided at the health facility (SA; 2003). As part of the operationalization of this stipulation, the Primary Health Care (PHC) Package of Care and Norms and Standard Policy Guidelines were developed, focusing on all four pillars of primary healthcare including rehabilitation services (DoH; 2000).

The developments in Health post-democracy, such as the establishment of the district health system through legislation, facilitated the development of transformational health strategy documents in the Western Cape Department of Health, namely Health Care 2010 (WCDoH, 2003). The focus of this strategy was to enable to devolvement of specialized and non-specialised services to lower levels of care to improve access to services. (WCDoH, 2003).

The National Department of Health developed and published various policy documents that supported the development as well as monitoring and evaluation of rehabilitation services, in the context of primary healthcare. Amongst these policies were the National Rehabilitation Policy (DoH,2001) and The Primary Health Care Norms and Standards Policy (DoH; 2000).

The PHC Core Package (DoH, 2000) sets the following core package for rehabilitation services within primary healthcare:

- Follow up of all discharged clients from hospital
- Low intensity rehabilitation services rendered by at least a physiotherapist and or an occupational therapist for at least 1-2 hours per day but not necessarily everyday
- Screening and Assessment
- Education and Training and support of the patient, family and caregivers or HBC
- Establishing adequate and safe systems of nutrition
- Therapeutic and support groups
- Issuing of appropriate assistive devices

- Correct prescription and issue of wheelchair or buggies including postural seating
- Correct prescription and supply of other required assistive devices
- Facilitating the achievement, with varying degrees of assistance as required, of a basic degree of functional independence in self-care, mobility, safety, communication

The delivery of rehabilitation services have been provided at **primary level** at the following sites in the Western Cape:

- District Hospital Rehabilitation Services for example, G.F. Jooste Hospital
- Community Health Centre or Community Day Centre, for example Gugulethu Community Health Centre;
- Community Outreach to community-based facilities by the rehabilitation team based at the Community Health Centre or those part of the District Health Team.

A specialist in-patient rehabilitation service is provided at the Western Cape Rehabilitation Centre in Mitchell's Plain. Whilst this service is a provincial referral service, accessibility remains a constraint due to the limited number of beds. Access to this service for the rural person with disability is also problematic. Some of the barriers are physical accessibility, distance and inability of family members to stay as a support system for long periods. The Cape Metro has additional services that are State-supported such as Intermediate Care Facilities for adults (such as Booth Memorial) and children (Sarah Fox) where in-patient rehabilitation services are provided for people with long-term conditions who require rehabilitation over an extended period.

The PHC Norms for Rehabilitation Services was set out to:

“Improve access to comprehensive health services for the disabled. (National: Year 2000 Goals Objectives and Indicators.)

Have a responsive and area-specific disability information system in place, which will feed into the general information system of the district and clinic.

Institute a functional referral system between the community-clinic-district hospital, as well as other relevant sectors.

Institute a system of obtaining, repairing and maintaining essential assistive devices for rehabilitation “

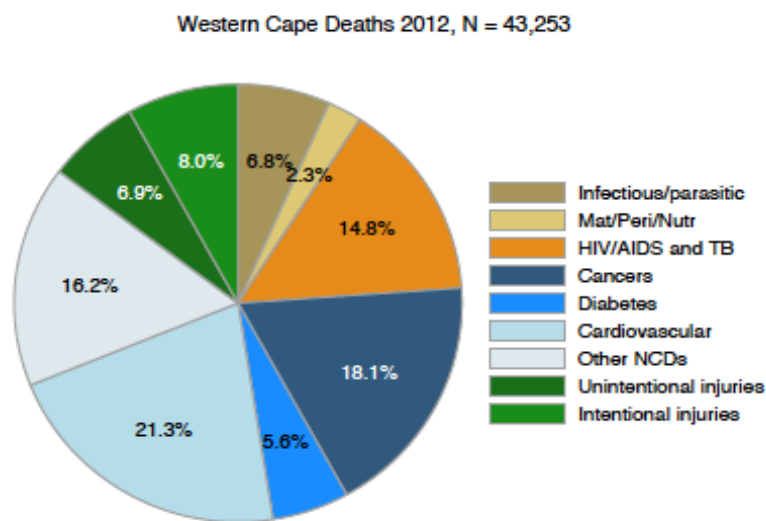
(DoH, 2000)

Whilst the policy documents are clear about service delivery norms and, despite the fact that there was reference made to the establishment of a disability information system, no provincial or national information system has been put in place that is over and above “Head Counts” for Rehabilitation Services (SINJANI, 2013)

Attainment of the aforementioned goals is heavily dependent on re-engineering the health system to one that is based on a primary healthcare approach (DoH, 2013). More emphasis is required on promotive and preventive healthcare that should underpin all interventions needed to achieve the outputs. (DoH, 2013) The PHC service would therefore include all health services for people with disabilities. It is therefore important for rehabilitation services to be responsive to the burden of disease in the particular service area thereby ensuring that the package of care is aligned to the burden of disease

2.4 Burden of Disease

The second highest cause of death in Cape Town is HIV/AIDS, as it is in Gugulethu. However, 22,49% of people in Gugulethu die of HIV/AIDS whilst the city average is only 10,27% (Groenewald et al; 2008). Tuberculosis (TB) is an indicator condition for AIDS and there is evidence that the TB epidemic is being fuelled by the HIV epidemic. This dual impact has a huge effect on the premature mortality in the city of Cape Town (Groenewald, et al; 2008)



WC Mortality Report, 2012

There is, however, sufficient evidence on morbidity (Bradshaw D., Schneider M, Norman R, Bourne D, undated report; The Lancet, undated) in that the burden of chronic diseases of lifestyle has a substantial effect on the health status of society. This is supported by more recent reports where the same trends are identified. (MRC, 2008; Groenewald, et al; 2008)

Some of the health indicators highlighted at the Department of Health Annual Review Session (April, 2014) indicated that 76% of deaths are as a result of chronic conditions;

80% of headcounts in Cape Metropole (Metro District Health Services) are for chronic conditions; 28% of PHC headcounts nationally are for Chronic Conditions and that there is high prevalence of co-morbidity. (Pienaar, D; 2014)

There is a substantial role for rehabilitation services in the prevention and management of chronic diseases. The PHC package also stipulates the role of rehabilitation professionals in primary prevention (DoH, 2001) as well as the prevention of decompensation of patients (DoH, 2001). At PHC level, rehabilitation services should not merely deal with the current burden of persons with disabilities but should render a preventive and promotive service to minimise disability (DoH, 2001; Kloppers, 2013; Felix, 2015)

Mitra and Samboorthi (2013) found, in an international study that included 54 countries, that disability is more prevalent in adults (14% global prevalence rate), disability prevalence is generally higher in developing countries especially among women and the elderly. Their study confirmed that based on the high prevalence that the rehabilitation needs are significant and unmet. (Mitra et al., 2011)

Disability has direct and indirect consequences to the person with the disability as well as the family and may include costs such as transport (for self and carer), assistive devices and possible costs for regular transport to attend healthcare facilities. (Schneider, et al., 2011)

Rehabilitation

The complex nature of defining disability, as well as the comprehensive nature of rehabilitation services, has influenced the South African Government to give cognizance to this by introducing the White Paper on an Integrated National Disability Strategy (SA,

1997). This document acknowledges the various models on disability and, in addition, acknowledges the need from the disability sector for government to move from the medical model to the social model on disability. It is against the background of the Integrated National Disability Strategy (INDS) that there was a move in health and social policy (DoH, 2003; DoH, 2000; SA, 2004) to lean more towards the social model on disability. This necessitated a re-think of service delivery processes.

The context of rehabilitation has been changing along with shifts in health policy and systems development (WCDoh, 2012; WCDoh, 2014). There is increased acknowledgement of CBR and ICF in Western Cape planning processes whereby the use of the ICF philosophy in planning, with regard to needs of the broader population at various levels, and including those members of the population with disabilities (DoH, 2014).

Historically there has been a strong focus and presence of medical rehabilitation where rehabilitation services were mostly rendered at hospital level. The PHC norms and standards policy document considers rehabilitation services to be "...an integral part of services provided at primary level [and] constitutes a reorientation of rehabilitation from mainly institution-based services to community orientated and community based services." (DoH, 2003) Further more Helander (1999) describes rehabilitation to include "...all measures aims at reducing the impact of disability on an individual enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation.

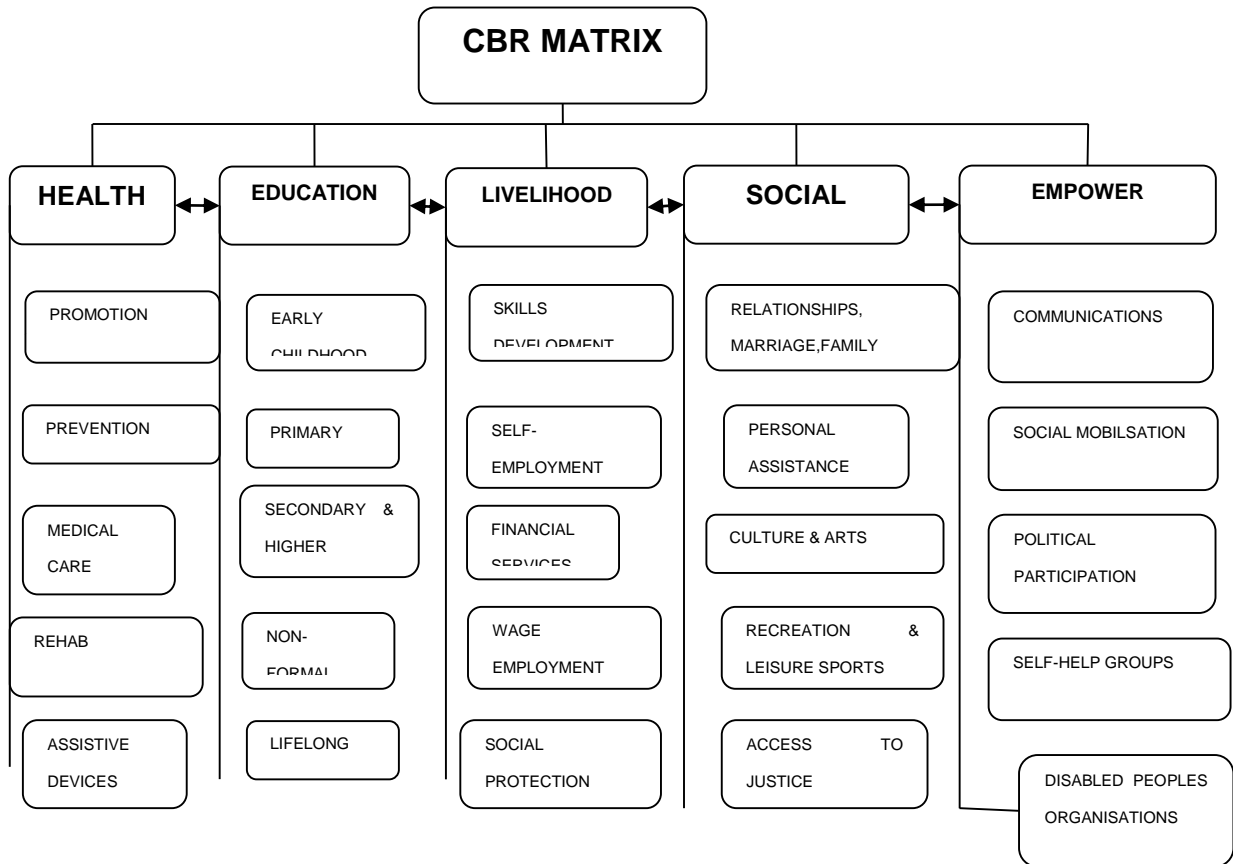
As part of the support to improve access to healthcare for people with disabilities, the Department of Health launched the National Rehabilitation Policy (DoH, 2000). The

Minister of Health at that time stated in her introductory remarks that the policy should improve general accessibility of health services, especially rehabilitation services, to all people with disabilities (DoH, 2000). In addition to the National Rehabilitation Policy and in support of the notion of systems strengthening of PHC, Free Health Care for people with disabilities was introduced at hospital level (DoH; 2003).

The Western Cape Department of Health has identified the strengthening of the PHC services as a priority in line with national health priorities. The department has strengthened the PHC platform expanding this platform to community-based level (CBS). This resulted in the establishment of a funded vehicle for service delivery at PHC and specifically CBS level, subsidized and governed by the Department of Health through national conditional grant funding as well as donor funding. There is significant evidence in the strategic documents from the Western Cape Department of Health that there is more focus on the rehabilitative aspect of PHC (WCDoH; 2012; WCDoH; 2013)

CBR, at its very core, encapsulates the social model on disability as it places the emphasis on the role of persons with disabilities and ensures that participation is facilitated. The CBR Matrix as developed by the World Health Organisation is depicted in the figure below:

FIGURE 2.3: WHO – CBR MATRIX (Source: WHO, undated)



South Africa has witnessed the inclusion of persons with disabilities in the apartheid era in various platforms. This included the establishment of Disabled People South Africa (DPSA), the pre-democracy platform in the form of the Commission for Democracy in South Africa (CODESA) and then post democracy, the Office on the Status of Disabled People (OSDP). (Howell, et al, 2006:50-51). Despite this level of inclusion and consultation South Africa has no disability legislation in place.

The Department of Health has included CBR in the National Rehabilitation Policy; however the debate on whether CBR is a philosophy or a service has limited implementation of CBR. Neither the National Department of Health nor the Department of Social Development have commissioned research pertaining to CBR. These are the lead departments in the management of services for people with disability. Helander's description of what rehabilitation entails, would go beyond what Health and Social services currently provides (Helander, 1999)

Monitoring and Evaluation

The South African Government has as far back as 2007 developed a policy framework on Monitoring and Evaluation (M & E) within government. In motivating for the importance of M & E the framework states that "...M & E helps to provide an evidence base for public resource allocation decisions and helps to identify how challenges should be addressed and successes replicated." It is added that "[it is]...extremely complex, multidisciplinary and skill intensive". (SA; 2007)

At an international level, the United Nations Development Programme (UNDP) in its M & E Framework, motivates that Monitoring and Evaluation is a tool "...to learn from past experiences and current interventions thereby consistently gauging relevance and aiding in decision-making regarding status of programmes or interventions, progress and or success and whether future interventions should be in line with current practices or not". (UNDP; 2009)

Proponents of research in healthcare supports the relevance for assessing appropriateness of services ensuring proper design of health programmes (Katzenellenbogen, et al , 1997) It should therefore be considered to what extent

services to persons with disabilities and specifically rehabilitation within the health sector is monitored and evaluated with the purpose of improving service delivery and planning.

2.5 Disability and Measurement

Loeb (2008) holds that the purpose for measurement plays a role in the determination of the type of disability data to be collected. He identifies three major purposes for collecting data on disability namely: (a) monitoring the level of functioning in a population; (b) designing service provision and; (c) assessing the equalization of opportunity (Loeb; 2008). For the purpose of this study the measurement of the level of functioning in a sub-set of a population as well as designing service provision would be key. The study aims to add value in terms of measuring the outcomes of rehabilitation services and suggesting improvement to services.

Whilst there is a policy milieu that is potentially of a supporting and facilitating nature, the realities around disability and rehabilitation are quite stark. Defining '*disability*' has proven to be contentious as the various perspectives on disability and the models adopted deepen the complexity of the definition as well as the measurement of disability at population level (Loeb, et al., 2008; Schneider, 2009). This is evident in the documentation of prevalence of disability internationally. (Ústún et al 2003; Loeb et al; 2008; Schneider, 2009) .According to Loeb (2008) the complexities around measuring disability could be ascribed to the fact that the definition of disability often differs due to the variances in cultural contexts, as in the case of measuring disability prevalence in Zambia. The authors are of the opinion that measurement of disability based on functionality and participation in community roles seems to be far more successful than focusing on impairments. Loeb (2008) furthermore suggests that the Washington Group

(WG) Model for determining prevalence may be exemplary for all prevalence studies on disability. This is supported by the study by Schneider (2009) in the case of measuring disability in censuses in South Africa.

The Community Survey of 2007 reported the South African Disability prevalence as 4% of the population. This was a significant reduction from the 1996 report when the prevalence rate was at 6.5% of the population. This report also identified physical disability to be the most prevalent disability, at 1.6 % of the population. (StatsSA; 2007) The 2001 Census report indicated that 5% of the population was disabled with just over 2, 3 million people being enumerated in this category. As with the 2007 Community Survey, physical disability was once again identified as the most prevalent type within the group of disabilities (StatsSA, 2001).

There was a change in the Census 2011 questions on disability because of the need to align with international practices and tools thereby ensuring comparability of disability prevalence. The previous tools were replaced with general health and functioning questions (StatsSA; 2011). Whilst the alignment resulted in more comparability and alignment internationally, it resulted in census 2011 figures are not comparable to the previous census figures. The census 2011 does not report on disability prevalence per se but on “the degree of difficulty hearing, seeing, communicating, walking or climbing stairs...” (StatsSA, 2011). The results showed that the majority of the people (more than 90%) “...had no difficulty or limitation that prevented them from carrying out certain functions...” (StatsSA, 2011).

It is vital to be able to measure a patient’s level of functioning at the onset of rehabilitation. There for this study will focus on a group of patients known to have some

degree of impairment and then objectively testing to see whether or not there are difficulties and or limitations in their level of functioning.

2.6 The International Classification of Function as a Framework

The *International Classification of Function (ICF)* has been recognized as a tool that can be used for baseline measurement of functional ability in people with disability (Loeb et al, 2008; Schneider et al 2009; Ústún, et al, 2003). The ICF has moved through various stages of development, starting off in the 1980s as the International Classification of Impairments, Disabilities and Handicaps (ICIDH) and subsequently developing into the ICIDH-2 until it was published in 2001 as the International Classification of Function (WHO; 2001). Initial detractors of the tool described it as another medical model tool that identifies disability as a cause of an illness or injury only (Pfeiffer as cited in Tora Dahl's article). Pfeiffer furthermore criticized the International Classification of function (ICF) as being a threat to the disability sector due to the opinion that it remains medicalized (Dahl, 2002).

The ICF has been described as ‘...provid[ing] a new foundation for our health function and disability [and] represents an advance that is universal framework and classification system to comprehensively describe human experience in relation to functioning and disability.’(Cieza, et al., 2008). The ICF has been aptly described as a tool that comprehensively described experiences in various spheres of life in relation to experiences in the environment (Cieza et al., 2008; Wang, 2006; Masala et al., 2008). Dahl (2002) also motivated that both professionals and people with disabilities’ understanding of functioning is aligned to the conceptual framework. Davis et al. (2012)

confirms that the ICF has been applied in a variety of settings across a multitude of health conditions to support health and disability reporting and evaluation.

The ICF aims to do the following:

” ... 1) to provide a scientific basis for understanding and studying health and health related states, outcomes and determinants; 2) to establish a common language for describing health and health-related states in order to improve communication between different users, such as healthcare workers, researchers, policy makers and the public, including people with disabilities; 3) to permit comparison of data across countries, healthcare disciplines, services and time; and 4) to provide a systematic coding scheme for health information systems.” (WHO; 2001)

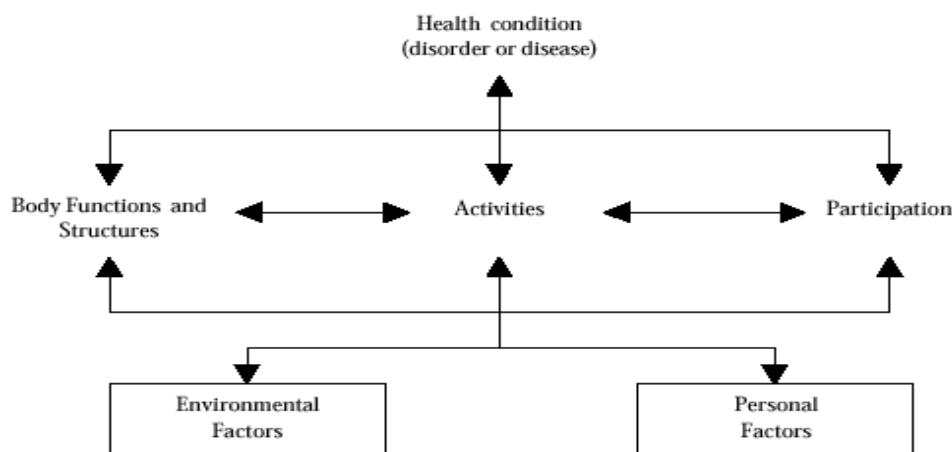
The World Disability Report (2011) promotes the International Classification of Function (ICF) as

“a bio-psycho-social model...represent(ing) a workable compromise between medical and social models” and “understands disability as a dynamic interaction between health conditions and contextual factors, both personal and environmental” (WHO, 2011)

The components of the ICF includes: body structure and function; activity limitations as well as participation restrictions. *Body structure and function* is the domain most closely related to the medical model as it refers to the physiological and psychological functions of body systems. Body structures are defined by the ICF as “anatomic parts of the body such as organs, limbs and their components.” (WHO; 2001) This domain relates to very specific capabilities, for example being able to lift one’s arm over one’s head or produce

articulate speech sounds. This domain is referred to as impairment within this study. *Activities* pertain to a wide range of deliberate actions performed by an individual. “These are basic deliberate actions undertaken in order to accomplish a task, such as walking or climbing stairs “(WHO,2001) One can also describe it as a combination of tasks that related to the day-to-day functioning of an individual. *Participation* refers to “...activities that are integral to economic and social life and the social roles that accomplish that life, such as being able to attend school or hold a job.” (WHO, 2001)

FIGURE 2.4: SCHEMATIC REPRESENTATION OF ICF



(WHO, 2001)

It is due to comprehensive nature and general international and local interest, that the ICF has been applied as a conceptual framework in the study.

2.7 Outcomes and outcome measurement tools

An outcome measure is defined as a “...measurement tool (instrument, questionnaire, rating form, etc.) used to document change in one or more patient characteristics over time” whilst a standardized measure is defined as a “...published measurement tool, designed for a specific purpose in a given population, with detailed instructions provided

so as to when and how it is to be administrated and scored, interpretation of scores, and results of investigations of reliability and validity (Cole, 1995).

With the ICF set as the framework for measurement in the disability landscape careful consideration should be given on the factors surrounding the implementation of such a broad framework (WHO, 2013). Cole (1995) shares some insights into barriers to the use of standardized outcome measures. Cole describes a survey done with 209 physical therapists and directors. Of the therapists, 56% identified multiple barriers to implementing standardized outcome measures whilst only 5% thought there were none. Barriers included amongst others, limited knowledge on instruments, time, limited knowledge on instrument developments, lack of consensus on what to use. Most of the staff members identified the limited knowledge on the subject as the biggest barrier and found it challenging to apply in terms of research (Cole, 1995).

More recent research reports a significant increase in the use of standardized outcome measures by clinical physiotherapists (Finch, et al, 2002). In 1992, 20% of respondents who participated in a survey used at least one published outcome measure whilst this increased in 1998 when 97% of the sample used one of a provided list of 22 outcome measures (Finch et al, 2002).

It is with this in mind, that one would have to consider standardized tools that would be appropriate for use at Gugulethu CHC where the burden of disease at rehabilitation services point to the following diagnostic groups: CVAs, , Arthritis, Lower Back Pain, Upper Limb Injuries and Lower Limb Injuries. One would therefore have to consider outcome measures that will be able to be aligned to the concepts in the ICF such as activities (or activity limitations), participation, impairment (bodily structure and function)

Martin (2010) advocates for the following criteria when implementing the outcome measurement tools: utility, validity, reliability, precision, feasibility and cost. (Martin, et al, 2010).

2.7.1. Tools for Lower Limb Injuries

The Clinical Mobility Scale is a user-friendly tool to determine the patient's mobility over time. (Hariharan & Svirbely, 2008) Whilst there is limited evidence available on the tool, its user-friendly nature and availability made it a good choice to use as the data could be generalizable to other studies as well.

The Clinical Mobility scale links with the ICF in terms of the activity and participation domains.

2.7.2 Tools for Strokes/CVA

The Barthel Index (BI) has been proposed by Wade & Collin (1988) to be one of the standardized tools to determine the level of functional impairment for people with CVAs (Mahoney & Barthel; 1965). They describe the ability for the clinician to observe changes in function as recovery takes place. Detractors of the Barthel Index are of the opinion that the sections in the tool are not sensitive enough and they propose that the BI be used with other tools to improve the validity.

Other proponents of the BI motivate that the BI is reliable, easy to understand and use by professional and untrained people in the evaluation of persons who have had CVAs (Collin, et al., 1988). Wallace et al (2002) confirmed that the BI is sensitive in order to gauge changes over a three-month period.

Kwon, et al (1999) could not find additional advantages in using the Modified Rankin Scale, nor the Functional Independence Measure (FIM). The BI links to the ICF in terms

of activities and participation. In terms of usability; the tool can be used by professional and non-professional people. It is freely available for academic use (Mahoney & Barthel, 1965). It is for these reasons that the BI was deemed the most appropriate for the study.

2.7.3 Tools for Arthritis

The Arthritis Impact Measurement Scales 2 – Short Form (AIMS2-SF) is known as a valid and reliable tool for the assessment of patients with arthritis at activity level as well as body functions and structures. Like the Barthel Index, it is also user-friendly and available at no cost.

Haavardsholm, et al (2000) were of the opinion that the AIMS 2-SF fared well compared to other tools used for assessing people with arthritis functional ability.

2.7.4 Tools for Upper Limb Injuries

Schoneveld, et al (2009) reported in a systematic review performed on outcome measures for upper limb injuries, that out of fifteen tools compared, the DASH (Disability of the Shoulder and Hand) was appropriate to determine activity as well as body structure and function domains of the ICF. Compared to the rest of the tools, the DASH showed the best quality in terms of test re-test reliability {ICC>0.7}

The DASH is available free of charge, is widely accepted and the use of data for generalizability is accepted. The DASH tests the domains of impairment, activity and participation and is therefore a good tool to use in this study.

CHAPTER 3

METHODOLOGY

This chapter describes the methodology in more detail. It includes a description of the design, the setting, study population, sampling as well as the various outcome measures that were used during the study. Ethical considerations are also described towards the end of this chapter.

3.1 Study Design

Study design is described as “...the overall research approach or strategy taken” (Katzenellenbogen, Joubert & Karim; 1997). Salkind (2012) defines a descriptive study as one that describes the current state of some phenomenon. The purpose of descriptive studies is described as providing service providers and planners with information that will assist them with appropriate service planning and allocation of resources (Katzenellenbogen, Joubert & Karim, 1997)

This study has a descriptive design with pre-and post-rehabilitation tests measuring changes in functional ability of clients. Quantitative methodology was followed. It identifies the five most prevalent conditions referred to rehabilitation services at Gugulethu Community Health Centre. It describes the functional ability of these clients at referral or at the first rehabilitation session prior to seeing the therapist, and again, either at discharge or three months after rehabilitation has ceased (in the case of defaulters). All clients have had some form of rehabilitation intervention.

The study design enabled the researcher to gather information regarding the types of conditions seen as well as whether there are any differences on functional abilities,

bodily functions and structure post rehabilitation. In addition some demographic and environmental factors that may have influenced the level of participation in the rehabilitation programme were also included.

3.2 Research site

This section will provide an overview of the research site by providing a description of the general context, the general health context, then moving to the health system catchment area and referral system, and lastly an overview of the rehabilitation service provision.

3.2.1 The General Context

The catchment area for the Gugulethu Community Health Centre was the suburb of Gugulethu, which was about 6,24 square kilometres as well as parts of Nyanga, Philippi and Crossroads (CoCT; 2012).

According to the 2011 census the total population of Gugulethu was 70,159, with a density of 11,264 people per square kilometre (Stats SA, 2011). Just over ninety-eight per cent (98, 6%) of the population of Gugulethu is Black African ethnic group. Gender distribution is described to be mostly female with 52.65% being female and 47, 35% of the population being male. The predominant language in Gugulethu is isi-Xhosa with 94.25% of the population using it as their first language (Stats SA, 2011).

According to the 2011 Census, 56% of the labour force of Gugulethu is employed but 65% earned less than R3200 a month. The provincial average of employment is lower, at 49.7%. Regarding education, 7% of the population of Gugulethu has a University Degree and only 31.23% completed their schooling and completed their Grade 12

qualification. As much as 2.3% of adults in Gugulethu have had no schooling at all (Stats SA, 2011).

Sixty six percent of people in Gugulethu live in a brick house and 33.5% in an informal dwelling or shack; 98.6% use electricity for lighting; and 73.7% have access to piped water inside their dwelling (Stats SA, 2011).

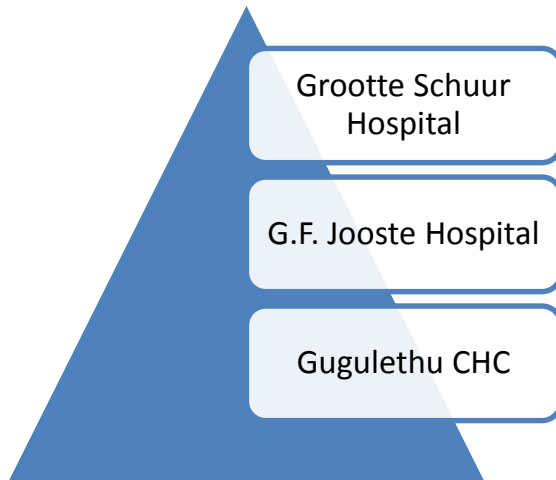
3.2.2 The Health Context

The Western Cape has nine health districts. Four of these are in the Metro or also called the City of Cape Town. Each district is divided into two sub-districts. Gugulethu is located within the Klipfontein sub-district that forms part of the Klipfontein Mitchell's Plain district. The research project has been located at the Gugulethu Community Health Centre (GCHC) and serves a population of just under 171,000 people (SA; 2001).

Gugulethu CHC forms part of the District Health System and is located within the facility-based services platform. The service package includes a doctor-driven service which is supported by a team of professionals, including rehabilitation professionals who are either allocated there on a full-time basis or who provide an outreach support service to the broader district.

3.2.3 Health system catchment area and referral systems

The Gugulethu CHC is a 24-hour primary healthcare and trauma facility. The centre receives its referrals from G.F. Jooste Hospital and Groote Schuur Hospital as its tertiary referral hospital. Figure 3.1 depicts the referral system from tertiary to primary healthcare level.

FIGURE 3.1: DESCRIPTION OF CATCHMENT AREA AND REFERRAL SYSTEM

3.2.4 Rehabilitation Services

The rehabilitation service at Gugulethu Community Health Centre is run by a full-time physiotherapist, who also provides an outreach support service to a satellite clinic one afternoon a week. The occupational therapist provides a service one day per week. The orthopaedic aftercare nurse, although based at GCHC, only provides services there one day per week. The rest of the time he provides support to the whole district as well as the Southern Western District of the WCDoH and the Western sub-district.

The physiotherapy service is focused on acute cases and the rehabilitation interventions are on a one-to-one basis. The occupational therapist also sees patients on a one-to-one basis as well as the orthopaedic aftercare nurse.

The physiotherapist and occupational therapist provide a team-based outreach support service to day care centres in the area.

3.3 Study Population

The study population included all patients who attended Gugulethu Community Health Centre and who were referred to Rehabilitation during the study period.

3.4 Study Sample

The study sample included all patients with the five most prevalent conditions who entered the physiotherapy service at GCHC during the period February 2012 to April 2012 (with post-tests being done until September 2012). During the period February 2012 to April 2012 a total of 216 new patients were referred to rehabilitation services. Rehabilitation referrals for the three-month period (February to March 2012): were 78 for physiotherapy, 79 for occupational therapy, and 59 for orthopaedic aftercare, Patients with the five most prevalent conditions were included in the sample.

3.5 Sampling methods

The following inclusion and exclusion criteria were applied:

3.5.1 Inclusion Criteria

All patients with one or more of the five most prevalent conditions who were referred to Rehabilitation

Patient proficient in English, Afrikaans or Isi-Xhosa

All patients who consented in writing to participate

All patients older than 18-years of age

3.5.2 Exclusion Criteria

Patients with co-morbidity where there is a diagnosis of mental illness or intellectual disability.

Patients with receptive and or expressive aphasia who are unable to perform a three-step command test.

3.5.3 Preparatory work

The researcher requested the monthly statistical reports for last six months of 2010. The physiotherapist, occupational therapist and orthopaedic aftercare nurse supplied the researcher with these statistical reports. The reports for each of the professionals were varied in the sense that the diagnosis was not uniformly recorded. It included medical diagnoses as well as descriptions of symptoms. The researcher performed an analysis of all diagnoses and, based on the level of variance, grouped it according to Upper Limb Injuries, Lower Limb Injuries, Lower Back Pain, CVA, Arthritis, Traumatic Brain Injuries, Developmental Delay and Spinal Cord Injuries. Upper Limb injuries and Lower Limb Injuries included fractures; nerve palsy due to injuries, for example stabs. Arthritis included Osteoarthritis and Rheumatoid Arthritis, mostly of the knee. The five most common conditions were Upper Limb Injuries, Lower Limb Injuries, Lower Back Pain, CVA, Arthritis. Conditions that were not included were Traumatic Brain Injuries, Developmental Delay and Spinal Cord Injuries.

3.5.4 Sampling process

Every consecutive patient with one of the five most prevalent conditions was eligible for participation in the study. The patients were approached and an information session has

been given to them. Only once written consent was given were they included as participants in the study.

A total of 72 participants were recruited of which four were incorrectly enrolled.

3.6 Data Collection Procedure

A fieldworker was recruited on recommendation from the health facility. The fieldworker had a matric qualification, was resident in the drainage area and was familiar with the health facility.

The fieldworker was trained on the following:

an overview of research project;

the various outcome measures that had to be used

an orientation on research which included the importance of obtaining informed consent, data management, confidentiality and the management of appointments.

The researcher observed the fieldworker after the training to ensure that she was competent in the correct completion of the data collection tools. Telephonic support was offered when clarification was required. In addition, the researcher had fortnightly contact sessions with the fieldworker to check completeness, get feedback on progress, to discuss questions of clarity and provide general support.

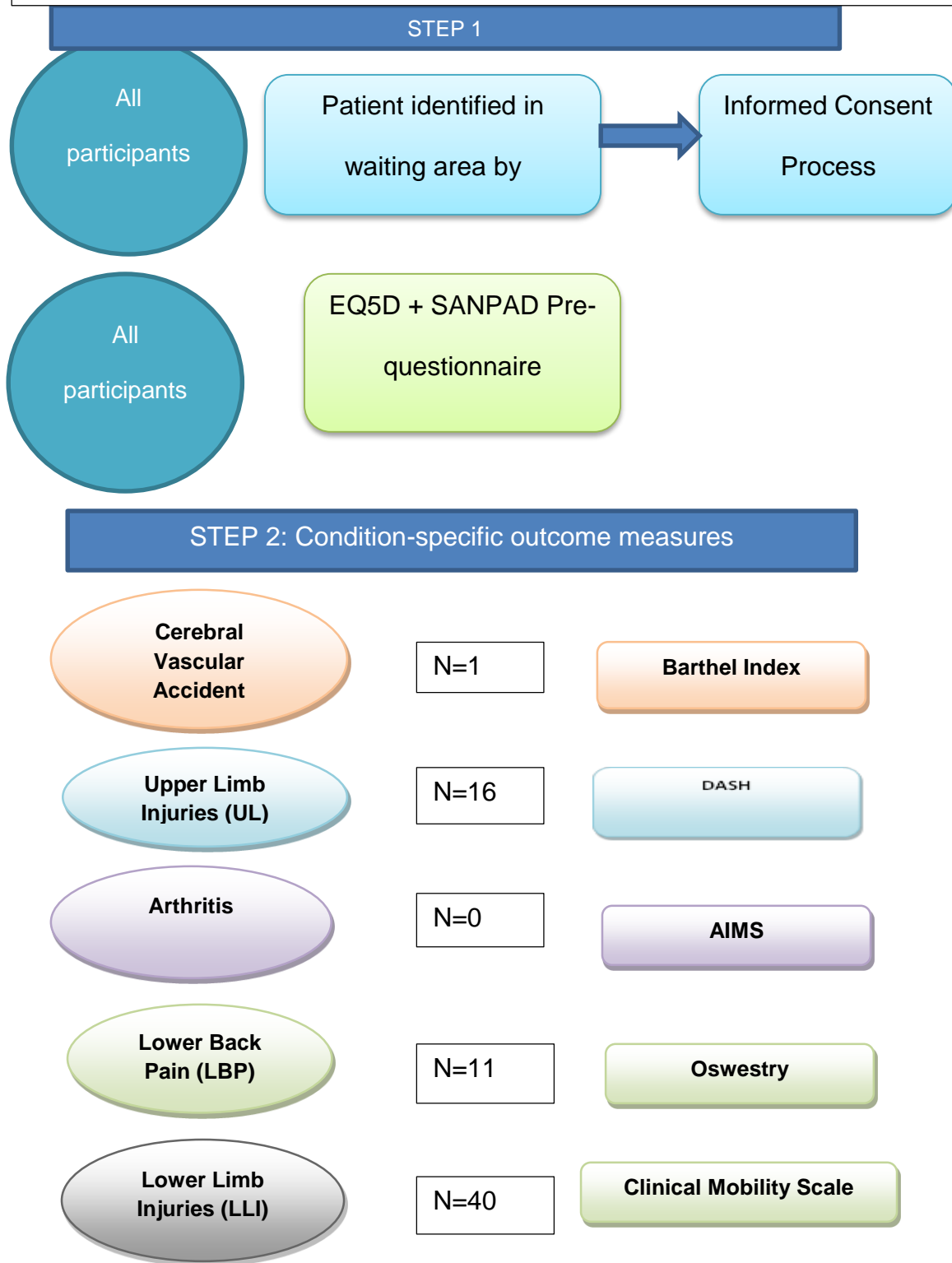
Initially, the physiotherapist would book the patients for the fieldworker once the referral had been received. Operational implications, however, resulted in a change of the process. After redesigning the process flow with the therapist, the fieldworker subsequently recruited the patients in the waiting area at the physiotherapy department on a daily basis. She ensured that only first time patients were recruited, then confirmed

the condition and eligibility with the physiotherapist. The fieldworker confirmed whether the diagnosis formed part of the five most prevalent conditions. Once this was confirmed, the participants underwent an informed consent process and an interview of about 45-minutes to an hour during which various instruments were applied to gather the information required for the study.

The interviews were held in an office located within the rehabilitation area of the CHC. The office allowed for the interview to take place in an uninterrupted fashion as there were low noise levels. The room was well-lit and access to the tools was easy. The same room was used for pre- and post-testing except where patients did not return to the rehabilitation service. The participants were then followed up through a home-visit and were then interviewed in the home setting.

The outcome measures included standardized and self-developed measures to determine outcomes at activity, participation and environmental levels. The self-developed outcome measures were used for all participants as well as the EQ5D which is a standardised tool. The rest of the standardised outcome measures were only applicable on the condition of the patient. The diagram (Figure 3.2) depicts the application of outcome measures during the data collection phase.

FIGURE 3.2: DESCRIPTION OF APPLICATION OF OUTCOME MEASURES DURING DATA COLLECTION



STEP 3: Medical Records Review

For all Participants

STEP 4: EQ5D + SANPAD Post Questionnaire + Step 2 repeated - condition-specific outcome measures completed.

3.7 Data Collection Outcome measures

The study formed part of a bigger SANPAD-funded study. Due to the collaborative nature of the study, the tool development process as well as decision on the choice of standardized outcome measures was done in collaboration with the researchers linked to the three other research sites within the Western Cape.

The reliability and validity of outcome measures, especially the self-developed outcome measures, were dealt with by a panel of rehabilitation experts. The panel looked at the content to ensure that it linked strongly to the ICF, thereby measuring activity, bodily functions and structures as well as activity and participation.

3.7.1 Self-developed outcome measures

These outcome measures were developed with the ICF as a conceptual model. During the development phase of the outcome measures, the CBR Guidelines were used to ensure alignment to the main focus areas, for example access to transport and citizenship. This expert group ensured the inclusion of potential environmental barriers and facilitators that influenced rehabilitation outcomes. Whilst the majority of the tools were outcomes-based and focused on functional ability (activity limitations and

participation restrictions) the medical records review captured the level of impairment at the initiation of the rehabilitation process.

3.7.1.1 SANPAD Questionnaire 1 [Pre-Questionnaire] (Addendum A)

This questionnaire enabled the researcher to obtain information on the following areas:

a) personal information focusing on medical history and rehabilitation history as well as some demographic specifics such as race, gender and educational history; b) Income; c) Transport; d) Assistance; e) Habitat which focuses on the home environment; f) Community involvement to ascertain to what extent the patient is active in community activities; and lastly, g) Research to ascertain whether the patient has been involved in any other research before this project.

3.7.1.2 SANPAD Questionnaire 2 [Post-Questionnaire] (Addendum B)

This questionnaire was administered either on discharge or on follow-up after three- to four-months post initial assessment. It enabled the researcher to gather information about the patients' current status, i.e. either on discharge or follow-up. The information obtained included sources of income, accessibility, community involvement, uptake of referral services such as rehabilitation professionals, home-based care, etc., as well as environmental factors which might have influenced compliance with rehabilitation, for example access to transport.

3.7.1.3 Medical Records Review Tool (Addendum C)

This was a self-developed tool, developed by the SANPAD-group. The tool was required to assess to what extent impairment was present at the onset of the study. The tool had to take into consideration the bodily functions and structures in an appropriate manner to ensure that all conditions included in the broader study would be addressed. The tool

is a detailed tool. It includes the following nine sections: Stroke, Spinal Cord Injuries, Traumatic Brain Injury, Peripheral Neuropathy, Back Pain, Arthritis, Developmental Delay, Lower Limbs and Upper Limbs. Each of the sections includes relevant elements such as Range of Motion (ROM); Pain, Sensation, Muscle Power, Balance and Cognitive Functions. As mentioned, only the relevant sections were used for the purpose of this study.

All three self-developed outcome measures were piloted by the wider SANPAD group who acted as a panel of rehabilitation specialists. These outcome measures were discussed at length prior to the pilot at Bishop Lavis Rehabilitation Centre and after the pilot period minor adjustments were made. After finalization, the outcome measures were translated and back-translated by the University of the Western Cape's Language Centre, thereby ensuring that the outcome measures remained valid after translation.

3.7.2 Standardised outcome measures

All standardized outcome measures were identified by means of literature reviews. The appropriateness was driven by the conditions prevalent at the various sites. In the case of this study, the outcome measures had to be appropriate for measuring rehabilitation outcomes in the following conditions: 1) Lower back pain; 2) Strokes; 3) Arthritis; 4) Lower limb injuries and 5) Upper limb injuries.

Table 3.1 summarizes the outcome measures linked to the five most prevalent conditions at Gugulethu Community Health Centre.

CONDITION	TOOL
Lower back pain	Oswestry
Strokes	Barthel Index
Arthritis	AIMS (Arthritis Impact Measure)
Lower Limb Injuries	Clinical Mobility Scale
Upper Limb Injuries	DASH (Disability of the Arm, Shoulder and Hand)

Table 3.1: SUMMARY OF STANDARDISED OUTCOME MEASURES

Each tool will be discussed in terms of purpose, developers, general applicability, reliability and validity as well as its link to the ICF. Table 3.2 depicts which domain of the ICF will be covered in each of the standardized outcome measures.

TOOL	APPLICATION		
	IMPAIRMENT	ACTIVITY	PARTICIPATION
BARTHEL	0	X	0
AIMS	X	X	X
CLINICAL MOBILITY	0	X	X (LIMITED)
OSWESTRY	X	X	X
DASH	X	X	X

Table3.2: DESCRIPTION OF TOOL LINK TO ICF

3.7.2.1. Barthel Index (Addendum D)

This tool was developed in the 1960's by Mahoney and Barthel. It was used for the measurement of functional independence in personal care and mobility. The tool is a 10-item performance-based tool that measures activities of daily living (ADL's) The Barthel Index had subsequently been used for the measurement of treatment outcomes as part of pre- and post-evaluation of patients (Cole, et al; 1995). The tool can be used

for individuals with stroke, spinal cord, neurological conditions, burns, cardiac problems, rheumatoid arthritis and elderly people.

The tool is widely applied for both clinical and research purposes. Reliability and validity as described by Cole is high, with inter-rater reliability for chart reviews at 89% (Cole, et al; 1995). Cole also describes physical assessments of stroke patients indicated an inter-rater reliability of more than 95% and content validity as high, as the evaluation includes most functions of ADL's.

For the purpose of this study the tool was applied with participants who had suffered strokes. It links to the ICF in terms of activities and participation

3.7.2.2 Oswestry Low Back Pain Disability Questionnaire (Addendum E)

The tool was developed with the aim to assess the level of functional independence of individuals with low back pain. It was developed by Fairbank, Couper, Davies and O'Brien (Cole, 1995). This is a 10-item questionnaire where each item is scored on a 6-point scale rated from 0 to 5. The final score is represented as a percentage. Higher scores represent more disability. The following ten areas of ADL's are covered, namely pain, personal care, lifting, walking, standing, sitting, sleeping, sex life, social life and travelling. The tool can be used in the following patient groups: acute, sub-acute and chronic back pain; various conservative, surgical and behavioural intervention groups.

The Oswestry has been applied for screening, treatment planning, and evaluation. In addition it is also used as an outcome measure for research purposes (Fairbank, J.; Pynsent, B; 2000). Good internal consistency was reported with test-retest reliability reported as excellent. Cole describes the content validity as "fair-poor" as the initial

intent was to assess disability yet its primary aim is to address disability based on pain (Cole, et al; 1995).

The tool links to the ICF in terms of bodily structure and functions, activities and participation.

3.7.2.3 DASH (Addendum F)

The DASH (**Disabilities of the Arm, Shoulder and Hand**) Outcome Measure was developed by the Institute for Work and Health in Toronto and the American Academy for Orthopaedic Surgeons in Illinois. (Finch, et al, 1998) It is a 30-item, self-report questionnaire designed to “...quantify symptoms and disability among individuals with upper extremity, musculoskeletal disorders and to evaluate changes over time.”(Finch, et al, 1998)

The tool can be applied to all adults with wrist/hand, elbow and shoulder disorders, with psoriatic arthritis and cumulative trauma disorder. For the purpose of this study the tool will be applied to any upper extremity disorder reported. The tool provides clinicians and researchers with the advantage of having a single, reliable instrument that can be applied to assess any or all joints in the upper extremity.

The tool is valid, reliable and responsive and can be used for clinical and/or research purposes (www.dash.iwh.on.ca.htm). The DASH links to the ICF in terms of bodily functions and structures, activities as well as participation.

3.7.2.4 Clinical Mobility Scale (Addendum G)

The Clinical Mobility Scale’s purpose is to measure a person’s degree of functional mobility over time. It focuses on the following parameters: a) upright posture; b) walking; c) gait; d) sitting; e) stair climbing; f) hand-held appliances; g) wheelchair; h) time usage.

Each parameter is measured in one of four possible responses depending on the patient's level of independence. The tool links with the ICF in terms of activities and participation. There is very limited information available on the Clinical Mobility Scale in terms of reliability and validity.

3.7.2.5 Arthritis Impact Measurement Scale (Addendum G)

The Arthritis Impact Measurement Scale (AIMS) was developed by Meenan and Mason from the Boston University School of Public Health (Finch et al, 1998) Its purpose is to measure the health status component of outcomes in clients with rheumatic diseases and to compare health status across chronic disease groups. The AIMS were derived from two health status measures namely the Bush's Index of Well-being and the Rand Health Insurance Study batteries. This particular tool could be used as a self-report questionnaire. The following components are measured: mobility, physical activity, dexterity, household activities; activities of daily living; anxiety; depression; social activity and pain (Finch et al, 1998). The tool relates to the ICF in terms of body structure and functions, activities and participation.

3.7.2.6 EQ5D Health Questionnaire (Addendum H)

This is a self-administered questionnaire that enables a person to report on their health and functional status. It includes areas such as mobility; self-care; usual activities such as work, family life and leisure activities; pain/ discomfort; and anxiety. It also provides the person with a tool to compare their current status with that of a year ago. In addition, there is also a scale that the person can use to rate their health status experienced on the day. The tool also provides for some demographic information.

The EQ5D Xhosa version was tested for reliability and validity (Jelsma, Mkoka, Amosun & Nieuwveldt; 2003). The isi-Xhosa version of the tool was found to be valid and reliable even though an opportunity was identified to examine some of the domains further. (Jelsma, et al; 2003)

3.7.3 Pilot study

The pilot study was done in two phases. The first phase was to test user-friendliness of the self-developed tools, to ensure that the tool provides the necessary information that it was intended for, and lastly, to test availability of data.

The pilot study was at Bishop Lavis Rehabilitation Centre which is a community-based facility linked to the Community Health Centre. It offers similar services to the rehabilitation services at GCHC. The SANPAD group used this as a combined pilot opportunity to test applicability of tools in the setting. The pilot study was done amongst all the diagnostic groups and included 11 pre-tests and 10 post-tests. The purpose of the pilot was to determine the duration of the test, its cultural appropriateness, as well as clients' understanding of the questions. After the first phase of the pilot, the team of rehabilitation experts met to collate comments on the experience of data collection using the self-developed tools. The tools were adjusted slightly based on comments from the relevant team members. The following changes were made:

The demographic questionnaires (SANPAD Pre and SANPAD Post) content validity was ensured by changing the terminology which was misunderstood and misinterpreted by patients and fieldworkers who were unfamiliar with medical terminology. In addition, some inconsistencies were identified with the pre- and post-questionnaires. These were

changed to ensure that the options are identical in the pre-test as well as the post-test. This would improve comparability of data.

Any scientific terminology that complicated the understanding of the questionnaires was explained to the fieldworkers in layman's terms to ensure better understanding of the concepts. An example is mobility.

The time taken to complete all the instruments was also measured to ascertain whether it would be a fair process in terms of time spent for research purposes. The total time spent during the pilot was less than an hour. The group decided that this would be feasible.

In addition to the technical pilot that focused on the tools, a pilot study was undertaken at the site, with the main purpose of assisting with the training and orientation of the fieldworker. By doing so, there was confirmation of the process flow for fieldworker. The fieldworker attended a training session where she was introduced to the overall aim and objectives of the study. She was then trained in the administration of each of the outcome measures and was provided with a role-play opportunity to apply her new knowledge. The first 10 cases were identified as pilot cases after which the researcher checked completeness of clinical research forms. These cases formed part of the main study.

3.8 Data Management and Analysis

3.8.1 Quality Control and Quality Assessment

The quality assessment process included training of the fieldworker regarding use of outcome measures, confidentiality and completeness of questionnaires. The researcher visited the fieldworker every two weeks to look at quality control of the data collection

process. At each visit a sample of completed questionnaire was taken. The fieldworker was advised on how to ensure that the tools were complete and correct.

3.8.2 Data management

All completed questionnaires were marked with a unique identifier that included the site as well as the number of patient enrolled. The unique identifier read “GUG 001” specifying it as Gugulethu case number 1. Questionnaires were batched per participant, then batched according to pre-or post-assessment. The pre- and post tests were stored in separate lockable concertina folders. The data were given to the researcher in these folders. During transport to the facility where data capturing was done, all data were kept safe and secure.

3.8.3 Data Capturing

Main study data were captured by a data-capturer who as employed via the SANPAD-funded study. Data capture sheets were developed on advice from statistician, ensuring that all outcome measures were included. The data-capturer used the database to capture the Gugulethu data into. He first captured all the pre-tests per batch. Each batch contained the pre-test outcome measures per participant. He then continued to capture the post-tests per batch meaning that once he completed the post-test batch of a participant, the data for that participant would be complete.

3.8.4 Data Analysis

A statistician was employed to do the data analysis thereby ensuring quality analysis. Descriptive statistics were used, looking at changes in patients’ functioning over time. The database that was completed by the data-capturer in the Microsoft Excel

programme was provided to the statistician. The data were merged and was named the complete merged data set.

The merged dataset was provided to the researcher to do data cleansing. All unclear areas were clarified, areas where there was no data deleted where appropriate and areas where there was limited data were clarified with a note. Once the data were cleansed, it was forwarded to the Statistician. The new version of the data set was renamed and the new date was included in the name of the dataset.

The statistician exported the dataset into the statistical programme called STATISTICA version 1, which is a programme used for data analysis. [StatSoft Inc. (2013) STATISTICA (data analysis software system), www.statsoft.com.].

Summary statistics were used to describe the variables. Distribution of variables is represented with histograms and or frequency tables. Medians or means used are the measure of central location for ordinal and continuous responses; and standard deviations and quartiles as indicators of spread.

Within STATISTICA the data were analysed for each of the standardized tests by means of the Wilcoxon Rank Sum Test, which is used to test for the difference between two samples or repeated measures.

<http://www.stat.ufl.edu/~ssaha/3024/CHAPTER14Examples.pdf> (downloaded on 20/09/2013 11:32 am)

The bootstrap test was applied in the analysis of sub-totals for activity limitations, participation restrictions and impairment in each of the outcome measures. This test was applied in addition to the Wilcoxon Rank Sum test to deepen the significance of the results (Johnson, 2001).

For all tests applied, a p-value of $p < 0.05$ represents statistical significance in the hypothesis testing and 95% confidence intervals will be used to describe the estimation of unknown parameters. P values will be rounded to the second decimal. Percentage values are rounded to the nearest percentage point.

3.9 Ethical Considerations

The study has been approved the Health Ethics Committee of the University of Stellenbosch (Addendum I). In addition, the Department of Health also approved the study as it was performed at a provincial health facility, thereby approving access to the facility, patient records, as well as patients. (Addendum J)

Information sessions about the study were conducted in the waiting area of the physiotherapy department. The information session included aims and objectives of the study as well as the role of the patient in the project. Patients were invited to participate and informed consent was obtained in cases where patients indicated their interest and willingness. Patients were also informed of their right to exit from the research project. Once informed consent was obtained, the participant would be interviewed on a one-on-one basis in an office that ensured confidentiality.

All information was dealt with confidentially, hence the use of alphanumerical codes. A master list was used to enable tracking of patients to alphanumerical codes for future work and follow-up. Patient folders were used on the premises to extract data from the folder. No information was copied or removed from the files.

3.10 Reporting of Results

As part of the ethical basis of the research process all participants, including the health management and service providers, were informed that they would be invited to a

feedback session once the study has been concluded and published. This will ensure that information is made accessible and the communities involved may use the information to their advantage.

The outcome of the research project may be published in a peer-reviewed journal, either as a stand-alone article or as a comparison of data and findings in similar settings. The data may also be presented at appropriate conferences.

CHAPTER 4

RESULTS

This chapter will provide a report of the results generated from the research study. The results will be presented in sub-sections according to the objectives of the study. With this in mind, this chapter will therefore be divided into four (4) main sections to ensure alignment to the reporting on the objectives.

Objective 1 will be discussed in Section 1 and Objective 2 will be discussed in Section 2. Discussion in Chapter 3 included a description in terms of the preparatory work of the type of conditions that were referred to rehabilitation services. Objective 3 was covered in the Methodology Chapter 3 and will therefore not be discussed in the results. Reference will; however, be made to the various outcome measures that were used when the outcome measures of objectives 4 & 5 are discussed. Objectives 4 and 5 will be reported on in a combined manner under Section 4.

4.1 Section 1

This section will focus on Objective 1 of the study:

“To determine the demographic profile of the rehabilitation clients attending Gugulethu Community Health Centre”

This section will include two parts:

Part 1 includes the description of the study cohort including general demographic information such as gender, age, marital status and socio-economic status.

Part 2 includes a description of the access to basic services the cohort reported experiencing namely waiting time to get an appointment at the rehabilitation service;

general access to transport to the health facility, including cost and waiting times; infrastructure and access to basic services, including to what extent the participants needed personal support. Community Involvement is an integral part of CBR hence the description included in this section. Recreational activities and participating in rights-based citizenship roles is also reported upon.

4.1.1 Part 1: Introduction to Cohort

The number of patients who were approached to participate in the study was 73 of whom 72 participants were consented. One (1) did not meet the inclusion criteria due to being diagnosed with a Traumatic Brain Injury. An additional four (4) participants were dis-enrolled where source documents were missing. The cohort that will be reported on is 68 cases. The results reported are on cases where participants responded to the particular questions

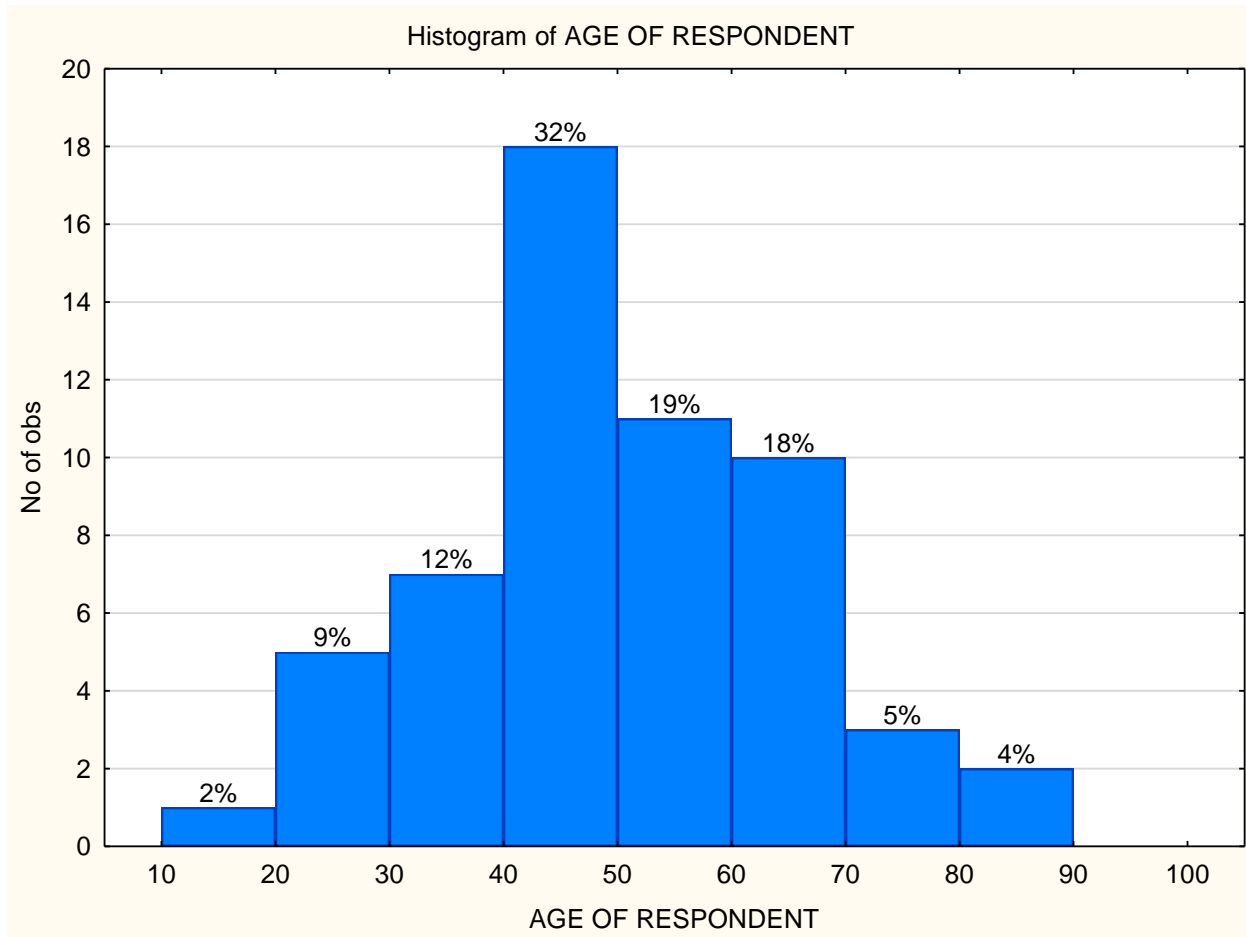
4.1.1.1. General demographics of participants

In terms of gender distribution, 62% (N=41) of participants were female and 38% (N=25) male and all (N=68) were of Christian faith. (Table 4.1)

TOTAL PARTICIPANTS	100%	COUNT (N)
MALE	38%	25
FEMALE	62%	41
CHRISTIAN	100%	68

TABLE 4.1: DEMOGRAPHIC DESCRIPTION OF COHORT

Figure 4.1 describes the age distribution of the cohort in more detail. The mean age is 49-years and 7-months, with the youngest being 20-years and the oldest being 84-years old.

FIGURE 4.1: DECRPTION OF AGE OF COHORT

4.1.1.2 Educational levels and Socio-economic Status

Sixty-two percent (N=42) of the participants had secondary level schooling; about 28% (N=19) had some form of primary level schooling, with 9% (N=6) having some form of tertiary level education. Only 1% (N=1) indicated they had no formal schooling background.

In terms of income levels, 75% (N=38) reported a monthly income between R1001 and R2000, 16% (N=8) reported an income between R2001 and R5000, only 4% (N=2) had an income between R5000 and R10 000, with about 6% (N=3) earning less than R1000.

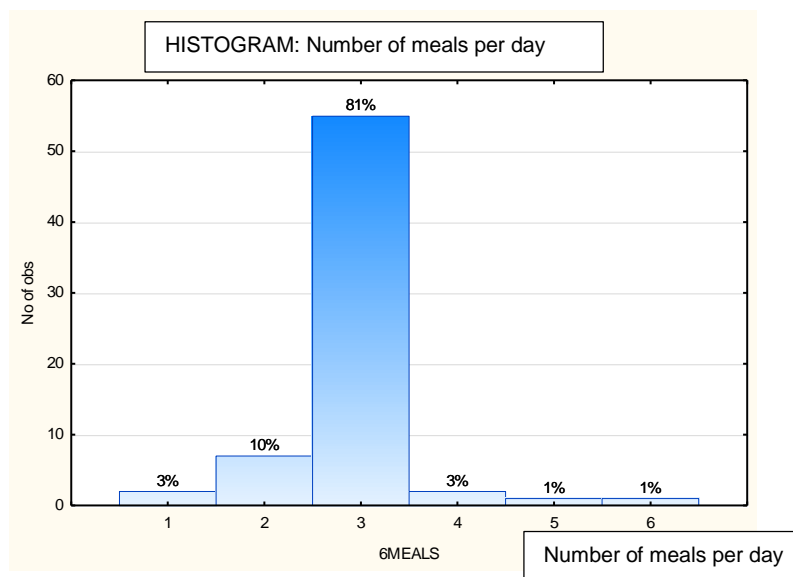
FREQUENCY TABLE: INCOME LEVELS				
INCOME CATEGORY	COUNT	CUMULATIVE COUNT	PERCENT	CUMULATIVE PERCENT
0	1	1	1.96	1.96
1	2	3	3.92	5.88
2	38	41	74.51	80.40
3	8	49	15.69	96.08
4	2	53	3.92	100

Key:0= No income; 1=R1-1000; 2= R1001-2000; 3=R2001-5000; 4= R10001-15000; 6=> R15 000)

TABLE 4.2: BREAKDOWN OF COHORT MONTHLY INCOME

The majority (81%) of participants, where N=55, reported that they had 3 meals per day; 10% (N=7) had 2 meals per day whereas two participants (3%) reported that they only had 1 meal per day. Four percent of participants (N=4) responded that they had between 4 and 6 meals per day. Figure 4.2 describes the status of food security within the cohort.

FIGURE 4.2: DESCRIPTION OF FOOD SECURITY

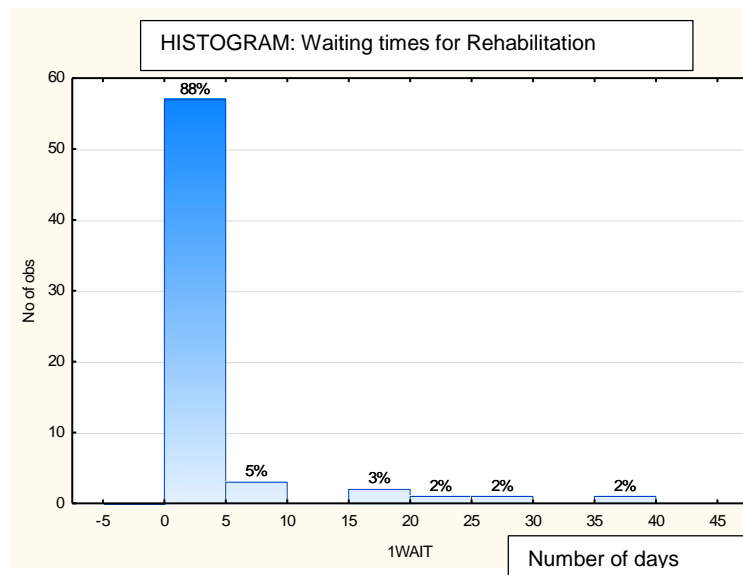


4.1.2 Part 2: Access to services

4.1.2.1. Waiting time

Participants' responses show that the majority (88%) where N=57, waited 0-5 days to get an appointment to rehabilitation services whereas 5% (N=2) waited 5-10 days and the rest between 15-30 days and 2% (N=2) waited 35-40 days.

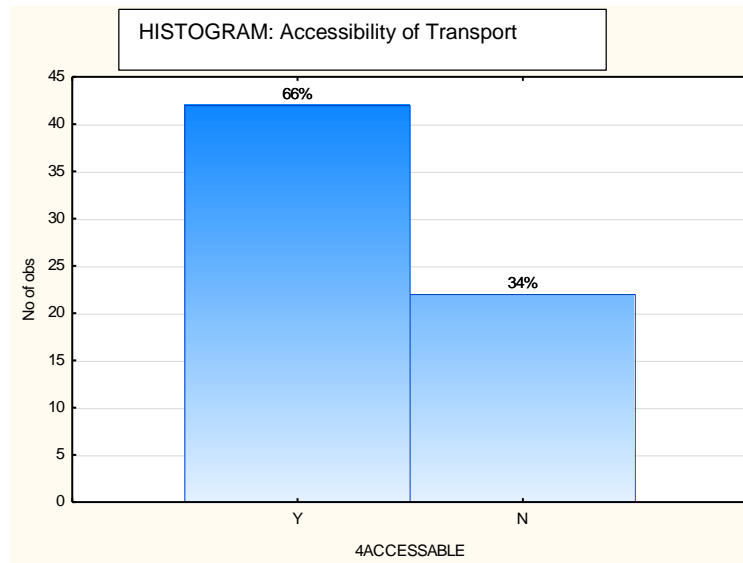
FIGURE 4.3: HISTOGRAM DEPICTING WAITING TIMES FOR REHABILITATION SERVICE



4.1.2.2 Transport

The majority (65%, where N=44) of the participants travelled by taxi, 22% (N=15) walked to the health facility and the rest (N=9; 14%) had other means of transport. In terms of whether transport was available at appropriate times, 84% (N=54) of the participants responded positively whilst 16% (N=10) reported that the transport was not available at appropriate time.

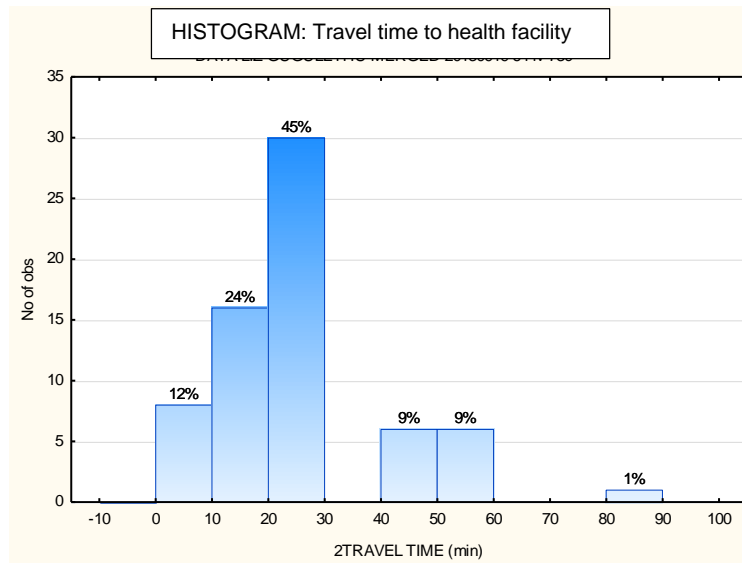
With regards to accessibility, 66% (N=42) reported that the transport was generally accessible while 34% (N=22) responded that the transport service was not accessible (refer to Figure 4.3).

FIGURE 4.4: HISTOGRAM DEPICTING ACCESSIBILITY OF TRANSPORT

As far as affordability is concerned, 52% of the participants (N=33) reported that the transport was not affordable whilst 48% (N=31) reported that it was affordable. The majority of the participants (95%, where N=61) reported that the transport service was sufficient whilst only 5% (N=3) reported that it was not sufficient.

As far as travel time to the health facility is concerned, there was a varied response, where 69% (N=46) of participants travelled between 10 and 30 minutes; 12% (N=7) travelled less than 10 minutes and 18% (N=12) travelled between 40 and 60 minutes (Figure 4.5). The participants (N=67), where one participant did not indicate travelling time, reported the mean travel time to be 29 minutes, the median 30 minutes and the minimum and maximum being five (5) and ninety (90) minutes respectively (Table 4.3).

FIGURE 4.5: HISTOGRAM OF TRAVEL TIME TO HEALTH FACILITY

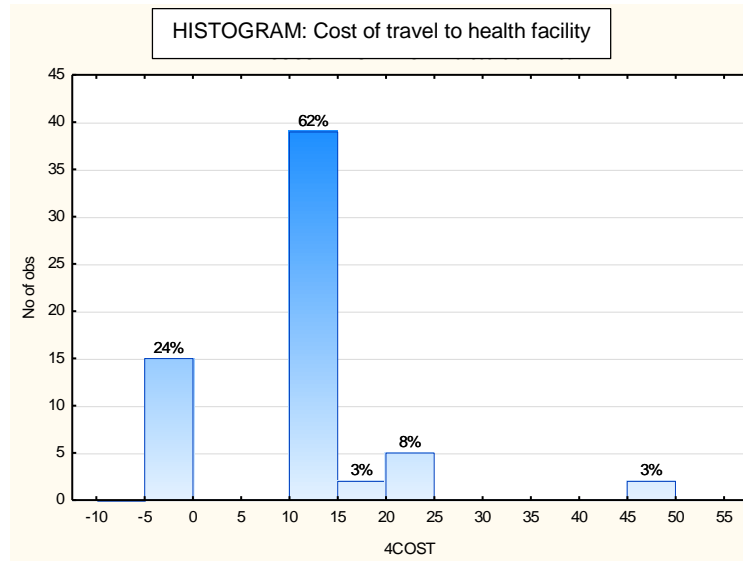


DESCRIPTIVE STATISTICS								
VARIABLE	VALID N	MEAN	MEDIAN	MINIMUM	MAXIMUM	LOWER QUANTILE	UPPER QUANTILE	STD DEVIATION
WAIT (DAYS)	65	3.79	1.43	0.112	40.00	0.29	4.00	7.12
TRAVEL TIME (MINUTES)	67	29.48	30.00	5.00	90.00	20.00	30.00	15.93
COST (RAND)	63	11.52	12.00	0.00	50.00	12.00	12.00	9.70

TABLE 4.3: DESCRIPTIVE STATISTICS OF WAITING TIME, TRAVEL TIME AND COST

4.1.2.3 Affordability

The cost of transport to the health facility was reported by participants as follows: 62% of participants (N=39) spend R10-15; 11% (N=7) spend between R15 and R25; 3% (N=2) spend R45-R50. The rest do not incur any transport expenses. The minimum spent is R0 with the maximum being R50, with the mean R11, 50 (Refer to Table 4.4 and Figure 4.6).

FIGURE 4.6: BREAKDOWN OF COST TO TRAVEL TO HEALTH FACILITY

4.1.2.4 Infrastructure and basic services

The participants (N=68) reported that stairs inside and outside their houses posed minimal access challenges: 96% (N=65) reported no stairs inside their homes whilst 75% (N=51) reported to have stairs outside their homes. In terms of access to running water inside their homes, 71% (48) responded positively. As far as access to electricity is concerned, 97% of participants, (where N=66) have access to electricity inside their homes and only 2 participants make use of alternative power sources namely, gas and paraffin.

About 93% of participants (N=63) have access to either a cellular phone or a home telephone line. Regarding access to toilet facilities, 94% (N=63) had access to a flush toilet inside their home whilst only 6% (N=4) reported access to outside toilet facilities.

Table 4.5 depicts the cohort's home infrastructure and their access to basic services.

SERVICE	COUNT YES	YES (%)	COUNT NO	NO (%)
STAIRS INSIDE	3	4	65	96
STAIRS OUTSIDE	17	25	51	75
WATER	48	71	20	29
PHONE	63	93	5	7
TOILET	63	94	4	6
ELECTRICITY	66	97	2	3
PARIFFIN	1	1	67	99
GAS	1	1	67	99
OTHER POWER SOURCES (SOLAR, GENERATOR, OTHER)	0	0	68	100

TABLE 4.5: DESCRIPTION OF INFRASTRUCTURE AND ACCESS TO BASIC SERVICES

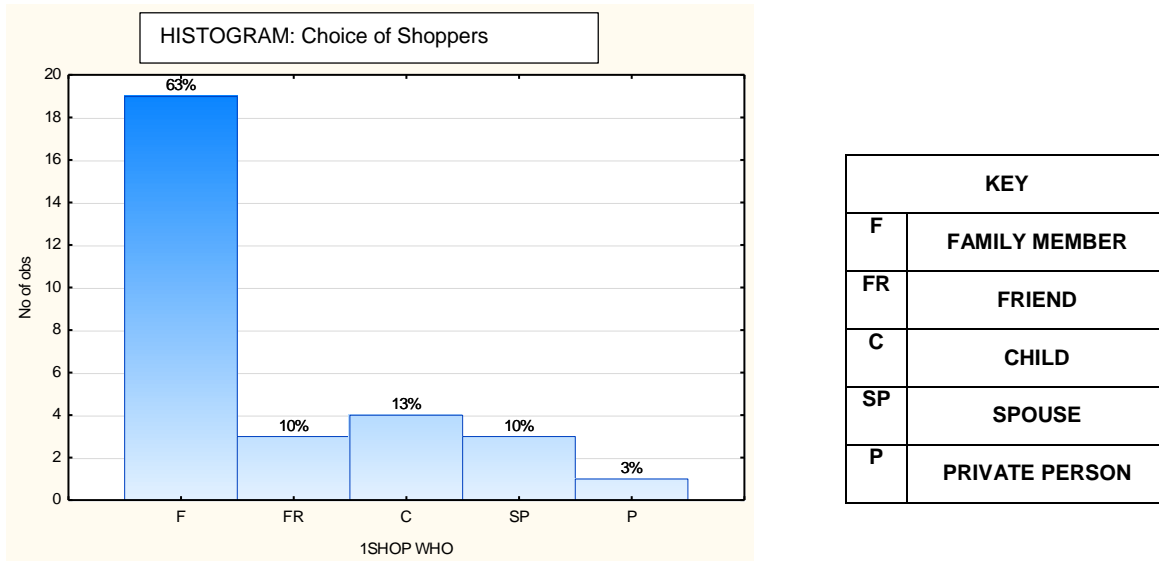
4.1.2.5 Assistance

More than half (55%) of the participants reported that they have some assistance at home whilst less than half (45%) indicated that they had none. Most of the participants (96%) reported that they did not pay those who assisted them at home whilst 4% indicated that they remunerated their assistants.

4.1.2.6 Community Involvement

More than half (N=37; 55%) of the participants indicated that they did their own shopping, whilst 45% (N=30) did not. Of the latter, 63% (N=19) would have their other family members do their shopping for them; 13% (N=4) had their children assist in shopping and 10% (N=3) their spouse. Friends and Private Person rated 10% (N=3) and 3% (N=1) respectively. Figure 4.7 depicts the description of choice of shoppers as a histogram.

FIGURE 4.7: DESCRIPTION OF CHOICE OF SHOPPERS



4.1.2.7 Recreational Activities

The majority of participants (N=48; 71%) indicated that they participate in recreational activities whilst the rest (N=20; 29%) did not. The recreational activities of choice include Community Hall Activities and Church Activities (both at 77%; N=37) whilst the majority (N=45; 94%) watched television as a recreational option. Table 4.6 provides detail of the description of the cohort’s participation in recreational activities.

RECREATIONAL ACTIVITY	COUNT YES	YES (%)	COUNT NO	NO (%)
Sport	2	4	46	96
Community Hall activities	37	77	11	23
Hobbies	9	19	39	81
Church Activities	37	77	11	23
Theatre	0	0	48	100
Watching Television	45	94	3	6
Volunteering	1	2	47	98
Other	1	2	47	98

TABLE 4.6: DESCRIPTION OF PARTICIPATION IN RECREATIONAL ACTIVITIES

The participants who indicated that they did not participate in recreational activities did not report reasons why they did not.

4.1.2.8 Rights-based knowledge and citizenship

Only one quarter of participants, where 25% (N=13) were aware that there was a health committee in the area and 9% (N=5) reported that they participated actively in the committee's activities. Almost 60% of participants (N=31) were not aware that they could complain about health services they received. Table 4.7 provides a breakdown of aspects regarding citizenship.

DESCRIPTOR	COUNT YES	YES (%)	COUNT NO	NO (%)
KNOWLEDGE ABOUT HEALTH COMMITTEE	13	25	40	75
PARTICIPATION IN HEALTH COMMITTEE	5	9	48	91
AWARE OF RIGHT TO COMPLAIN	22	42	31	58

TABLE 4.7: DESCRIPTION OF COHORT'S RIGHTS-BASED KNOWLEDGE

4.1.2.9 Research

Only 18% of participants (N=55) indicated that they have participated in research before.

4.2 Section 2

In this section of the results chapter, the cohort will be described generally in terms of their medical condition, its causes and participants' risk factor profile.

4.2.1 The most prevalent conditions

The distribution of cases according to diagnostic categories is described in table 4.8.

59% of the cohort (N=40) had Lower Limb injuries, close to 24% Upper Limb injuries (N=16), 16% Lower Back Pain (N=11) and 1% with CVA (N=1).

FREQUENCY TABLE: DIAGNOSTIC GROUP QPP				
CATEGORY	COUNT	CUMULATIVE COUNT	PERCENT	CUMULATIVE PERCENT
LL	40	40	58.82	58.82
LBP	11	51	16.18	75.00
UL	16	67	23.53	98.53
CVA	1	68	1.47	100

TABLE 4.8: BREAKDOWN OF CO-HORT PER DIAGNOSTIC GROUP

4.2.2 Causes

The vast majority of participants N=48 reported the cause of their condition as traumatic whilst other participants N=21 reported causes to be of a chronic nature (Table 4.9). One participant reported two causes but by the time of data capturing no determination could be made regarding the primary cause so both were recorded as such.

CAUSES	COUNT YES	YES (%)	COUNT NO	NO (%)
Trauma	48	72	19	28
Chronic	21	31	46	69
Congenital	0	0	67	100
Unknown	0	0	67	100

TABLE 4.9: BREAKDOWN OF CAUSES

4.2.3 Risk factors

Most of the participants reported that they did not participate in high-risk behaviour. Ninety-nine percent (99%) have never used drugs (N=67), 78% have never smoked (N=53) and 69% do not use alcohol (N=47). Table 4.10 describes the breakdown per risk factor.

RISK FACTORS	COUNT YES	YES (%)	COUNT NO	NO (%)
Smoking	15	22	53	78
Alcohol	21	31	47	69
Drugs	1	1	67	99

TABLE 4.10: DESCRIPTION OF RISK BEHAVIOUR

4.3 Section 3

This section will focus on the last two objectives of the study.

“To determine the functional status (activity limitations and participation restrictions) of clients on entry of rehabilitation services;

To determine the rehabilitation outcomes of the patients on discharge in terms of activity limitations and participation restrictions. ”

These two are reported on together in order to strengthen the comparison between the pre- and post- testing results.

In addition, the results of the condition-specific outcome measures will be reported. Thereafter, a breakdown of results will be presented per ICF domains, namely the total pre- and post-results as well as pre- and post-comparisons as they relate specifically to activity limitations, participation and impairments.

4.3.1 Measurement of Perceived Health Status: Eq5d Results

This is the only standardized tool that was used for the whole cohort of the study.

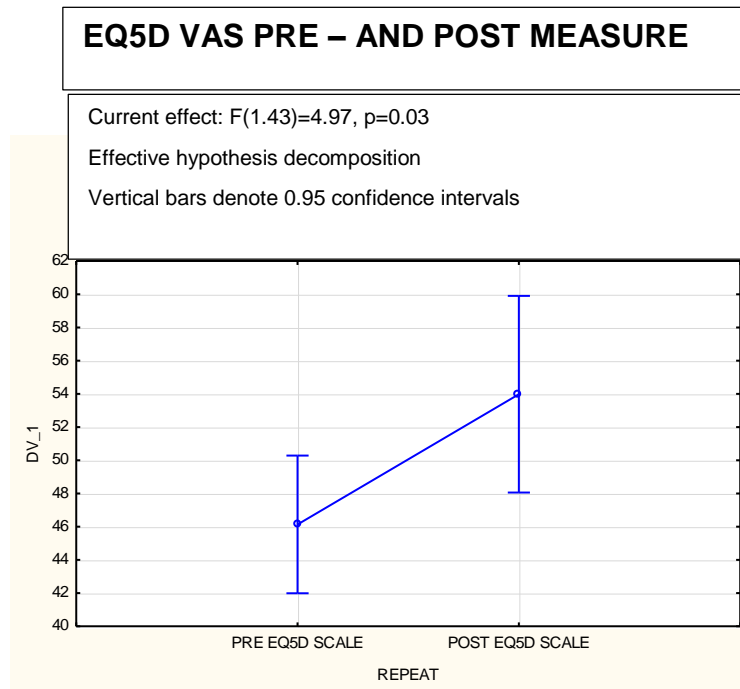
The tool also enabled the participants to rate their health state by use of a tool like a thermometer, called a Visual Analogue Scale (VAS) indicating health state from zero to 100 (0-100), with zero being your worst imaginable health state and 100 being the best imaginable health state.

A T-test was applied for dependent samples and this shows a significant improvement in the cohort's self-rated health state with a p-value of 0.03. (Refer to Table 4.11 and Figure 4.8):

REPEATED MEASURES ANALYSIS OF VARIANCE; STIGMA-RESTRICTED PARAMETERIZATION; EFFECTIVE HYPOTHESIS DECOMPOSITION					
EFFECT	SS	DEGREE OF FREEDOM	MS	F	p
Intercept	2220500.3	1	2205 00.3	751.77	0.00
Error	12612.2	43	293.3		
REPEAT	1352.6	1	1352. 6	4.97	0.03
Error	11709.9	43	272.3		

TABLE 4.11: REPEATED MEASURES ANALYSIS (EQ5D PRE AND POST)

FIGURE 4.8: ANOVA DESCRIPTION OF PRE-&POST EQ5D SCALE



The descriptive statistics for the pre- and post-VAS is detailed in Table 4.11

VARIABLE	DESCRIPTIVE STATISTICS							
	VALID N	MEAN	MEDIAN	MINIMUM	MAXIMUM	LOWER QUARTILE	UPPER QUARTILE	STD.DEV.
PRE VAS	58	45.4	50	10	80	40	55	15.93
POST VAS	52	53.2	60	0.0	100	40	67.5	19.9

TABLE 4.11: ANOVA REPEATED MEASURES ANALYSIS (EQ5D PRE AND POST)

The tool assessed the extent of the participants’ **activity limitations** as well as some **impairment** indicators. The activity domains tested included mobility, self-care and usual activities (work, study, family activities). Impairment domains included pain/discomfort and anxiety/depression. The elements such as mobility, self-care and usual activities will be described as activity limitations. Similarly the pain/discomfort and anxiety/depression will be described as impairment.

The analysis of data from the EQ5D indicates that there is no significant difference when one compares the pre- and post-test results specifically for the mobility, self-care and usual activities (Table 4.12)

RESPONSES TO THE DIFFERENT DIMENSIONS ON THE EQ5D

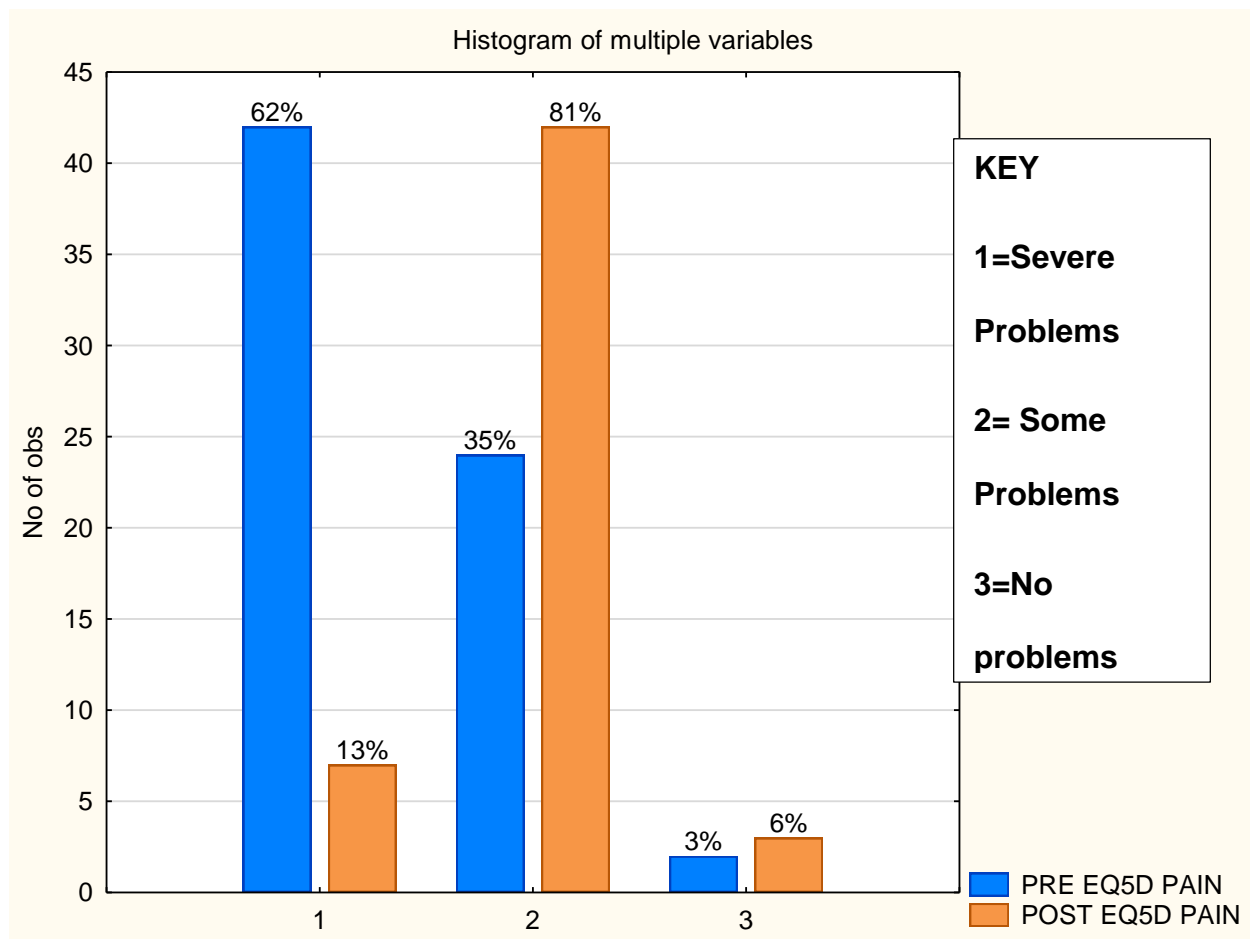
ELEMENT	DESCRIPTION	RESPONSES PRE		RESPONSES POST	
		FREQUENCY	%	FREQUENCY	%
MOBILITY	No Problems	15	22	5	15
	Some Problems	41	60.3	39	75
	Severe Problems	12	17.6	8	9.6
	Total	68		52	
	Chi-squared Value	4.7 $P=1.20$			
	Missing	5		21	
SELF-CARE	No Problems	13	19	13	25
	Some Problems	47	69	33	63.5
	Severe Problems	8	11.8	6	11.5
	Total	68		52	
	Chi-squared Value	6.2 $P=0.18$			
	Missing	5		21	
USUAL ACTIVITIES	No Problems	11	16	10	19
	Some Problems	46	67.7	39	75
	Severe Problems	11	16	3	5.8
	Total	68		52	
	Chi-squared Value	3.26 $P=0.51$			
	Missing	5		21	
PAIN/ DISCOMFORT	No Problems	2	3	3	5.8
	Some Problems	24	35.3	42	80.8
	Severe Problems	42	61.8	7	13.5
	Total	68		52	
	Chi-squared Value	6.68 $P=0.15$			
	Missing	5		21	
ANXIETY/ DEPRESSION	No Problems	6	8.8	3	5.8
	Some Problems	16	23.5	42	80.8
	Severe Problems	46	67.6	7	13.5
	Total	68		52	
	Chi-squared Value	2.78 $P=0.60$			
	Missing	5		21	

TABLE 4.11: RESPONSES TO THE DIFFERENT DIMENSIONS ON THE EQ5D PRE AND POST

The analysis of the data for the EQ5D with regard to the elements pertaining to Pain/Discomfort as well as Anxiety/Depression shows significant improvement in the self-reported health status in these elements. Figures 4.9 and 4.10 depict the responses in the pre- and post-tests.

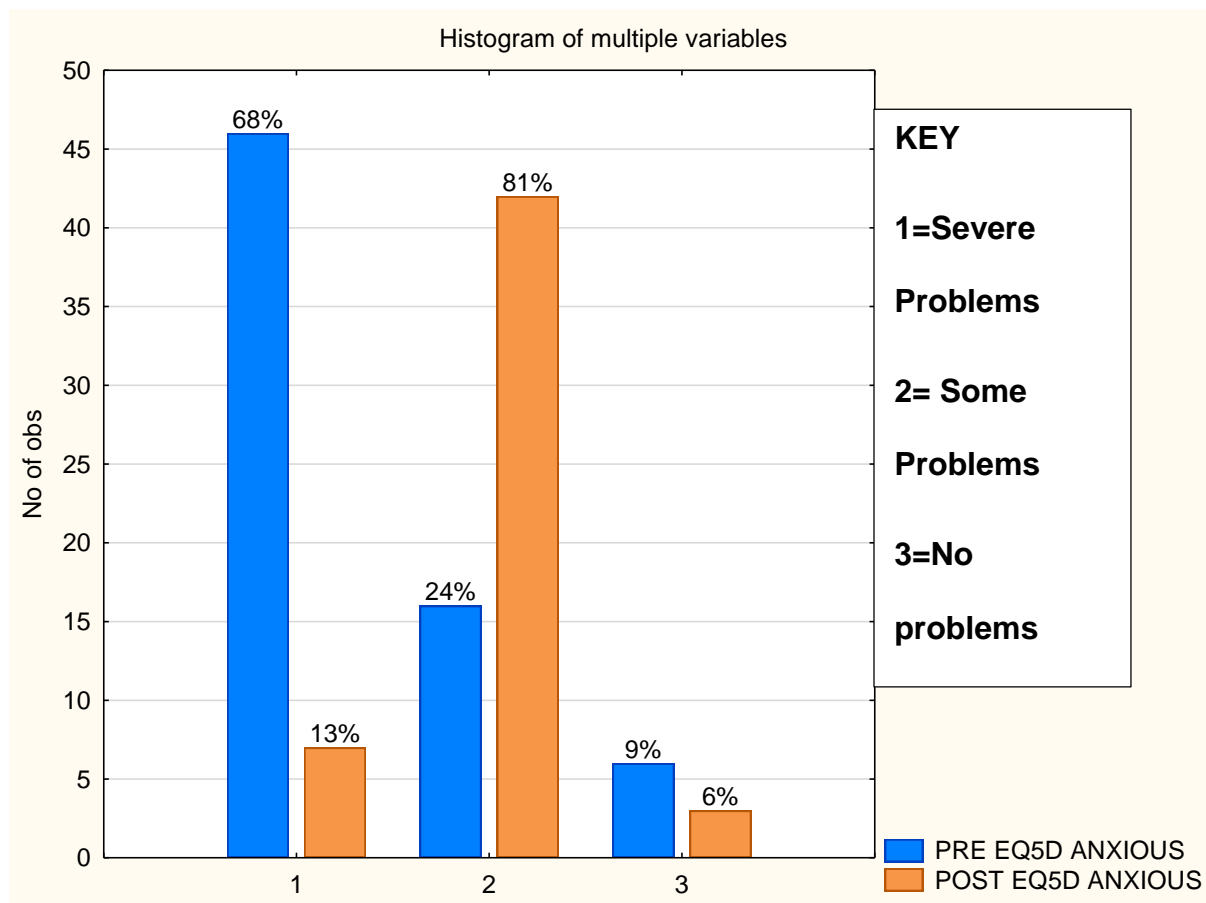
During the pre-tests 62% of participants described their level of pain/discomfort as a “severe problem” whereas only 13 % rated their pain/discomfort as “severe” during the post-tests. During the post-testing, significantly more (81%) reported that they have some problems. This indicates that the participants experienced significantly less pain and discomfort by the time that the post-test was administered.

FIGURE 4.9: DESCRIPTION OF PRE-&POST EQ5D SCALE: PAIN/DISCOMFORT



During the pre-tests 68% of participants described their level of anxiety/depression as a “severe problem” whereas only 13% rated their anxiety/depression as “severe” during the post-tests. During the post-testing, significantly more (81%) reported that they have some problems. This indicates that the participants experienced significantly less anxiety and depression by the time that the post-test was administered.

FIGURE 4.10: DESCRIPTION OF PRE-& POST EQ5D SCALE: ANXIETY/DEPRESSION



4.3.2 Measurement of Functional Ability as Affected by Injuries to the Lower Limbs: Clinical Mobility Scale Results

This instrument has seven (7) elements relating to the **activity** domain and one (1) to the **participation** domain. The analysis of data from the Clinical Mobility Scale (N=23) indicates a significant difference in **activity** levels prior to rehabilitation interventions as

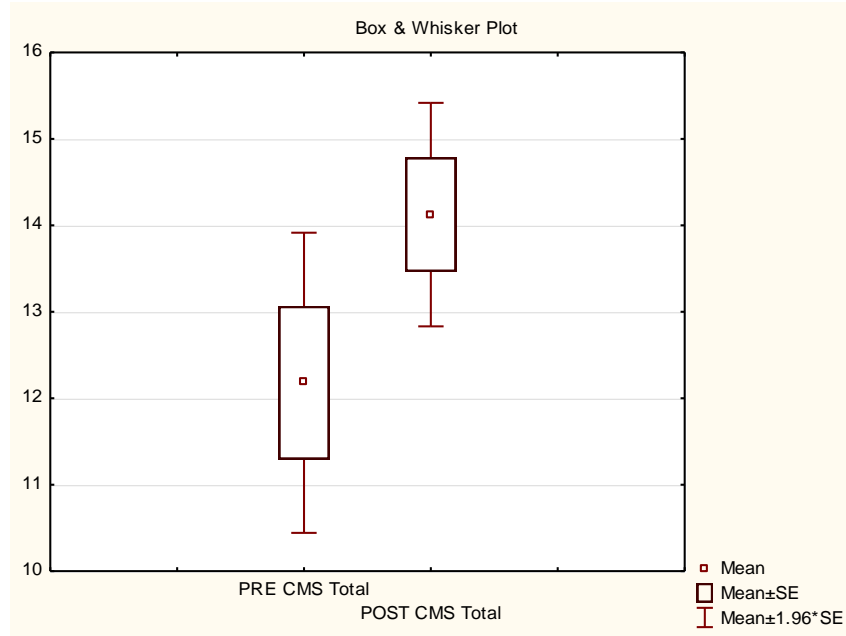
opposed to participants' activity levels when they were re-tested. The four activity domain elements, where a significant difference is shown, are **walking, gait, stair climbing and hand-held appliances**. There was no statistical significance in the comparison of the element related to **participation restrictions**. (Table 4.12 depicts the results of the CMS)

Descriptor	Domain	P value	Significance
Posture	Activity	0.06	NS
<i>Walking</i>	<i>Activity</i>	<i>0.02</i>	<i>Significant Difference</i>
<i>Gait</i>	<i>Activity</i>	<i>0.00</i>	<i>Significant Difference</i>
Sitting	Activity	0.16	NS
<i>Stair Climbing</i>	<i>Activity</i>	<i>0.01</i>	<i>Significant Difference</i>
<i>Hand-held Appliances</i>	<i>Activity</i>	<i>0.03</i>	<i>Significant Difference</i>
Wheelchair	Activity	0.73	NS
Time-usage	Participation	0.46	NS
<i>Total</i>		<i>0.02</i>	<i>Significant Difference</i>

TABLE 4.12: DESCRIPTION OF CLINICAL MOBILITY RESULTS

Figure 4.11 is a schematic representation of the mean of the population tested with the Clinical Mobility Scale. There is a significant difference in the pre- and post- test results.

FIGURE 4.11 BOX & WHISKER PLOT DEPICTING CMS PRE & POST TOTAL (MEAN)



4.3.3 Measurement of Functional Ability as Affected by Back Pain: Oswestry Results

The Oswestry has six (6) elements relating to the **activity** domain, one (1) to the **impairment** domain and three (3) related to the **participation** domain. The non-parametric comparison of the variables within the Oswestry as shown on Table 4.13 the following results:

Descriptor	Domain	P value	Significance
Pain	Impairment	0.14	Not Significant (NS)
Personal Care	Activity	0.42	Not Significant (NS)
Lifting	Activity	0.28	Not Significant (NS)
Walking	Activity	0.42	Not Significant (NS)
Sitting	Activity	0.11	Not Significant (NS)
Standing	Activity	0.69	Not Significant (NS)
Sleeping	Activity	0.20	Not Significant (NS)
Sex life	Participation	0.11	Not Significant (NS)
Social Life	Participation	0.04	Significant Difference (SD)
Travel	Participation	0.04	Significant Difference (SD)
Total		0.04	Significant Difference (SD)

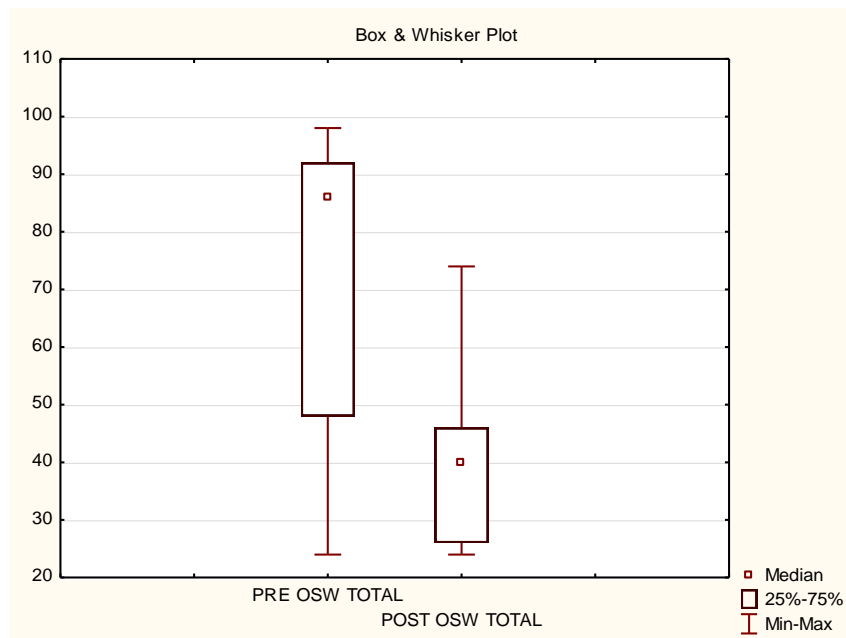
TABLE 4.13: DESCRIPTION OF OSWESTRY RESULTS

Table 4.13 demonstrates no significance in **impairment and activity** domains; however there was a significant difference in the results in the domains of **participation** namely social level and travel.

The application of the Box and Whisker Plot (Figure 4.12) depicts the **pre- and post-totals for the** Oswestry was applied. The p-value for both elements was 0.04 which indicates statistical significance.

FIGURE 4.12: BOX & WHISKER PLOT DEPICTING OSWESTRY PRE & POST TOTAL

Box & Whisker Plot



4.3.4 Measurement of Functional Ability, Social and Emotional Status: Dash Results (For Upper Limb Injuries)

This instrument has sixteen (16) elements relating to the **activity** domain, seven (7) to the **participation** domain and seven (7) to the **impairment** domain. Eight (8) additional elements were used for those employed and participating in Sports/Recreational Activities.

The non-parametric comparison of the variables within the DASH showed the following four (4) indicators pertaining to the **activity** domain being statistically significant:

‘push heavy door’;

‘garden /yard work’;

‘make bed’, and;

‘pull over sweater’.

In terms of the **participation** domain, there was a significant statistical difference in four of the seven (4/7) elements. These include:

‘recreational activities – requiring minimal effort’;

‘recreational activities – move arm freely’;

‘managing transport needs’; and;

‘sexual activities ‘.

As far as the **impairment** domain is concerned, one element showed a significant difference namely:

“tingling in arm, shoulder, hand”.

Table 4.14 depicts all the elements with the results as per the three domains within DASH.

Descriptor	Domain	P-value	Significance
Open Jar	Activity	0.16	NS
Write	Activity	0.02	NS
Use key	Activity	0.21	NS
Prepare a meal	Activity	0.05	NS
Push heavy door	Activity	0.04	Significant Difference (SD)
Place shelf above head	Activity	0.28	NS
Heavy Household chores	Activity	0.74	NS
Garden/yard work	Activity	0.03	Significant Difference (SD)
Make bed	Activity	0.03	Significant Difference (SD)
Carry shopping bag	Activity	0.50	NS
Carry heavy object	Activity	0.40	NS
Change overhead light bulb	Activity	0.35	NS
Wash/blow hair	Activity	0.18	NS

Wash back	Activity	0.12	NS
Pullover sweater	Activity	0.04	Significant Difference (SD)
Use knife-cut food	Activity	0.14	NS
Rec activities –little effort	Participation	0.01	Significant Difference (SD)
Rec activities – take some force/impact	Participation	0.05	NS
Rec activities – move arm freely	Participation	0.0	Significant Difference (SD)
Manage transportation needs	Participation	0.01	Significant Difference (SD)
Sexual activities	Participation	0.01	Significant Difference (SD)
Normal social activities	Participation	0.59	NS
Work activities	Participation	0.16	NS
Arm, shoulder or hand pain	Impairment	0.11	NS
Arm, shoulder or hand pain – performed activities	Impairment	0.07	NS
Tingling in arm, shoulder or hand	Impairment	0.02	Significant Difference (SD)
Weakness in arm, shoulder or hand	Impairment	0.14	NS
Stiffness in arm, shoulder or hand	Impairment	0.08	NS
Difficulty sleeping	Impairment	1.00	NS
Less capable, confident, useful	Impairment	0.37	NS
DASH Disability Score		0.05	Significant Difference (SD)

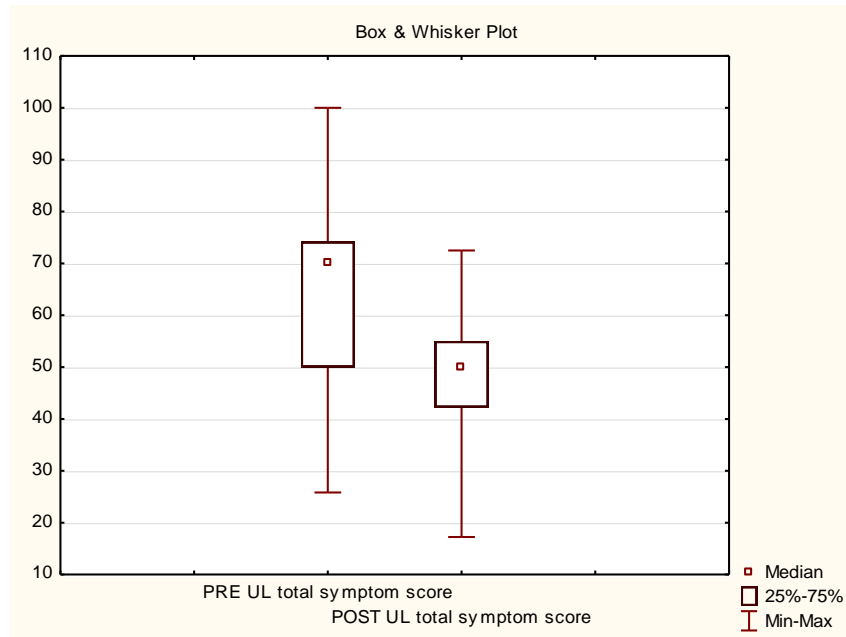
TABLE 4.14: DESCRIPTION OF DASH RESULTS

The eight additional elements applied to those working and **participating** in sports activities did not show any significant difference as only 2 to 3 participants responded in these elements.

The figure 4.13 represents the difference in **pre- and post-testing** for participants with upper limb injuries. The figure reflects the results totalled for the **activity, impairment and participation** domains.

FIGURE 4.13: DASH PRE & POST TOTAL

Box & Whisker Plot



4.3.5 Measurement of Physical, Social and Emotional Well-Being: Aims Results (For Arthritis)

A Nonparametric comparison of the variables within the AIMS showed that throughout the application of the AIMS no significant differences were identified in the twelve elements related to the **activity** domain, the six related to the **impairment** domain and the eight elements related to the **participation** domains. This can be attributed to the fact that only two participants were re-tested during the post-test phase.

4.3.6 Measurement of Functional Status In CVAs: Barthel Results

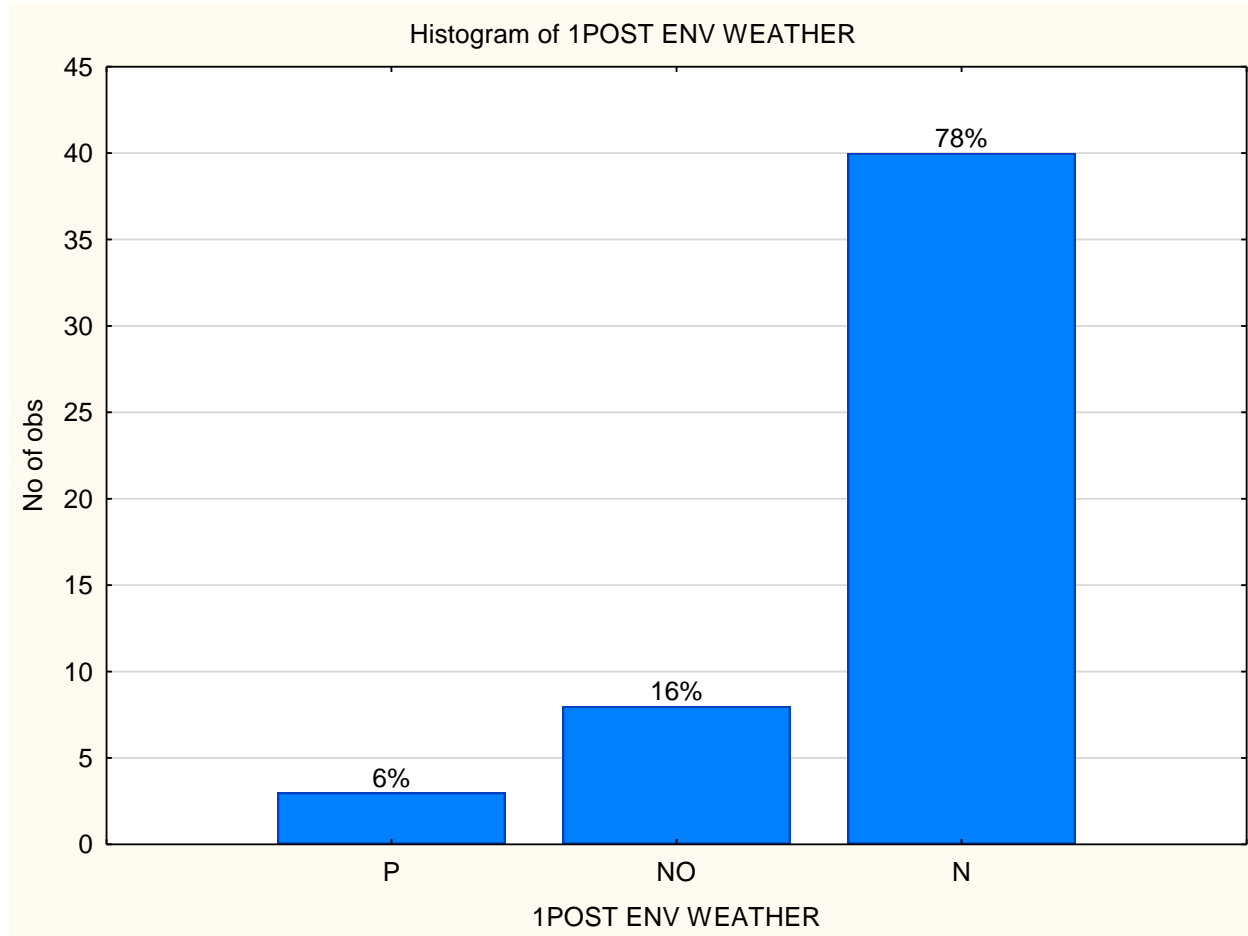
The comparison of pre- and post-test data proved challenging as there was only one person with a CVA and no post-test was performed on this participant.

4.3.7 Environmental Factors

In this section, the results of participants' reports on the extent to which certain environmental factors had an effect on their therapy are analysed. The SANPAD Post Questionnaire provided participants the option to rate which environmental factor influenced their therapy. There were three possible responses and included **Positive (P)**, **None (NO)** or **Negative (N)**. These descriptors will be used in the histograms that follow.

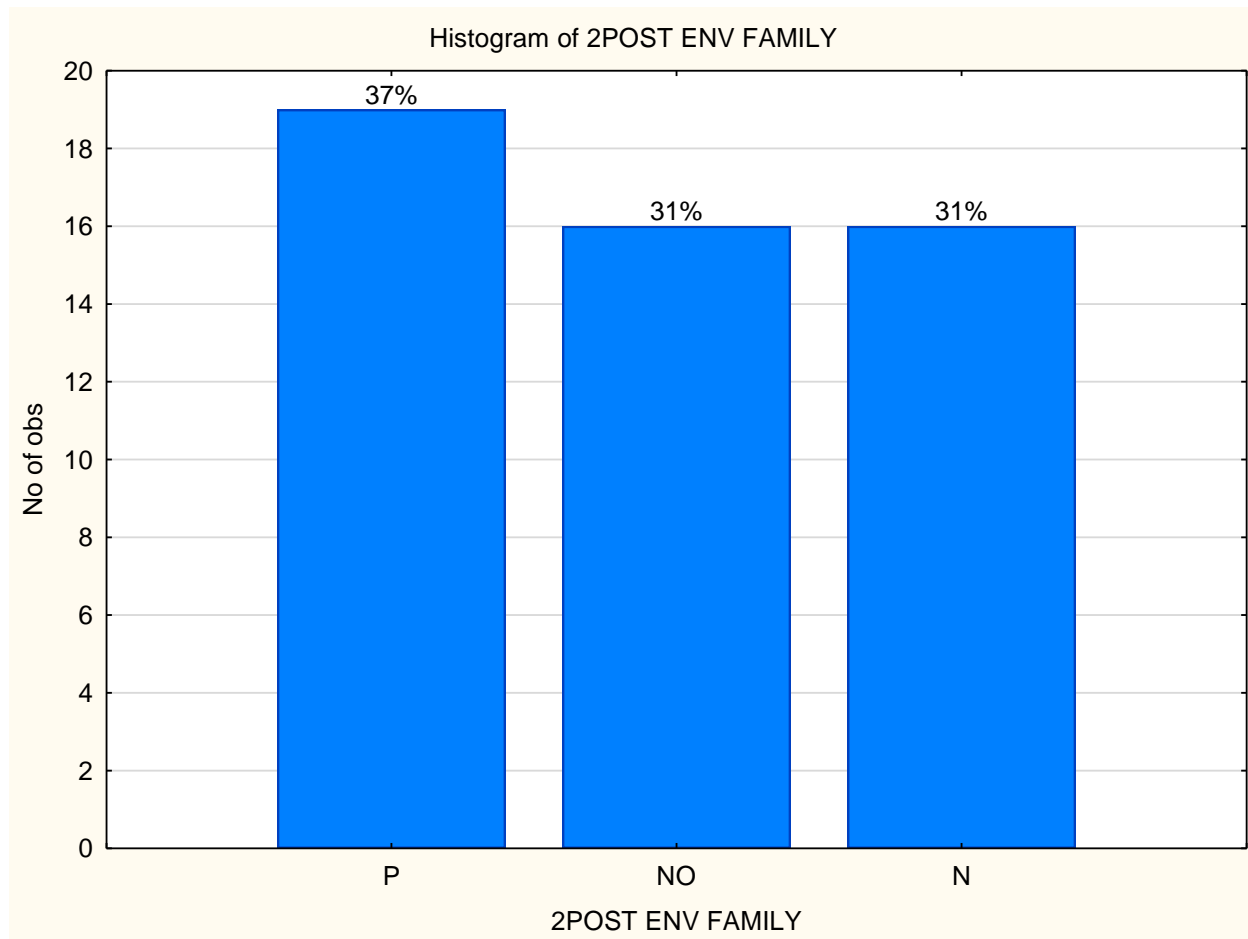
4.4.1 Weather

This environmental factor affected the participants negatively. The majority (78%) of these participants where N=51 indicated that the weather affected their therapy negatively. (Fig 4.14)

FIGURE 4.14: HISTOGRAM DEPICTING HOW WEATHER AFFECTED COHORT THERAPY

4.4.2 Family

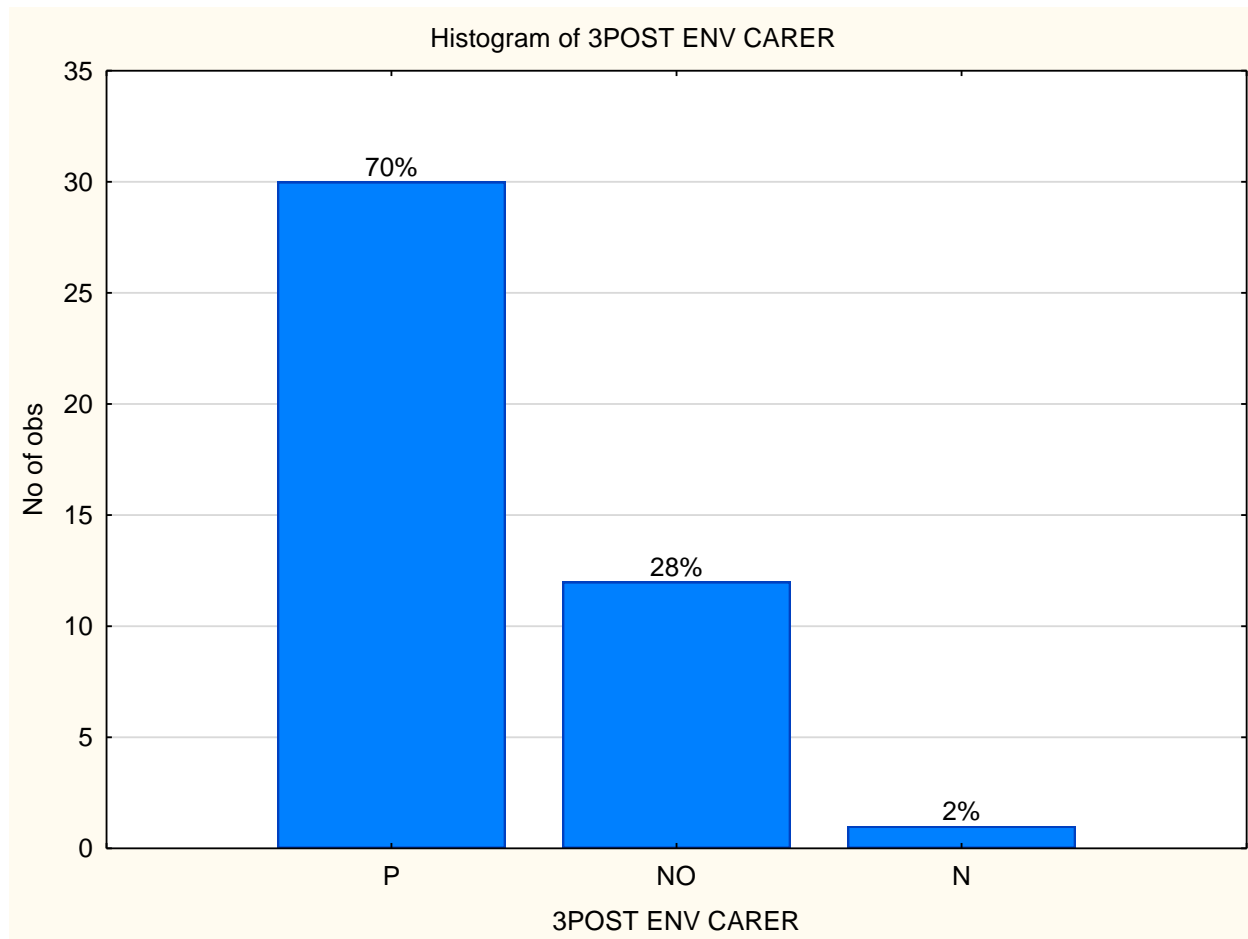
The responses to whether the family context had a positive, negative or no effect on their therapy were divided. Thirty-one percent responded that it had either a negative or no effect on their therapy whilst 37% felt that their family had a positive effect on their therapy. The histogram (Figure 4.15) depicts the cohort's response to how family affected their therapy.

FIGURE 4.15: HISTOGRAM DEPICTING HOW FAMILY AFFECTED COHORT'S THERAPY

4.4.3 Carer and Rehabilitation Professionals

The effect that the carer and rehabilitation professionals (namely the physiotherapist, occupational therapist and speech and language therapist) had on the cohort was divided.

The cohort responded that the carer, physiotherapist and occupational therapist had a very positive effect on their therapy. In Figure 4.16 the histogram depicts 70% of participants where N=43, reporting that the carer had a positive effect, 28% had no effect and 2 % reported that their carer had a negative effect on their therapy.

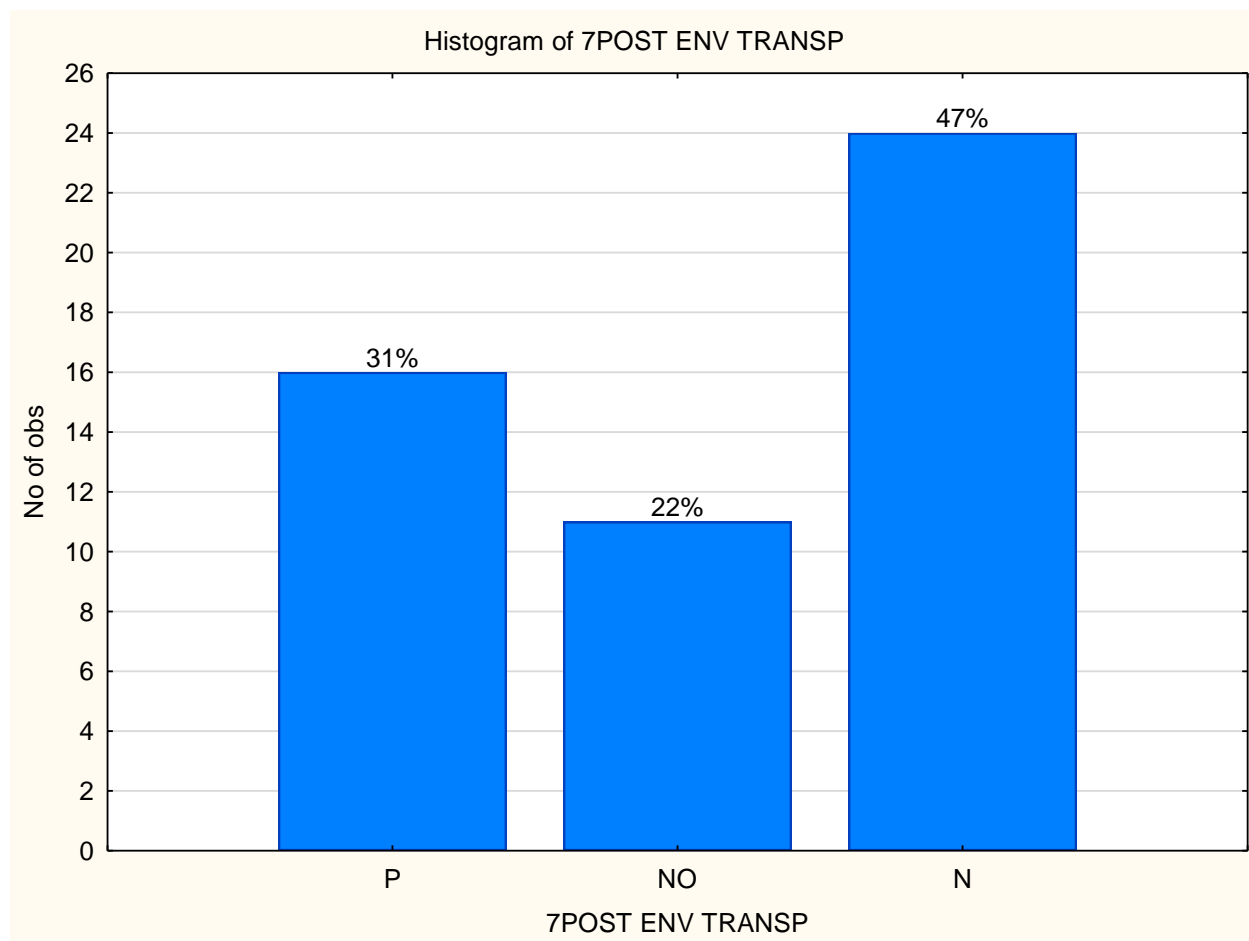
FIGURE 4.16: HISTOGRAM DEPICTING HOW CARERS AFFECTED COHORT'S THERAPY

As far as the cohort's response on the effect that the physiotherapist and occupational therapist (OT) had on their therapy, both professionals had a positive effect. The majority of participants (98%), where N=50, reported the physiotherapist's influence on their therapy as positive and only 2% reporting no influence. Of the 42 participants who responded regarding the OT's influence, 93% reported that the OT affected their therapy positively and 7% reported that the OT had no effect on their therapy. Forty-two percent of participants (N=42) reported that the Speech and Language therapist had a positive effect on their therapy.

4.4.4 Transport

This environmental factor influenced the cohort's therapy negatively. Of the 51 participants who responded to the question, close to half (47%) indicated that transport had a negative effect on their therapy, 31% indicated that transport was a positive factor and 22% reported that it had no effect on their therapy. Figure 4.17 depicts the results regarding the effect that transport had on the cohort's therapy.

FIGURE 4.17: HISTOGRAM DEPICTING HOW TRANSPORT AFFECTED COHORT'S THERAPY

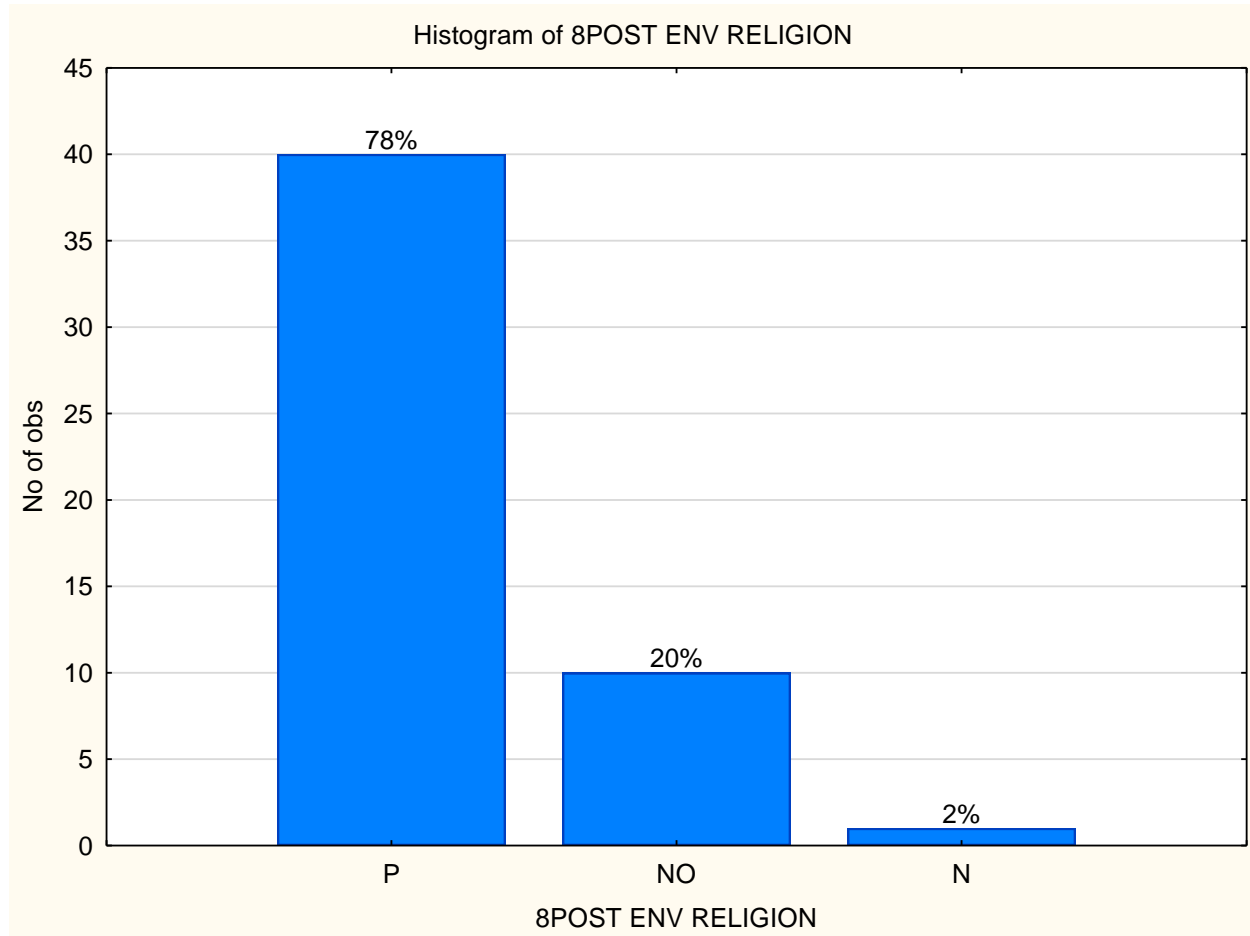


4.4.5 Religion

Of the participants (N=51) who responded to the question regarding the effect that their religion had on their therapy, 78% indicated that religion had a positive effect on their therapy, 20% responded that it did not influence their therapy and 2% indicated that

religion had a negative effect on their therapy. Figure 4.18 depicts the distribution of responses.

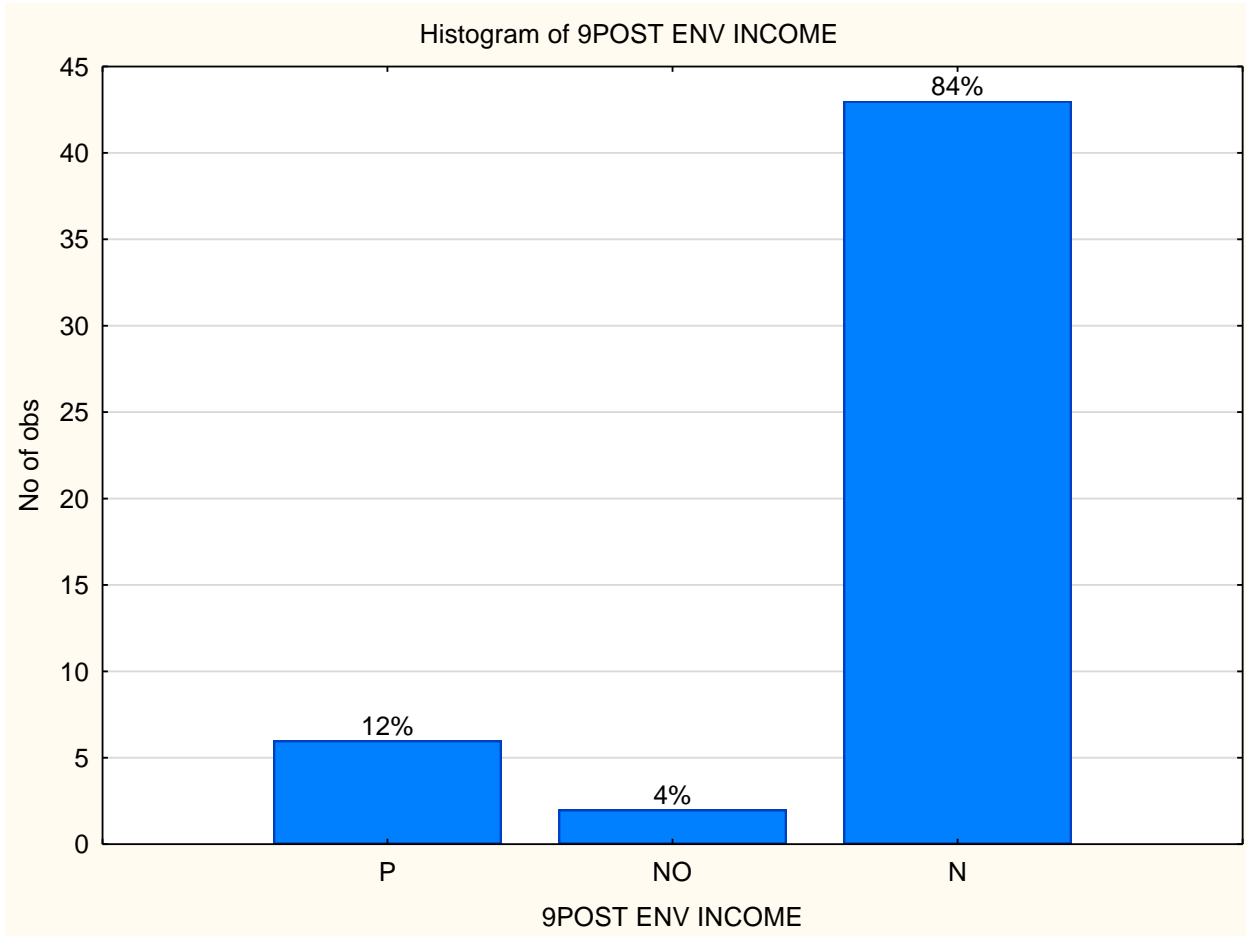
FIGURE 4.18: HISTOGRAM DEPICTING THE EFFECT OF RELGION ON COHORT’S THERAPY



4.4.6 Income & home environment

Fifty-one (51) participants responded to the questions on the elements of income and home environment. The majority (84%) indicated that income had a negative influence on their therapy, 12 % reported that income resulted in a positive effect whilst 4% indicated that income had no effect on their therapy. The histogram in Figure 4.19 depicts the results of the effect of income on therapy.

FIGURE 4.19: HISTOGRAM DEPICTING HOW INCOME AFFECTED COHORT’S THERAPY

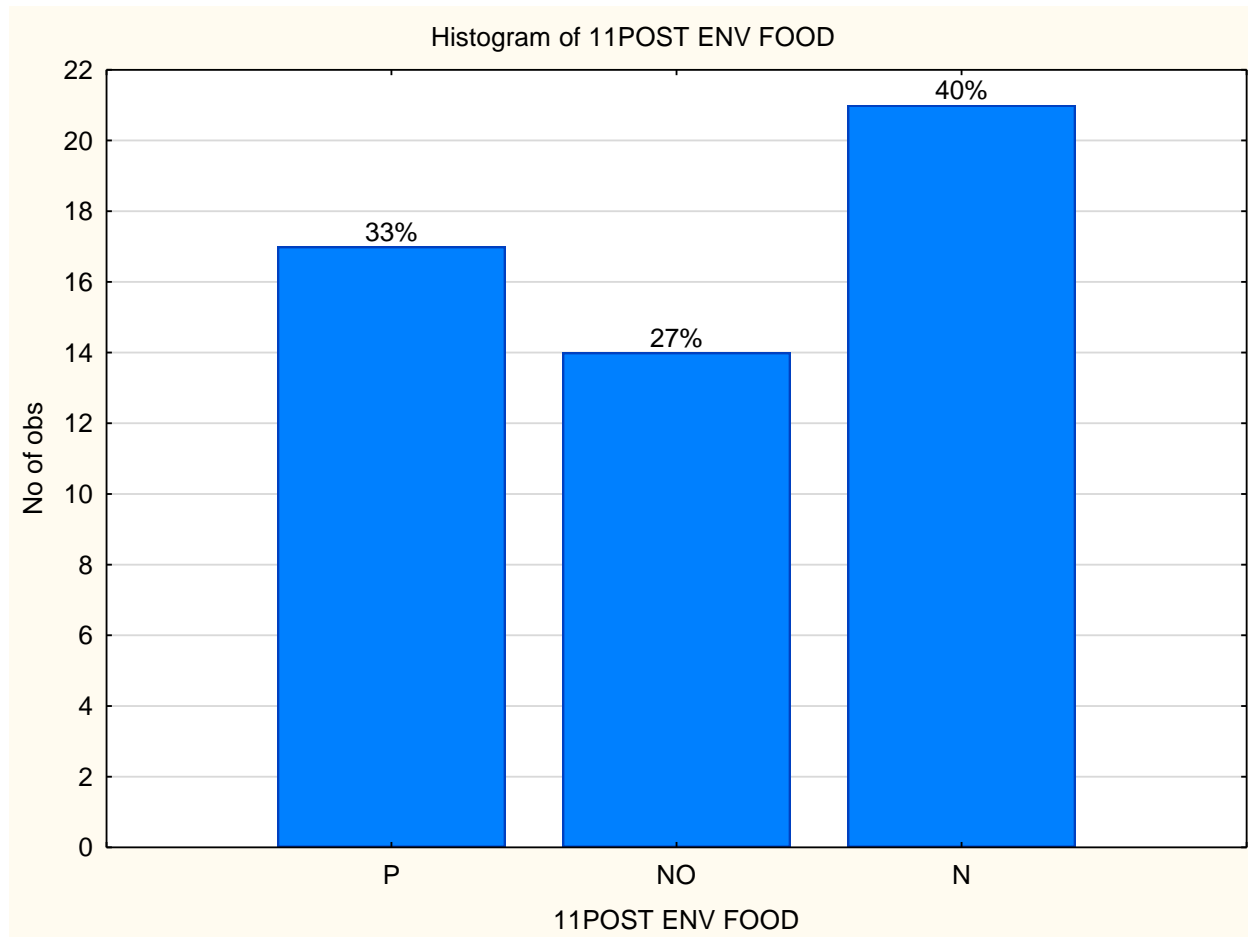


The assessment of the structural home environment showed a different pattern, where the majority (84%) of the cohort (N=51) indicated that the structural home environment affected their therapy positively, 8% reported that their structural home environment influenced their therapy negatively and the rest (8%) indicated that their structural home environment had no influence on their therapy.

4.4.7 Availability of Food

The majority of participants (40%) where N=52, indicated that the availability of food had a negative influence on their therapy; whilst 33% indicated that the availability of food influenced their therapy positively and 27% indicated it had no effect on their therapy. Figure 4.20 depicts participants' responses to the effect of availability of food of their therapy.

FIGURE 4.20: HISTOGRAM DEPICTING HOW FOOD AVAILABILITY AFFECTED COHORT'S THERAPY

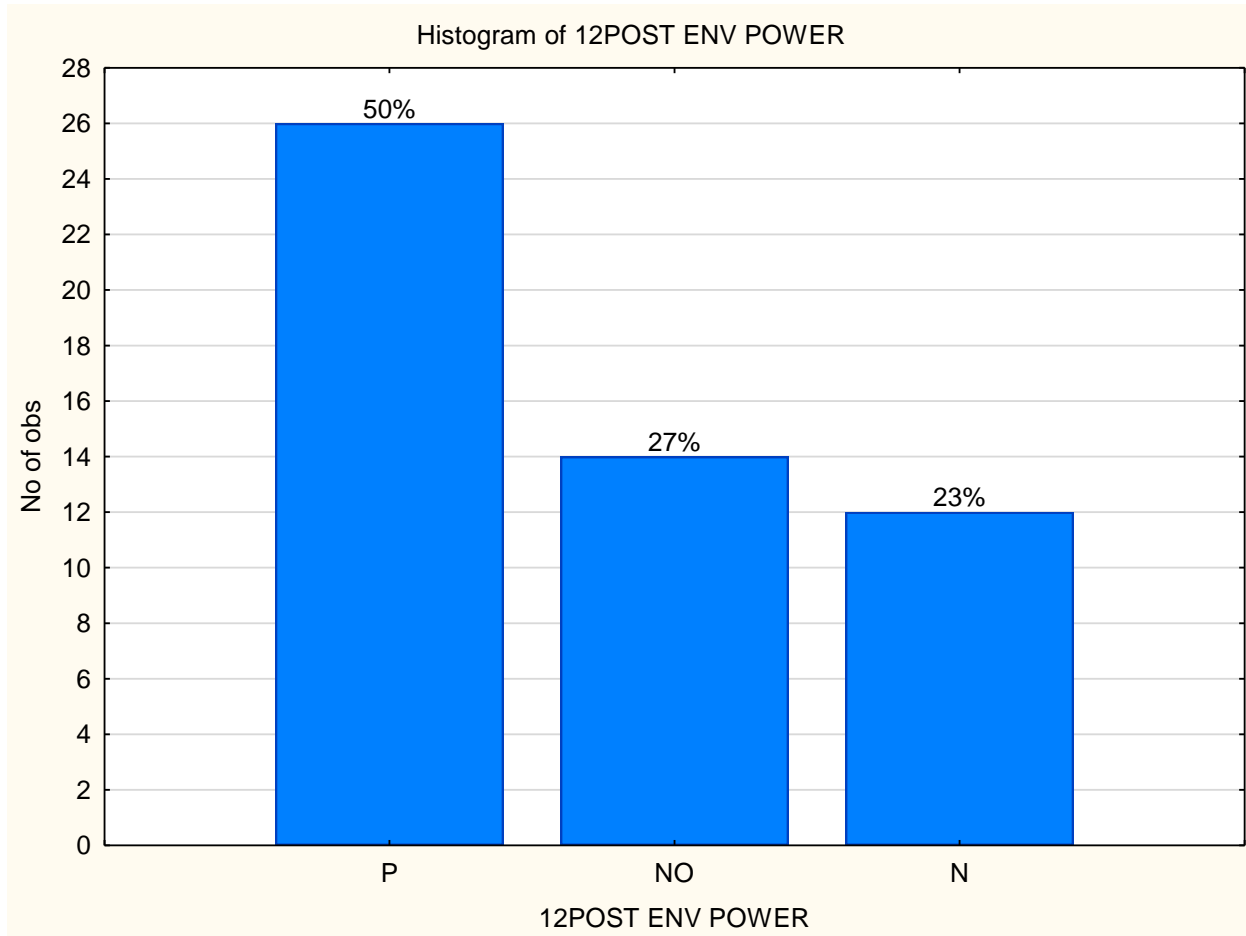


4.4.8 Access to Basic Services

4.4.8.1 Power

This section will include the effect access to basic services had on the participants' therapy. This includes the availability of power, water, toilet facilities and the structure of facilities in the community. Fifty (50) percent of participants where N=52 indicated that the availability of power had a positive effect on their therapy; 23% reported that it had a negative effect on their therapy and 27% reported that it had no effect on their therapy. Figure 4.21 depicts participants' responses with regard to how the availability of power affected their therapy.

FIGURE 4.21: HISTOGRAM DEPICTING EFFECT OF AVAILABILITY OF POWER ON COHORT'S THERAPY



4.4.8.2 Water

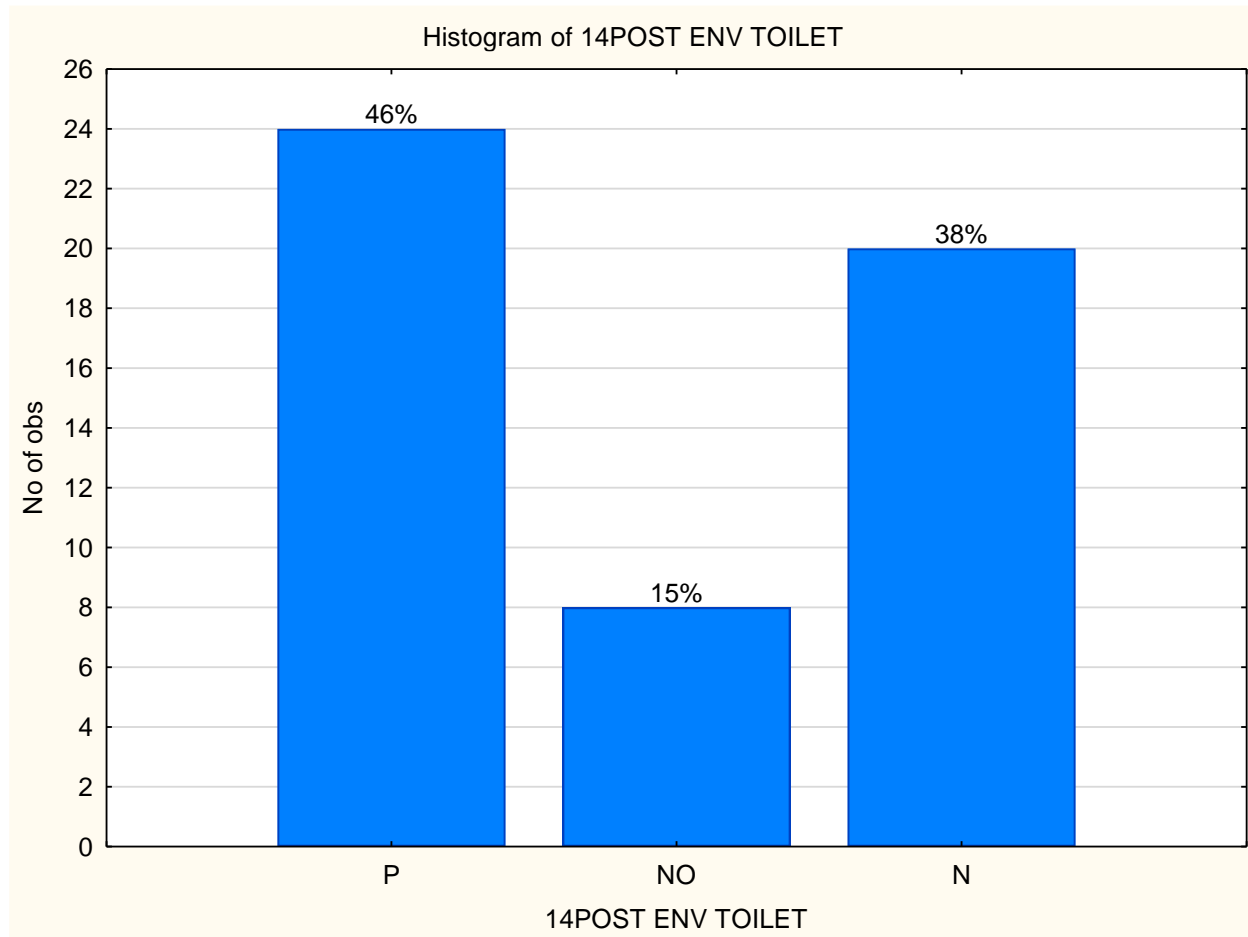
The majority (78%) of participants where N=51 indicated that the availability of water had a positive effect on their therapy, whilst 14% indicated it had a negative on their therapy and only 8% indicated that the availability of water had no effect on their therapy.

4.4.8.3 Toilet facilities

The response on the effect of the availability of toilet facilities on the therapy of participants was varied. 46% of participants (N=52) indicated that the availability of toilet facilities had a positive effect on their therapy whilst 38% indicated it had a negative

effect and 15 % indicated that it had no effect. Figure 4.22 depicts the cohort's responses on the effect of availability of toilet facilities on their therapy.

FIGURE 4.22: HISTOGRAM DEPICTING EFFECT OF AVAILABILITY OF TOILET FACILITIES ON COHORT'S THERAPY



4.4.8.4 Structure of Community Facilities

With regard to the effect that the structure of facilities in the community had on their therapy, the majority (81%) where N=52 indicated that it had a positive effect on their therapy, whilst 12 % indicated it had a positive effect and 8 % indicated it had no effect on their therapy.

4.4.8.5. Community's Attitude

As far as the community's attitude affecting the cohort's therapy, the majority (77%) indicated that the community's attitude towards them as disabled affected their therapy positively, 8 % indicated that the community's attitude towards them influenced their therapy negatively and 15% indicated it had no effect on their therapy

4.4.9 Participation in Rehabilitation Programmes

4.4.9.1 Previous Rehabilitation

The majority (69%) of participants have not previously participated in a rehabilitation programme whilst 31% of the participants have had access to rehabilitation services for other reasons prior to participating in the study.

4.4.9.2 Access to assistive devices

The majority (81%) of participants who required devices and had received their assistive devices, 80% were happy with the devices and 79% were using them. Table 4.16 provides a breakdown of access to assistive devices.

ASSISTIVE DEVICES	COUNT YES	YES (%)	COUNT NO	NO (%)
DEVICES RECEIVED	43	81	10	19
HAPPY WITH DEVICES	40	80	10	20
USING DEVICES	38	79	10	21

TABLE 4.16: DESCRIPTION OF ACCESS TO ASSISTIVE DEVICES

Some of the reasons reported as to why participants did not receive the required assistive devices (N=10) included that an assistive device was not prescribed, being waitlisted due to non-availability, and no longer needing the device.

4.5 Summary of Results

The cohort's self-rated report on health status showed a significant improvement at post-testing phase. This means that the majority of participants reported that they had an improved health state. The analysis of data from the EQ5D furthermore indicates that there is no significant difference when one compares the pre- and post- test results specifically for the activity domains. There is, however, a significant statistical difference in the analysis of pre- and post-test results in the data related to the impairment domain. This may be linked to a general improvement in pain and other elements pertaining to bodily function and structure. The participation domain was not tested with the entire cohort.

In terms of condition-specific measures, the participants with LLIs showed a general improvement in activities specifically around mobility. No changes in pre-and post-testing could be found in the domains related to participation for people with LLIs.

As far as participants with ULIs are concerned significant positive changes were reported in all three domains of the ICF namely activities, impairment and participation.

Participants with LBP reported improvements in participation only whilst activities and impairment domains did not have any reported improvements.

Those participants who had strokes and arthritis did not report statistically significant changes however this may be due to the poor re-testing and low participant numbers.

CHAPTER 5

DISCUSSION AND INTERPRETATION OF RESULTS

The discussion and interpretation of results will follow the same format as the results section and will be address according to the objectives of the study.

5.1 Demographic Profile

Education, Income and Food Security

In terms of educational levels, the study results indicate that the majority (62%) of the participants had secondary-level schooling; about 27% had some form of primary level schooling, with 8% having some form of tertiary level education. Only 1% indicated they had no formal schooling background. The national census results indicate that only 7% of the population of Gugulethu has a University Degree with only 31.23% of the population having completed their schooling and obtained their Grade 12 qualification. In addition, the census indicates that as many as 2.3% of adults in Gugulethu, have had no schooling at all. (StatsSA, 2011). These results have a direct impact on the socio-economic circumstances of the population.

As far as income levels, 75% of participants in the study reported a monthly income between R1001 and R2000. This shows that the majority of participants' income is aligned to Social Security payouts for either Disability Grants or Older Persons Grants. National census figures furthermore indicate 56% of the population of Gugulethu forms part of an active labour force (StatsSA, 2011). Most of the cohort was either unemployed or they had social-security related income. Whilst other studies, Kloppers (2013) and Felix (2015) showed similar patters with regard to limited education levels and

subsequent income, this cohort seems to have more access to temporary disability social security options despite strict rules and processes governing access to these grants.

Despite the aforementioned limited income, as well as confirmations from the Labour Force Survey by StatsSA, the majority of participants had reported that their level of food security was high, with 81% reporting that they have three regular meals per day (StatsSA, 2011). The questionnaire did not elicit information on the content of the meals or the nutritional value. Limited food security could be a barrier to rehabilitation as the energy levels of the patients may be low due to their limited intake of calories. In addition, the high prevalence of chronic lifestyle conditions may be exacerbated due to limited lifestyle changes such as healthy eating. Similar findings were reported by Kloppers (2013)

Transport, Infrastructure and access to basic services

Article 9 of the UNCRPD describes the aim of accessibility “..to enable persons with disabilities to live independently and participate fully in all aspects of life [therefore] taking appropriate measures to ensure to persons disabilities access, on an equal basis with others, ...” (UN,2006)

In terms of basic services, access to transport seemed to pose a general challenge to patients attending rehabilitation services. The majority (66%) reported that they had access to transport, 65% travelled by taxi, 22%, or walked to the health facility whilst 13% had other means of transport. The majority indicated that transport was available at appropriate times.

With regards to accessibility, 66% reported that the transport was generally accessible while 34% responded that the transport service was not accessible. There is a well-established taxi and bus service in the Gugulethu.

There is a strong link between income levels as either a barrier or a facilitator to rehabilitation and reintegration into society. The cost however may impede regular visits to the rehabilitation service as one trip would cost about R15 for the majority of people (62% of participants reported spending R10-15 per trip). Similarly, the majority indicated that this environmental factor influenced the cohort's therapy negatively. Of the 51 participants who responded to the question, close to half (47%) indicated that transport had a negative effect on their therapy. This could be directly related to patients' ability to access rehabilitation services. These findings were similar to other studies in the Western Cape (Whitelaw, et al, 1994; Kloppers, 2013; Felix, 2015)

If one considers that of those people requiring affordable access to public transport, close to half reported affordability as a barrier. This raises a red flag for general accessibility to rehabilitation services. This could lead to patients potentially dropping out of rehabilitation due to the unaffordability of travel to the health facility where the rehabilitation services are available.

As far as travel time is concerned, there was a varied response, where 69% of participants travelled between 10 and 30 minutes to get to the health facility, 12% travelled less than 10 minutes and 18% travelled between 40-60 minutes. Only 1% reported that they travel between 80-90 minutes. If one considers that the majority of the cohort, 59% with Lower Limb Injuries and 16% Lower back Pain, had difficulty moving, accessibility in terms of availability of transport would be a facilitator. Whilst

access to transport seems generally accessible in Gugulethu, the public transport service operates on main routes only. People with activity limitations pertaining to mobility would have difficulty accessing public transport.

Felix (2015) reported that in a study in Paarl, where taxi routes were less developed, the majority of participants in her study reported walking as primary mode of accessing rehabilitation services. Similar to the situation in Gugulethu, most patients had challenges with mobility (Felix, 2015). With this said, it is therefore understandable that transport to a facility where rehabilitation services are provided is an essential facilitator for adherence to treatment and rehabilitation programmes.

Housing Infrastructure

A person's environment has a significant influence on their disability and it is often seen as the most prevalent cause of disability (Maart et al, 2007). The majority of participants reported good accessibility to their own houses as far as stairs in and outside the houses were concerned. According to Census 2011, 66 % of people in Gugulethu live in a brick house and 33.5% in an informal dwelling or shack (Stats SA, 2011). As far as access to electricity is concerned, the cohort's response is in alignment with the national census figures, where the research showed that 97% have access to electricity and the census figures being 98,6% (Stats SA, 2011). This has been identified as a facilitator to the cohort's rehabilitation process.

Assistance, Community Involvement & Recreational Activities

McColl et al (1998) noted the fact that community integration is multi-dimensional. Some of the themes in the various definitions explored, included **relationships with others**, **independence in living and situations**, and **activities to fill time**.

More than half (55%) of participants who indicated that they have some assistance from family members, neighbours and or friends. Only 4% indicated that they remunerated their carers. This may not only be indicative of financial pressures in the home of a person with a disability as someone with a limited form of income. It also speaks to how people in this community have been socialized to provide support to one another. Interestingly no participants mentioned interaction with home-based care services that are reasonably well-established within the community. This means that the strong relationships within households are a strong facilitator to rehabilitation as these family members and friends further support the patients at home when they are not attending rehabilitation services. Kloppers (2013) reported that the level of assistance had a direct impact on the level of dependence of the co-hort. She reported for example that the number of carers required reduced significantly as the patients' level of functioning improves. This supports the notion of carer support as part of the rehabilitation process.

More than half of the cohort (55%) indicated that they do their own shopping whilst the remainder used various other family/community members to do their shopping. This can be explained by the limitations in functioning as identified by the results under the Clinical Mobility Scale, where there was a significant difference in the activities related to mobility namely walking, gait, stair-climbing and hand-held appliances. Whilst this was reported, similarly the level of participation, namely 'time usage' showed no significant difference. This may also be an indication that participants may have partaken in other activities in a limited fashion due to various other factors such as cost and accessibility. When one considers the limited achievements in changing the participants' level of independence in activities as measured by the EQ5D namely mobility, self-care and usual activities (work, family, study) limitations pre-and post-

testing phases, the poor participation in community involvement can thus be explained as it points to limitations or difficulty in moving around.

Rights-based knowledge and citizenship

Only 25% of participants were aware of health committees in the area and only 9% were actively participating. This, despite the UNCRPS's optional protocol, stating "... that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programmes, including those directly concerning them, ..." (UN, 2006). Whilst the study did not delve into the details of reasons of participation or non-participation, there may be other reasons why there was such limited awareness about these processes and structures. Carling (1995) and McColl et al (1998) emphasize the importance of community integration as being full participation and membership. Whilst the awareness of the structures and process may have been limited in the case of this Gugulethu cohort, it may be attributed to the general lack of interest and information to access rights-based options, as was also the case in the Bishop Lavis cohort (Kloppers; 2013)

5.2. Description of Health, Impairment, Activities and Participation

The ICF has its first aim "...to provide a scientific basis for understanding and studying health and health related states, outcomes and determinants." (WHO; 2001). The following section will include a discussion of the results as it pertains to the general cohort as well as the sub-cohort results.

5.2.1 The most prevalent conditions, causes and risk factors

The results showed that the majority (59%) of the participants have lower limb injuries, 24% having upper limb injuries followed by lower back pain (16%) and CVA (1%). The

causes were reported to be mostly of traumatic (72%) and chronic (31%) nature. Further evidence of studies in the Cape Metro and Cape Winelands suggests similar findings (Kloppers, 2013 and Felix, 2014) This is in line with the reports on causes of premature mortality in the Western Cape, where traumatic causes such as interpersonal violence and traffic accidents are generally higher than chronic causes such as Ischemic Heart Disease and Diabetes Mellitus. (DoH, 2007)

Whilst the results showed that the majority of participants did not partake in risk behaviour such as smoking, drinking alcohol and drug use, alcohol-related harm is often directly related to injury. With the aged group of the cohort being generally an older population, this can be well expected, however Gugulethu has been identified as one of the areas within the Cape Metropole where trauma is one of the main causes of premature mortality, with interpersonal violence being third to HIV/AIDS and TB within the Cape Metropole, and where the fifth cause is transport injuries. (Groenewald, et al; 2008)

5.2.2. Access to Rehabilitation Services

The National Rehabilitation Policy (DoH, 2000) as well as the PHC Norms and Standards highlights access to rehabilitation services at PHC level as a priority (DoH, 2001) and has its aim "...to improve accessibility to all rehabilitation services in order to facilitate the realization of every citizen's right to have access to healthcare services." . This service is described as a comprehensive service to include a multidisciplinary team. (DoH, 2001; DoH, 2000). The results show that the majority of participants (88%) waited less than five days to be seen at the rehabilitation services at this facility. This shows

that the rehabilitation service is generally accessible in terms of the waiting times. The rehabilitation team offers a multi-disciplinary service.

As far as access to assistive devices, the results showed that the majority (81%) of participants who required devices received their assistive devices. This means that there is budget availability for the purchase of assistive devices and that there are systems in place, for example a waiting list which addresses the inability to issue assistive devices. These practices are in line with the NRP objective "...to facilitate appropriate allocation of resources, and encourage their optimal utilization..." (DoH, 2000; DoH, 2001). The draft SA Country report to the UN on the implementation of the UNCRPD's concurs with support from the public service with regard to putting measures in place to ensure access to assistive devices through the free healthcare services to people with disabilities (SA, 2012).

5.3 Cohort: activities, participation and impairment

There was significant statistical difference in the analysis of pre- and post-results in the data related to the Pain/Discomfort elements of the EQ5D as well as the Anxiety/Depression elements. This means that whilst there was no statistically significant difference in mobility, self-care and their usual performance of activities, they reported significant differences in pain/discomfort as well as anxiety/depression. The significance in the improvement in pain/discomfort levels of participants also has far-reaching consequences on their mental health. This can be seen in the significant difference in the levels of anxiety and depression.

The **participants with lower limb injuries** are affected in all domains of the ICF. Whilst the body structure and function (impairment) domain was not included in the Clinical

Mobility Scale, there was sufficient testing within the activity limitations and participation restrictions domains respectively. Generally, people who have LLIs are expected to experience challenges with range of movement and/or muscle strength. In addition, they may experience sensory fall-outs such as pain as well as the inability to distinguish between hot and cold, and touch. Swelling of the lower extremity may also be present. (Fredericks; 2012)

Insofar as activity limitations are concerned, people with LLIs may have difficulty moving around. They may require mobility assistive devices to optimize their mobility in and around the household and beyond the household within the community where they live, work and learn. This restriction in mobility may cause the patients to have limited ability to perform their self-care and or household activities. Schneider, et al (2008) described similar patterns in a qualitative study done in Soweto, South Africa. Whilst the study focused on women with Rheumatoid Arthritis, some of the participants with LLIs may also have had comorbidity and the same will apply. The fact that patients who required mobility assistive devices could access them may have had a direct impact on their level of functioning and participation within community levels.

The analysis of data from the Clinical Mobility Scale (N=23) as administered to people with LLIs indicates a significant difference in activity levels prior to rehabilitation interventions as opposed to participants' activity levels when they were re-tested. The activity domain elements, where a significant difference is shown are walking, gait, stair-climbing and hand-held appliances. This is supported by the study in Soweto which found that mobility was an important activity limitation which affected other self-care activities. (Schneider, et al; 2008)

This indicates that participants in this study, who had lower limb injuries, experienced significant changes in their ability to perform activities related to mobility. The first element indicates that they were able to walk with less *assistance* at post-testing phase compared to their level of assistance at the pre-test phase. The second element relates to *gait* and describes the participants' ability to "walk slowly or not at all" on the one extreme and "can jog or run" on the other extreme. The element in the activity domain related to "*stair climbing*" ranged from "unable to climb stairs" to "climbs stairs unassisted". The positive changes in this element indicate that there would also have been significant changes in impairment such as pain and range of movement. The last element on "*hand-held appliances*" speaks to the participants' inability to use crutches (due to other medical/functional reasons) on the one extreme and "uses no hand-held appliances" on the other.

Impairment was not tested with this tool. Participation restrictions were tested and showed no statistically significant difference when comparing the pre-test results to the post-test results.

Based on the results it can be concluded that mobility is the functional domain that was most affected by the impairments in participants with Lower Limb Injuries. The results also show that the participants were able to experience an improved level of independence in their mobility by participating in a rehabilitation programme and the provision of assistive devices.

People who experience ULIs are affected in all domains in the ICF. As an outcome measure, the DASH was able to provide the researcher with sufficient information regarding impairment, activity limitations and participation restrictions.

The DASH tested body function and structure (impairment) in terms of pain, pain when performing activities, tingling sensation in the arm, weakness and stiffness. The only element pertaining to impairment, that showed a significant difference when comparing the pre-test results to the post-test results, is that of “tingling sensation in the arm”.

As with LLIs, this sub-set of the cohort may also have had some comorbidity. The results on activity limitations are to some extent in line with the study by Schneider and team in Soweto (Schneider, et al; 2008). Whilst the details of these activities are not exactly the same, they included some self-care and household activities such as walking, carrying things, washing and dressing (Schneider, et al., 2008). This indicates comparability. Similar results were seen in a clinical study in Norway on the outcome of nerve transfers for traumatic, complete brachial plexus avulsion where the DASH and another tools was employed (Liu, et al., 2011).

Of the seven (7) indicators related to the participation domain, the results showed a significant difference when comparing their ability to participate prior to rehabilitation as opposed to after rehabilitation within the following elements: “recreational activities that require little effort”, “recreational activities where the arm moves freely”, “the ability to manage transport needs” as well as “sexual activities”.

The systematic review by Roe, et al (2013), confirmed that the DASH, amongst other upper limb outcome measures, included twice as many concepts related to activity limitations and participation restrictions as opposed to elements related to the bodily function and structures domain (impairments). This is thus in line with the findings.

Noteworthy is the result that indicates an improvement of one element within the impairment domain and how that directly affects and leads to improvements in

participants' level of functioning. From this it can be seen that the improvement of body function and structure can lead to improvement in functional ability as far as activity limitations and participation restrictions are concerned. This particular finding was not described at all within the systematic review by Roe et al (2008) and did not address the relationship between the limited elements testing bodily function and structure and what possible results it may yield on functional outcomes.

In summary this sub-set of the cohort saw a general improvement in functional ability after participating in a rehabilitation programme. The study by Liu et al (2008) supports this finding in the sense that the treatment and rehabilitation of persons with upper limb injuries had on the functional outcomes of these patients (Liu et al; 2008). The environmental factors that were identified as facilitators, for example carers, may also have impacted greatly on the level of independence of people with ULIs.

People with LBP are affected in all domains of the ICF. In a Turkish cross-sectional population study, it was evident that, in addition to the problem of Lower Back Pain being very prevalent in developing countries and reportedly more so in Turkey, the effect the condition has on disability and quality of life is noteworthy as LBP is associated with occupation (Oksuz, 2006). In terms of impairment, they may experience pain. This pain may affect their ability to perform personal self-care activities, household activities and may affect their ability to participate meaningfully within the social environment.

Whilst there was no statistically significant difference in impairment and activity domains in people with LBP, a significant difference was reported with regard to the elements within the participation domain, namely social life and travel; pointing specifically to the participants' abilities around social life and travel. Some of the participants showed an

improvement as far as their pain levels were concerned. This is similar to the larger cohort where pain levels improved and subsequently the mental health aspect.

The aforementioned Turkish study by Oksuz (2006) is relevant as a large population of Gugulethu has a low educational level as related earlier, meaning that in terms of their occupation, the majority of participants who had LBP would have at some point in their lives been exposed to hard physical labour.

In a study by Gialanella, et al (2013) where they investigated the rehabilitative and economic effectiveness of an outpatient rehabilitation practice, they found economical effectiveness to be higher in low back pain carried out in group format. In addition, there was evidence created that the effectiveness of rehabilitation was higher in an outpatient rehabilitation setting and the rehabilitative effectiveness is higher than economical one (Gialanella, et al; 2012) Interestingly, in a randomized control trial of 75 patients with lower back pain, general pain relief was reported in all three groups where interventions took place. In addition, the Oswestry was applied to measure disability, they found that back school classes (therapy) reduces disability at follow-up (Morone, et al; 2011)

This sub-set of the cohort with LBP showed no statistically significant difference in impairment and activity limitations; however, with the differences reported in the pain results, it makes sense that there have been significant shifts in results pertaining to their participation restrictions.

People with arthritis may experience pain on a daily basis accompanied by joint stiffness and fatigue which affects their ability to perform self-care activities and household activities (Schneider, et al, 2008). In this study, only two participants were retested in this sub-set of the cohort. No differences were reported in the comparative

results of the twelve elements related to the activity domain, the six related to the impairment domain and the eight elements related to the participation domains. The fact that only two participants were re-tested during the post-test phase may have influenced the statistical significance of the results.

Noteworthy is the fact that some of the patients with Lower Limb Injuries and those with Upper Limb Injuries may have had a comorbidity of Arthritis, however due to the primary reason stated for attending rehabilitation they were categorized as such. A qualitative descriptive study done in Soweto, South Africa, investigating the social aspects of living with rheumatoid arthritis found that in terms of activity, their mobility and self-care activities were significantly affected (Schneider, et al, 2008). The study further found that all participants required personal assistance and technical assistance. Schneider (2008) described commuting and use of transport, as well as use of time, as areas that affected their meaningful participation in their life roles at home and in society.

In an overview of systematic reviews on Exercise for Bone and Muscle Health by Hagan et al (2012), there is sufficient evidence that suggests that exercise programmes are beneficial to people who experience health challenges due to the following conditions: osteoarthritis (OA), rheumatoid arthritis (RA), and ankylosing spondylitis (AS). An overview of exercise therapy in patients with osteoporosis (OP) identified a gap in the knowledge on how exercise therapy affects the disease.

Whilst this study in Gugulethu had limited results due to factors such as comorbidity and limited re-test opportunities, the existing research supports firstly rehabilitation in various forms to address domains for bodily structure and functions, as well as activity limitations

and participation restrictions in people who have arthritis and other conditions affected by the musculoskeletal system.

The comparison of pre- and post-test data proved challenging as there was only one person with a **CVA** and no post-test was performed on this participant.

During the preparation phase of the research, CVAs were registered as one of the five most prevalent conditions that were referred to rehabilitation services. This, however, has changed to the time when the data collection was initiated. Reasons for this may be that patients are directly referred from hospitals to the Community Based Services platform for home community-based care or that they are referred to the community health centre only for medical follow-up and not rehabilitation.

In terms of relevance of the ICF to people who have had strokes, this sub-set would have presented with challenges at body structure and function level (impairment), leading to challenges in mobility, performing self-care activities as well as household activities. Depending on the severity of the impairments, these people could potentially be excluded from participating meaningfully in family and community activities.

Recent research that was done in Italy on patients who had a first-time strokes and who were attending an inpatient facility showed that one of the predictors of having mastered independence in complex ADLs at discharge was the completion of a Barthel outcome measure on admission (Cioncoloni, et al; 2013). This is an important indication of creating awareness with the rehabilitation staff as well as the patient as to what their initial level of functioning is and using it as a baseline for rehabilitation.

Whilst the intake of participants with strokes was very low (N=1) compared to the prevalence of strokes generally, the philosophy of using outcome measures in a rehabilitation setting is key.

5.4 Summary

Low educational levels and subsequent low income levels were identified as major contributors to risk factors for disability. Limited income levels also contributed to the challenges around access to services specifically transport to rehabilitation services. An additional barrier to optimal rehabilitation was identified as food security, not in terms of quantity of meals but the potential quality thereof to sustain energy levels of patients with disabilities. As far as access to rehabilitation services was concerned, patients generally did not wait more than five days to see a therapist and the majority of patients who required assistive devices received them.

Close to half of the participants indicated that transport was not affordable. In addition, the accessibility of public transport was seen as a facilitator, however if this transport is not available in the outlying areas and only on the main routes, this may pose a challenge. It is therefore important that people with disabilities who are receiving rehabilitation at primary health facilities, are provided with options to ensure that they return to rehabilitation. Should patients indicate that regular attendance is not affordable; patients should be provided with options to ensure continued rehabilitation, for example home programmes.

While self-reported improvements regarding elements of Pain/Discomfort and Anxiety/Depression were significant for the whole cohort, there was no statistically significant reporting on mobility, self-care and usual activities. For those participants with

LLIs, there was significant improvement in the activity elements namely walking, gait, stair-climbing and hand-held appliances. Participants with LBP reported no statistically significant difference in the activity; however, their level of social life including travel was improved. Participants with ULIs reported improvements in some activity, impairment and participation domains.

Family, carers and religion were some of the environmental factors that were identified as facilitators of better rehabilitation outcomes, whereas transport, income and food security were the main inhibitors to improved rehabilitation outcomes.

CHAPTER 6

This chapter will provide a conclusion to the study as well as a discussion on some of the limitations identified by the researcher, how these could potentially have been improved and what impact they would have had should these have been addressed. The chapter ends off with key recommendations, based on the findings of the study, for service delivery and future research.

6.1 Conclusion

To determine the demographic profile of the rehabilitation clients attending Gugulethu Community Health Centre

The cohort showed that the majority of clients being referred for rehabilitation services are women. In addition, most of the participants were between 40 and 70 years old with the mean age being 49-years and 7-months. Low socio-economic conditions were prevalent with barriers to rehabilitation being identified as finances, access to transport and food security.

Whilst most participants had carers who assisted at home they were not remunerated. The majority of the participants indicated that they normally do their own shopping but would ask family members and neighbours to do their shopping while they have functional limitations.

To identify the five most prevalent conditions referred to rehabilitation services at Gugulethu Community Health Centre;

The most prevalent conditions that were referred were people with Lower Limb Injuries, Lower Back Pain, Upper Limb Injuries, Arthritis and CVAs.

To determine the functional status (activity limitations and participation restrictions) of clients on entry to rehabilitation services;

To determine the rehabilitation outcomes of the patients on discharge in terms of activity limitations and participation restrictions.

A significant difference was reported in the levels of pain/discomfort as well as the levels of anxiety/depression in the total cohort.

For participants with LLIs there were significant changes in mobility-related activities namely walking, gait, stair-climbing and also hand-held appliances.

Participants with Lower Back Pain, however, reported no significant changes in activity and impairment domains and significant changes in participation domain such as travelling and socializing.

Participants with ULIs reported significant differences in all domains even though only some of the elements that showed changes. These were changes in impairment (tingling in arm, hand and shoulder); activity-related elements such as pushing a heavy door, gardening/yard work, making a bed, pulling over a sweater, as well as some participation elements such as recreational activities, managing transport needs and sexual activities.

The results for pre- and post-testing of the AIMS and Barthel Index did not show statistical significance due to the limited number of participants.

6.2 Recommendations

Patients with LLIs

Participants with LLIs reported the best changes. They experienced positive shifts in all three domains of the ICF: impairment, activity limitations and participation restrictions.

Based on the findings in the research, the Clinical Mobility Scale is suggested as a tool to measure outcomes in patients with LLIs. Whilst there were areas where patients did not improve, this can be addressed with either new focus on patient goal-setting.

Patients with ULIs

As with the patients with LLIs, the recommendation is to use the DASH as an outcome measure for patients with ULIs. The outcome measure is practical and participants did not have any challenge answering any of the questions. The improvement in all three domains of the ICF points to effective therapy. This could be an excellent tool to use as rehabilitation outcome measure in this setting.

Patients with Arthritis

Whilst no statistically significant results were reported, the AIMS was a practical outcome measure to implement, easy to use and not long. As with the other measures it could provide therapists with excellent opportunities to work in more outcome-based manner.

Patients with LBP

The subset with LBP did not report significant changes in activity limitations and impairment. Despite the limited improvement in this research setting, the Oswestry is a practical outcome measure that can be implemented for people with LBP.

Opportunity for improved Information Management

With the proposal to implement some of the outcome measures, there is an opportunity to re-visit the information management system as it pertains to rehabilitation. A

systematic move to implement prioritized outcome-measures related to the highest burden of disease in the province is proposed.

An outcome measure such as the SANPAD pre-and post- questionnaires provides an excellent baseline for therapists regarding these demographic indicators.

6.3 Limitations

6.3.1 Limitations Of The Methodology

Quality Control and Quality Assessment

There should have been a much more improved quality control and quality assessment process outlined, particularly around gaps identified such as income data. Whilst the researcher was available to the fieldworker, telephonically, the fieldworker did not report any challenges.

Whilst the training of fieldworkers was comprehensive, the quality control process could have been strengthened as mentioned earlier. Some data elements with regard to income were lacking. This was a consistent pattern with the initial tools as completed by the fieldworker. Reasons may include refusal to divulge information or that the fieldworker omitted to ask the questions pertaining to income and other residents in the household.

Recruitment of participants

The researcher could have strengthened systems pertaining to the screening and recruitment of participants. This would have eliminated the incorrect recruitment of participants.

Arthritis was another condition that was identified as one of the conditions most often seen by the physiotherapist. There were four patients who were identified as ULI and Arthritis. The fieldworker completed both outcome measures. The researcher in consultation with the statistician classified these cases as Upper Limb injuries only. This enabled the analysis of the data to be clear.

The description of the rehabilitation process

This study focused on the pre- and post-testing of a particular population of patients who attended rehabilitation services. The methodology, however, did not include a description of the rehabilitation service. Should a description of the rehabilitation service per subset of the cohort been included, it could potentially have deepened the results and the interpretation of the rehabilitation outcomes.

6.3.2 Limitations Pertaining To The Participants And Results

Co-morbidity

The issue of co-morbidity impacted on the recruitment and subsequent categorization of participants. Due to this, a small number of participants were categorized with “Arthritis”. The researcher should have employed more measures to ensure screening of those participants with comorbidities, thereby ensuring correct outcome measures. As an alternative, generic outcome measures may be more practical.

6.4 Potential research

The question of why only one patient with a **stroke** was recruited needs to be answered. Potential research pertaining to stroke care and support could address sub-questions related to:

referrals of patients with strokes from other levels of care;

follow-up of patients with strokes at GCHC;

Care and support of patients with strokes at community-based level.

In terms of **co-morbidity**, there is an opportunity to do a more in-depth study around the rehabilitation of patients with arthritis, thereby developing a more in-depth understanding as to what this population looks like, what facilitation and inhibiting environmental factors there are in potential community-based rehabilitation interventions for this population.

The current rehabilitation process, including modalities of treatment relevant to the burden of disease, needs to be investigated. Particular focus needs to be given to the appropriateness of individual interventions in a setting where there is a large patient population.

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ADDENDUM A

SANPAD QUESTIONNAIRE

1



SANPAD PROJECT

Questionnaire 1

1. PATIENT NAME AND SURNAME:

2. GENDER:

1 M	2 F
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3. MARITAL STATUS:

SINGLE	MARRIED	DIVORCED	WIDOW/ER	LIVING TOGETHER	SEPERATED	OTHER
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4.

DIAGNOSIS:

5. DATE OF INCIDENT/INJURY/ONSET:

6. CAUSE OF INJURY

Congenital		1
Traumatic		2
Chronic disease		3
Other		5

7. WHAT PREVIOUS INJURIES/CO-MORBIDITIES DID YOU HAVE?:

Injury/Diagnosis	Date of onset

8. HAVE YOU HAD REHAB BEFORE?

1 YES	2 NO
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IF YES:

1 Where?	2 For what?	3 For how long?

9. DO YOU CURRENTLY:

1. Smoke?	1 yes	2 no
2. Use Alcohol?	1 yes	2 no
3. Use Drugs?	1 yes	2 no

PERSONAL INFORMATION (PI)

10. WHAT RACE ARE YOU?

White	1	
African	2	
Coloured	3	
Asian	4	
Other	5	

11. ARE YOU:

1. South African?

1 YES	2 NO
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If YES, are you:

1. Local?	
2. Migrant to area	Where do you also have a home and when do you go there?

If NO, are you:

3. Migrant?	Where do you also have a home and when do you go there?
-------------	---

12. WHAT RELIGION ARE YOU?

Muslim	1	
Christian	2	
Other	3	

13. WHO LIVES WITH YOU IN THE HOUSEHOLD?

	1 Male(s) + age	2 Female(s) +age	3 Employment	4 Income	5 Source of Income
1. Spouse					
2. Other					
3. TOTAL					

14. WHAT IS YOUR HIGHEST LEVEL OF EDUCATION?

1. Grade	1
2. Secondary	2
3. Tertiary	3
4. None	4

1. WHAT IS YOUR MONTHLY INCOME?

R 1 - 1000	1
R 1001 - 2000	2
R 2001 - 5000	3
R 5001 - 10000	4
R 10001 - 15000	5
> R15000	6

2. WHERE DO YOU GET YOUR INCOME FROM?

DG private/Allpay	1
Pension-private/Allpay	2
Childcare Grant	3
Carer dependency grant	4
Formal: Permanent/contract	5
Informal: Casual/Contract/Seasonal	6
Other	

3. WHAT ACTIVITY DO YOU DO TO MAKE AN INCOME?

1. HOW LONG DID YOU HAVE TO WAIT TO GET THIS APPOINTMENT?

2. WHAT WAS THE TRAVELLING TIME TO GET TO THIS APPOINTMENT?

3. HOW DID YOU GET TO THE REHAB CENTRE?

Walk	1
Own Car	2
Taxi	3
Hire Car	4
Train	5
Dial-A-Ride	6
Bus	7
Wheelchair	8
Other	9

4.

	YES	NO
1. Is the transport available at the appropriate times?	1	2
2. Is the transport user friendly?	1	2
3. Is the transport affordable?	1	2
4. Is the transport responsive?	1	2
5. Is the transport adequate?	1	2
6. What is the transport cost per visit?	R	

1. WHO HELPS YOU AT HOME?

	When/time of day?		
	Night	Day	Both
1. Nobody			
2. Spouse			
3. Family Member			
4. Private Person			
5. Child			
6. HBC			
7. Friend			
8. Other			

2. DO YOU PAY YOUR HELPERS?

1 YES	2 NO
-------	------

1. WHAT TYPE OF HOUSE DO YOU LIVE IN?

	Owner	Rent
1. Separate Dwelling	1	2
2. Traditional Dwelling (huts)	1	2
3. Flat/maisonette	1	2
4. Cluster, semi-detached	1	2
5. Informal/shack	1	2
6. Institution	1	2
7. Room in backyard	1	2
8. Other	1	2

2. HOW MANY ROOMS DO YOU HAVE TO LIVE IN?

1	2	3	4	5	>5
---	---	---	---	---	----

3. WHO SHARES YOUR BEDROOM WITH YOU?

1	2	3	4	5	more
---	---	---	---	---	------

4. ARE THERE STAIRS?

1. Inside	1 Yes	2 No
2. Outside	1 Yes	2 No

5. DO YOU HAVE A TELEPHONE OR CELLPHONE?

1 Yes	2 No
-------	------

6. HOW MANY MEALS DO YOU HAVE PER DAY?

--

7. DO YOU HAVE RUNNING WATER INSIDE YOUR HOUSE?

1. Yes	2. No
--------	-------

2. If NO, WHERE DO YOU FETCH YOUR WATER?

		Distance
Yard	1	
Communal tap	2	
Borehole	3	
Rain water	4	
River	5	
Dam, pool, stagnant	6	
Other	7	

8. WHO HELPS YOU IF YOU CANNOT GET WATER YOURSELF AT HOME?

Nobody	1
Spouse	2
Other family member	3
Private person	4
Friend	5
Child	6
HBC	7
Other	8

Electricity	1
Parafin	2
Gas	3
Generator	4
Solar	5
Other	6
<i>Specify</i>	61

9. WHAT POWER SOURCES DO YOU HAVE?

10. DO YOU HAVE A FLUSHING TOILET?

1. YES	1. Inside	2. Outside
2. NO		

2. If NO, why not?

Unable	1	
Inaccessible	2	
Too expensive	3	
Other	4	

1. DO YOU GO SHOPPING YOURSELF?

1 Yes	2 No
-------	------

2. If NO, who goes for you?

Nobody	1
Spouse	2
Other family member	3
Private Person	4
Friend	5
Child	6
HBC	7
Other	8

2. DO YOU PARTICIPATE IN ANY RECREATIONAL ACTIVITIES?

1 Yes	2 No
-------	------

1. If YES, which activities:

Sport	1	
Community Hall activities	2	
Hobbies (e.g. reading, sewing)	3	
Church Activities	4	
Theatre	5	
Watching Television	6	
Volunteering	7	
Other	8	

2. If NO, why not?

Unable	1	
Inaccessible	2	
Too expensive	3	
Other	4	

1. HAVE YOU BEEN INVOLVED IN ANY RESEARCH BEFORE THIS?

1 Yes	2 No
-------	------

1 If YES, did you receive any feedback?

1 Yes	2 No
-------	------

FORM COMPLETED BY:

DATE:

SIGNED BY RESEARCHER:

ADDENDUM B

SANPAD QUESTIONNAIRE

2

[POST-QUESTIONNAIRE]

SANPAD PROJECT

Questionnaire 2

Please fill in this questionnaire after treatment by asking the patient these questions.

G = GENERAL

PATIENT'S NAME:

DIAGNOSIS:

1. WHERE DO YOU GET YOUR INCOME FROM?

DG private/Allpay	1
Pension-private/Allpay	2
Childcare Grant	3
Carer dependency grant	4
Formal: Permanent/contract	5
Informal: Casual/Contract/Seasonal	6

2 WHAT ACTIVITY DO YOU DO TO MAKE AN INCOME?

3. Did you have difficulty moving around in the rehab centre?	1 YES	2 NO	
4. Did you have difficulty making an appointment for rehab?	1 YES	2 NO	Why?
5. Do you participate in any community recreation?	1 YES	2 NO	

5.1 If YES, which activities?

Sport	1
Community Hall activities	2
Hobbies (e.g. reading, sewing)	3
Church Activities	4
Theatre	5
Watching Television	6
Other	7

5.2 If NO, why not?

Unable	1
Inaccessible	2
Too expensive	3
Other	4

6. Are you aware that there is a community health committee?	1 YES	2 NO
7. Do you take part in the Health Committee?	1 YES	2 NO
8. Are you aware that you can complain about health services?	1 YES	2 NO
9. Have you received the assistive devices you need?	1 YES	2 NO
9.1.1 If YES, Are you happy with the assistive devices?	1 YES	2 NO
9.1.2 If YES, Are you using it	1 YES	2 NO
9.1.3 If NO, why not		
9.2.1 If NO, What do you need?		
9.2.2 If NO, why did you not get it?		

R = REFERRAL:

A. Who have you been referred to?	By whom	Did you attend?		How long did you wait
1 Counsellor		1 YES	2 NO	
2 Psychologist		1 YES	2 NO	
3 Nurse		1 YES	2 NO	
4 Pharmacist		1 YES	2 NO	
5 Social Worker		1 YES	2 NO	
6 Radiographer		1 YES	2 NO	
7 Prosthetist/Orhotist		1 YES	2 NO	
8 Traditional/Faith Healer		1 YES	2 NO	
9 Physiotherapist		1 YES	2 NO	
10 Occupational Therapist		1 YES	2 NO	
11 Speech Therapist		1 YES	2 NO	
12 Doctor		1 YES	2 NO	
13 Dietician		1 YES	2 NO	
14 HBC		1 YES	2 NO	
15 Other				

B Who did you go to see and how many times?










C. Who do you still want to see?	WHY?
1 Counsellor	
2 Psychologist	
3 Nurse	
4 Pharmacist	
5 Social Worker	
6 Radiographer	
7 Prosthetist/Orhotist	
8 Traditional/Faith Healer	
9 Physiotherapist	
10 Occupational Therapist	

11 Speech Therapist	
12 Doctor	
13 Dietician	
14 HBC	
15 Other	

S = ENVIRONMENTAL FACTORS

PLEASE MARK THE APPROPRIATE FACE AFTER EACH QUESTION AS YOU FEEL IT HAD AN EFFECT ON YOUR THERAPY:

WHAT INFLUENCE DID THE FOLLOWING HAVE ON YOUR THERAPY?	1 Positive (Facilitator)	2 None	3 Negative (barrier)	4 N/A
1 THE WEATHER?				
2 YOUR FAMILY ?				
3 YOUR CARER?				
4 YOUR PHYSIOTHERAPIST?				
5 YOUR OCCUPATIONAL THERAPIST?				
6 YOUR SPEECH THERAPIST?				
7 TRANSPORT (think of cost and availability)				
8 YOUR RELIGION				
9 YOUR MONTHLY HOUSEHOLD INCOME?				
10 THE STRUCTURE OF THE HOUSE YOU LIVE IN ?				
11 THE AVAILABILITY OF FOOD?				
12 THE AVAILABILITY OF POWER?				
13 THE AVAILABILITY OF WATER?				

14 THE PLACEMENT OF YOUR TOILET?				
15 THE STRUCTURE OF THE FACILITIES IN YOUR COMMUNITY?				
16 THE COMMUNITY'S ATTITUDE TOWARD YOU AS A DISABLED PERSON?				

SIGNED BY RESEARCHER: _____

DATE: _____

ADDENDUM C

MEDICAL RECORDS

REVIEW TOOL

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS : STROKE

I. Swallowing /Dysphagia:

Not documented:
Impaired
Not Impaired

2. Speech:

Not documented
Impaired
Not Impaired

2.1 Aphasia:

Not documented
Impaired
Not Impaired

2.1.1 Receptive:

Not documented
Impaired
Not Impaired

2.1.2 Expressive:

Not documented
Impaired
Not Impaired

2.2 Dysarthria:

Not documented
Impaired
Not Impaired

3. Cognitive function

3.1 Memory:
Not documented
Impaired
Not Impaired

3.2 Visual:
Not documented
Impaired
Not Impaired

3.3 Perceptual:
Not documented
Impaired
Not Impaired

3.4 Attention:
Not documented
Impaired
Not Impaired

4. Proprioception:
Not documented
Impaired
Not Impaired

5. Sensation:
Not documented
Impaired
Not Impaired

6. Defecation:

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not Impaired	<input type="checkbox"/>

7. Urination:

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not Impaired	<input type="checkbox"/>

8. Affection

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not Impaired	<input type="checkbox"/>

9. Muscle Power:

body part affected (specify)

Not documented	<input type="checkbox"/>	
0 = complete problem	<input type="checkbox"/>
1-2 = severe	<input type="checkbox"/>
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

10. Active selective movements

10.1 Upper limb: not documented impaired not impaired

10.1.1 Scapula shoulder elbow wrist hand

10.2 Lower limb: not documented impaired not impaired

10.2.1 Pelvis hip knee ankle foot

11. Muscle tone

muscle groups affected

- Not documented
- 0 = moderate to severe decreased tone
- 1 = slightly decreased tone
-
- 2 = normal tone
- 3 = not affected
- 4 = slightly increased tone
- 5 = moderate to severe increased tone

12. Balance:

- Not documented
- Impaired
- Not impaired

12.1 Standing:

- Not documented
- Impaired
- Not Impaired

12.1.1 Static:

- Not documented
- Impaired
- Not Impaired

12.1.2 Dynamic:

- Not documented
- Impaired
- Not Impaired

12.2 Sitting:

- Not documented
- Impaired
- Not Impaired

12.2.1 Static:

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not Impaired	<input type="checkbox"/>

12.2.2 Dynamic:

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not Impaired	<input type="checkbox"/>

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: SCI (Para- and quadriplegia)

13. Sensation

13.1 Pain

- Not documented
- Present
- Not present

13.2 Temp

- Not documented impaired
- Hot cold
- Not impaired

13.3 Touch (Light and deep touch)

- Not documented
- Impaired
- Not impaired

14. Muscle Power

Muscles affected

- Not documented
- 0 = complete problem
- 1+2 = severe
- 3 = moderate
- 4 = mild
- 5 = normal

15. Defecation

- Not documented
- Impaired
- Not impaired

16. Urination

- Not documented
- Impaired
- Not impaired

17. Balance

- Not documented
- Impaired
- Not impaired

17.1 Stand

- Not documented
- Impaired
- Not impaired

17.1.1 Static

- Not documented
- Impaired
- Not impaired

17.1.2 Dynamic

- Not documented
- Impaired
- Not impaired

17.2 Sit

- Not documented
- Impaired
- Not impaired

17.2.1 Static

- Not documented
- Impaired
- Not impaired

17.2.2 Dynamic

Not documented
Impaired
Not impaired

18. Respiration

Not documented
Impaired
Not impaired

19. Passive ROM

19.1 Upper limb

Not documented impaired not impaired

19.1.1 Scapula shoulder elbow wrist hand

19.2 Lower limb:

Not documented impaired not impaired

19.2.1 Pelvis hip knee ankle foot

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: TRAUMATIC BRAIN INJURY

20. Affect (mood)

- Not documented
- Affected
- Not affected

21. Memory

- Not documented
- Impaired
- Not impaired

21.1 Working memory

- Not documented
- Impaired
- Not impaired

21.2 Short term

- Not documented
- Impaired
- Not impaired

21.3 Long term

- Not documented
- Impaired
- Not impaired

22. Perception

- Not documented
- Impaired
- Not impaired

23. Cognitive Impairment

- Not documented
- Impaired
- Not impaired

24. Judgment (MMSE)

Not documented
Impaired
Not impaired

24.1 Problem solving

Not documented
Impaired
Not impaired

24.2 Decision making

Not documented
Impaired
Not impaired

25. Motivation

Not documented
Impaired
Not impaired

26. Attention span

Not documented
Impaired
Not impaired

27. Swallowing

Not documented
Impaired
Not impaired

28. Speech

Not documented
Impaired
Not impaired

28.1 Aphasia:

Not documented
Impaired
Not impaired

28.1.1 Receptive

Not documented
Impaired
Not impaired

28.1.2 Expressive

Not documented
Impaired
Not impaired

28.2 Dysarthria

Not documented
Impaired
Not impaired

29. Balance:

Not documented
Impaired
Not impaired

29.1 Stand

Not documented
Impaired
Not impaired

29.1.1 Static

Not documented
Impaired
Not impaired

29.1.2 Dynamic

- Not documented
- Impaired
- Not impaired

29.2 Sit

- Not documented
- Impaired
- Not impaired

29.2.1 Static

- Not documented
- Impaired
- Not impaired

29.2.2 Dynamic

- Not documented
- Impaired
- Not impaired

30. Proprioception

- Not documented
- Impaired
- Not impaired

31. Sensation

- Not documented
- Impaired
- Not impaired

31.1 Pain

- Not documented
- Present
- Not present

31.2 Temp

Not documented	<input type="checkbox"/>	Hot	<input type="checkbox"/>
Impaired	<input type="checkbox"/>	cold	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>		

31.3 Touch

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

32. Muscle power

		muscles affected
Not documented	<input type="checkbox"/>	
0 = complete problem	<input type="checkbox"/>
1+2 = severe	<input type="checkbox"/>
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

33. Active selective movements

33.1 Upper limb

Not documented	<input type="checkbox"/>	impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>
33.1.1 Scapula	<input type="checkbox"/>	shoulder	<input type="checkbox"/>	elbow	<input type="checkbox"/>
		wrist	<input type="checkbox"/>	hand	<input type="checkbox"/>

33.2 Lower limb

Not documented	<input type="checkbox"/>	impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>
33.2.1 Pelvis	<input type="checkbox"/>	hip	<input type="checkbox"/>	knee	<input type="checkbox"/>
		ankle	<input type="checkbox"/>	foot	<input type="checkbox"/>

34. Muscle tone

		Muscle groups affected
Not documented	<input type="checkbox"/>	
Impaired	<input type="checkbox"/>	
Not impaired	<input type="checkbox"/>	

- 0 = moderate to severe decreased tone
- 1 = slightly decreased tone
-
- 2 = normal tone
- 3 = not affected
- 4 = slightly increased tone
- 5 = moderate to severe increased tone

35. Defecation

- Not documented
- Impaired
- Not impaired

36. Urination

- Not documented
- Impaired
- Not impaired

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: PERIPHERAL NEUROPATHY

37. Sensation

37.1 Pain

Not documented
 Present
 Not present

37.2 Temp

Not documented
 Impaired Hot Cold
 Not impaired

37.3 Touch (light and deep)

Not documented
 Impaired
 Not impaired

38. Proprioception

Not documented
 Impaired
 Not impaired

39. Muscle power

Not documented muscles affected
 0 = complete problem

1-2 = severe

3 = moderate

4 = mild

5 = normal

40. Balance

Not documented

40.1 Stand

Not documented

Impaired

Not impaired

40.1.1 Static

Not documented

Impaired

Not impaired

40.1.2 Dynamic

Not documented

Impaired

Not impaired

40.2 Sit

Not documented

Impaired

Not impaired

40.2.1 Static

Not documented

Impaired

Not impaired

40.2.2 Dynamic

Not documented

Impaired

Not impaired

41. ROM

Not documented

Impaired

Not impaired

41.1 Passive ROM

Not documented

Impaired

Not impaired

41.1.1 Upper limb

Not documented impaired not impaired
 Scapula shoulder elbow wrist hand

41.1.2 Lower limb

Not documented impaired not impaired
 Pelvis hip knee ankle foot

41.2 Active ROM

Not documented
 Impaired
 Not impaired

41.2.1. Upper limb

Not documented impaired not impaired
 Scapula shoulder elbow wrist hand

41.2.2 Lower limb

Not documented impaired not impaired
 Pelvis hip knee ankle foot

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: BACK PAIN

42. Muscle spasm

Not documented
 Present
 Absent

43. ROM

Not documented
 Impaired
 Not impaired

43.1 Passive ROM

Not documented
 Impaired
 Not impaired

43.1.1 Upper limb

Not documented impaired not impaired
 Scapula shoulder elbow wrist hand

43.1.2 Lower limb

Not documented impaired not impaired
 Pelvis hip knee ankle foot

43.2 Active ROM

Not documented
 Impaired
 Not impaired

43.2.1. Upper limb

Not documented	<input type="checkbox"/>	impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>
Scapula	<input type="checkbox"/>	shoulder	<input type="checkbox"/>	elbow	<input type="checkbox"/>
		wrist	<input type="checkbox"/>	hand	<input type="checkbox"/>

43.2.2 Lower limb

Not documented	<input type="checkbox"/>	impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>
Pelvis	<input type="checkbox"/>	hip	<input type="checkbox"/>	knee	<input type="checkbox"/>
		ankle	<input type="checkbox"/>	foot	<input type="checkbox"/>

44. Nerve entrapment

Not documented	<input type="checkbox"/>
Present	<input type="checkbox"/>
Absent	<input type="checkbox"/>

45. Muscle power

Not documented	<input type="checkbox"/>	muscles affected
0 = complete problem	<input type="checkbox"/>
1-2 = severe	<input type="checkbox"/>
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

46. Sensation

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

47. Nerve mobility

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

48. Pain

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: ARTHRITIS

49. ROM

Not documented

Impaired

Not impaired

49.1 Passive ROM

Not documented

Impaired

Not impaired

49.1.1 Upper limb

Not documented Impaired Not impaired

Scapula shoulder elbow wrist hand

49.1.2 Lower limb

Not documented impaired not impaired

Pelvis hip knee ankle foot

49.2 Active ROM

Not documented

Impaired

Not impaired

49.2.1 Upper limb

Not documented Impaired Not impaired

Scapula shoulder elbow wrist hand

49.2.2 Lower limb

Not documented impaired not impaired

Pelvis hip knee ankle foot

50. Oedema

- Not documented
- Present
- Absent

51. Pain

- Not documented
- Present
- Absent

52. Sensation

52.1 Pain

- Not documented
- Present
- Not present

52.2 temp

- Not documented Hot
- Impaired cold
- Not impaired

52.3 Touch

- Not documented
- Impaired
- Not impaired

53. Muscle power

- Not documented Muscles affected
- 0 = complete problem
- 1-2 = severe
- 3 = moderate
- 4 = mild
- 5 = normal

Patient ID.....

**DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW
SANPAD**

DIAGNOSIS: DEVELOPMENTAL DELAY

54. Swallowing/dysphasia

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

55. Speech

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

55.1 Aphasia

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

55.1.1 Receptive

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

55.1.2 Expressive

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

55.2 Dysarthria

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

56. Cognitive function (Memory, visual, perceptual, attention)

56.1 Memory

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

56.2 Visual

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

56.3 Perceptual

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

56.4 Attention

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

57. Proprioception

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

58. Sensation

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

59. Defecation

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

60. Urination

Not documented

 Impaired

 Not impaired

61. Muscle power

Not documented		Muscles affected
0 = complete problem	<input type="checkbox"/>
1-2 = severe	<input type="checkbox"/>	
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

62. Active selective movements

62.1 Upper limb

Not documented	<input type="checkbox"/>	Impaired	<input type="checkbox"/>	Not impaired	<input type="checkbox"/>				
Scapula	<input type="checkbox"/>	shoulder	<input type="checkbox"/>	elbow	<input type="checkbox"/>	wrist	<input type="checkbox"/>	hand	<input type="checkbox"/>

62.2 Lower limb

Not documented	<input type="checkbox"/>	impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>				
Pelvis	<input type="checkbox"/>	hip	<input type="checkbox"/>	knee	<input type="checkbox"/>	ankle	<input type="checkbox"/>	foot	<input type="checkbox"/>

63. Muscle tone

Not documented	<input type="checkbox"/>	Muscle groups affected
0 = moderate to severe decreased tone	<input type="checkbox"/>
1 = slightly decreased tone	<input type="checkbox"/>
2 = normal tone	<input type="checkbox"/>
3 = not affected	<input type="checkbox"/>
4 = slightly increased tone	<input type="checkbox"/>
5 = moderate to severe increased tone	<input type="checkbox"/>

64. Balance

Not documented

64.1 Stand

Not documented

Impaired

Not impaired

64.1.1 Static

Not documented

Impaired

Not impaired

64.1.2 Dynamic

Not documented

Impaired

Not impaired

64.2 Sit

Not documented

Impaired

Not impaired

64.2.1 Static

Not documented

Impaired

Not impaired

64.2.2 Dynamic

Not documented

Impaired

Not impaired

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: LOWER LIMBS

65. ROM

Not documented

Impaired

Not impaired

65.1 Passive ROM

Not documented

Impaired

Not impaired

65.1.1 Lower limb

Not documented		impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>	
Pelvis <input type="checkbox"/>	hip <input type="checkbox"/>	knee <input type="checkbox"/>	ankle <input type="checkbox"/>	foot <input type="checkbox"/>		

65.2 Active ROM

Not documented

Impaired

Not impaired

65.2.1 Lower limb

Not documented		impaired	<input type="checkbox"/>	not impaired	<input type="checkbox"/>	
Pelvis <input type="checkbox"/>	hip <input type="checkbox"/>	knee <input type="checkbox"/>	ankle <input type="checkbox"/>	foot <input type="checkbox"/>		

66. Sensation

66.1 Pain

Not documented

Present

Not present

66.2 Temp

Not documented	<input type="checkbox"/>	Hot	<input type="checkbox"/>
Impaired	<input type="checkbox"/>	cold	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>		

66.3 Touch

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

67. Oedema

Not documented	<input type="checkbox"/>
Present	<input type="checkbox"/>
Absent	<input type="checkbox"/>

68. Muscle power

Not documented	<input type="checkbox"/>	Muscles affected
0 = complete problem	<input type="checkbox"/>
1-2 = severe	<input type="checkbox"/>
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

Patient ID.....

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

SANPAD

DIAGNOSIS: UPPER LIMBS

69. ROM

Not documented

Impaired

Not impaired

69.1 Passive ROM

Not documented

Impaired

Not impaired

69.1.1 Upper limb

Not documented	<input type="checkbox"/>	Impaired	<input type="checkbox"/>	Not impaired	<input type="checkbox"/>				
Scapula	<input type="checkbox"/>	shoulder	<input type="checkbox"/>	elbow	<input type="checkbox"/>	wrist	<input type="checkbox"/>	hand	<input type="checkbox"/>

69.2 Active ROM

Not documented

Impaired

Not impaired

69.2.1 Upper limb

Not documented	<input type="checkbox"/>	Impaired	<input type="checkbox"/>	Not impaired	<input type="checkbox"/>				
Scapula	<input type="checkbox"/>	shoulder	<input type="checkbox"/>	elbow	<input type="checkbox"/>	wrist	<input type="checkbox"/>	hand	<input type="checkbox"/>

70. Sensation

70.1 Pain

Not documented

Present

Not present

70.2 Temp

Not documented Hot

Impaired cold

Not impaired

70.3 Touch

Not documented	<input type="checkbox"/>
Impaired	<input type="checkbox"/>
Not impaired	<input type="checkbox"/>

71. Oedema

Not documented	<input type="checkbox"/>
Present	<input type="checkbox"/>
Absent	<input type="checkbox"/>

72. Muscle power

Not documented	<input type="checkbox"/>	Muscles affected
0 = complete problem	<input type="checkbox"/>
1-2 = severe	<input type="checkbox"/>
3 = moderate	<input type="checkbox"/>
4 = mild	<input type="checkbox"/>
5 = normal	<input type="checkbox"/>

ADDENDUM D

BARTHEL INDEX

**THE
BARTHEL
INDEX**

Patient Name: _____

Rater Name: _____

Date: _____

Activity	Score
----------	-------

FEEDING

- 0 = unable
- 5 = needs help cutting, spreading butter, etc., or requires modified diet
- 10 = independent

BATHING

- 0 = dependent
- 5 = independent (or in shower)

GROOMING

- 0 = needs to help with personal care
- 5 = independent face/hair/teeth/shaving (implements provided)

DRESSING

- 0 = dependent
- 5 = needs help but can do about half unaided
- 10 = independent (including buttons, zips, laces, etc.)

BOWELS

- 0 = incontinent (or needs to be given enemas)
- 5 = occasional accident
- 10 = continent

BLADDER

- 0 = incontinent, or catheterized and unable to manage alone
- 5 = occasional accident
- 10 = continent

TOILET USE

- 0 = dependent
- 5 = needs some help, but can do something alone
- 10 = independent (on and off, dressing, wiping)

TRANSFERS (BED TO CHAIR AND BACK)

- 0 = unable, no sitting balance
- 5 = major help (one or two people, physical), can sit
- 10 = minor help (verbal or physical)
- 15 = independent

MOBILITY (ON LEVEL SURFACES)

- 0 = immobile or < 50 yards
- 5 = wheelchair independent, including corners, > 50 yards
- 10 = walks with help of one person (verbal or physical) > 50 yards
- 15 = independent (but may use any aid; for example, stick) > 50 yards

STAIRS

- 0 = unable
- 5 = needs help (verbal, physical, carrying aid)
- 10 = independent

TOTAL (0–100): _____

ADDENDUM E

OSWESTRY LOWER BACK

PAIN DISABILITY

QUESTIONNAIRE

Orthopedic Specialists of Louisiana

Patient: _____

Date: _____

Oswestry Pain Questionnaire

This questionnaire has been designed to give Dr Nunley information as to how your pain has affected your ability to manage in everyday life. Please answer every section, and mark in each section **ONLY ONE BOX** which applies to you. We realize you may consider that two of the statements in any one section relate to you, but please just mark the box which *most closely* describes your problem.

Section 1 -- Pain Intensity
 I can tolerate the pain I have without having to use pain killers
 The pain is bad but I manage without taking pain killers.
 Pain killers give complete relief from pain
 Pain killers give moderate relief from pain
 Pain killers give very little relief from pain
 Pain killers have no effect on the pain and I do not use them

Section 2 -- Personal Care (Washing, Dressing, etc)
 I can look after myself normally without causing extra pain.
 I can look after myself normally but it causes extra pain
 It is painful to look after myself and I am slow and careful
 I need some help but manage most of my personal care
 I need help every day in most aspects of self care
 I do not get dressed, wash with difficulty and stay in bed

Section 3 -- Lifting
 I can lift heavy weights without extra pain
 I can lift heavy weights but it gives extra pain
 Pain prevents me from lifting heavy weights off the floor, but I can manage if they are conveniently positioned, e.g. on a table.
 Pain prevents me from lifting heavy weights, but I can manage light to medium weights if they are conveniently positioned
 I can lift only very light weights
 I cannot lift or carry anything at all

Section 4 -- Walking
 Pain does not prevent me from walking any distance
 Pain prevents me from walking more than 1 mile
 Pain prevents me from walking more than 1/2 mile
 Pain prevents me from walking more than 1/4 mile
 I can only walk using a stick or crutches
 I am in bed most of the time and have to crawl to the toilet

Section 5 -- Sitting
 I can sit in any chair as long as I like
 I can only sit in my favorite chair as long as I like
 Pain prevents me from sitting more than 1 hour
 Pain prevents me from sitting more than 1/2 hour
 Pain prevents me from sitting more than 10 minutes
 Pain prevents me from sitting at all

Section 6 -- Standing
 I can stand as long as I want without extra pain
 I can stand as long as I want but it gives me extra pain
 Pain prevents me from standing more than 1 hour
 Pain prevents me from standing more than 1/2 hour
 Pain prevents me from standing more than 10 minutes
 Pain prevents me from standing at all

Section 7 -- Sleeping
 Pain does not prevent me from sleeping
 I can sleep well only by using tablets
 Even when I take tablets I have less than six hours sleep
 Even when I take tablets I have less than four hours sleep
 Even when I take tablets I have less than two hours sleep
 Pain prevents me from sleeping at all

Section 8 -- Sex Life
 My sex life is normal and causes no extra pain
 My sex life is normal but causes some extra pain
 My sex life is nearly normal but is very painful
 My sex life is severely restricted by pain
 My sex life is nearly absent because of pain
 Pain prevents any sex life at all

Section 9 -- Social Life
 My social life is normal and gives me no extra pain
 My social life is normal but increases the degree of pain
 Pain has no significant effect on my social life apart from limiting my more energetic interests, e.g. dancing, etc.
 Pain has restricted my social life and I do not go out as often.
 Pain has restricted my social life to my home
 I have no social life because of pain

Section 10 -- Traveling
 I can travel anywhere without extra pain
 I can travel anywhere but it gives me extra pain
 Pain is bad but I manage journeys over two hours
 Pain restricts me to journeys of less than one hour
 Pain restricts me to short necessary journeys under 30 minutes
 Pain prevents me from traveling except to the doctor or hospital

Number of Points: _____

Total Possible: _____

Score: _____ %

ADDENDUM F

DASH

DISABILITIES OF THE

ARM, SHOULDER AND

HAND

DISABILITIES OF THE ARM, SHOULDER AND HAND

THE DASH

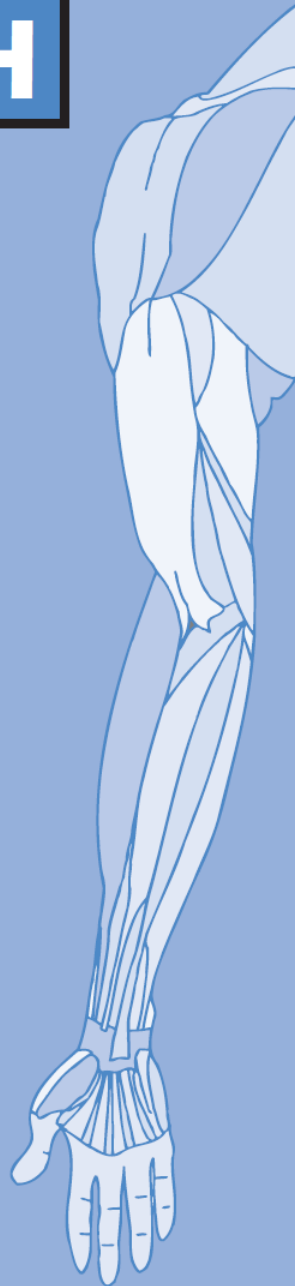
INSTRUCTIONS

This questionnaire asks about your symptoms as well as your ability to perform certain activities.

Please answer *every question*, based on your condition in the last week, by circling the appropriate number.

If you did not have the opportunity to perform an activity in the past week, please make your *best estimate* on which response would be the most accurate.

It doesn't matter which hand or arm you use to perform the activity; please answer based on your ability regardless of how you perform the task.



DISABILITIES OF THE ARM, SHOULDER AND HAND

Please rate your ability to do the following activities in the last week by circling the number below the appropriate response.

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. Open a tight or new jar.	1	2	3	4	5
2. Write.	1	2	3	4	5
3. Turn a key.	1	2	3	4	5
4. Prepare a meal.	1	2	3	4	5
5. Push open a heavy door.	1	2	3	4	5
6. Place an object on a shelf above your head.	1	2	3	4	5
7. Do heavy household chores (e.g., wash walls, wash floors).	1	2	3	4	5
8. Garden or do yard work.	1	2	3	4	5
9. Make a bed.	1	2	3	4	5
10. Carry a shopping bag or briefcase.	1	2	3	4	5
11. Carry a heavy object (over 10 lbs).	1	2	3	4	5
12. Change a lightbulb overhead.	1	2	3	4	5
13. Wash or blow dry your hair.	1	2	3	4	5
14. Wash your back.	1	2	3	4	5
15. Put on a pullover sweater.	1	2	3	4	5
16. Use a knife to cut food.	1	2	3	4	5
17. Recreational activities which require little effort (e.g., cardplaying, knitting, etc.).	1	2	3	4	5
18. Recreational activities in which you take some force or impact through your arm, shoulder or hand (e.g., golf, hammering, tennis, etc.).	1	2	3	4	5
19. Recreational activities in which you move your arm freely (e.g., playing frisbee, badminton, etc.).	1	2	3	4	5
20. Manage transportation needs (getting from one place to another).	1	2	3	4	5
21. Sexual activities.	1	2	3	4	5

DISABILITIES OF THE ARM, SHOULDER AND HAND

	NOT AT ALL	SLIGHTLY	MODERATELY	QUITE A BIT	EXTREMELY
22. During the past week, to what extent has your arm, shoulder or hand problem interfered with your normal social activities with family, friends, neighbours or groups? (circle number)	1	2	3	4	5

	NOT LIMITED AT ALL	SLIGHTLY LIMITED	MODERATELY LIMITED	VERY LIMITED	UNABLE
23. During the past week, were you limited in your work or other regular daily activities as a result of your arm, shoulder or hand problem? (circle number)	1	2	3	4	5

Please rate the severity of the following symptoms in the last week. (circle number)

	NONE	MILD	MODERATE	SEVERE	EXTREME
24. Arm, shoulder or hand pain.	1	2	3	4	5
25. Arm, shoulder or hand pain when you performed any specific activity.	1	2	3	4	5
26. Tingling (pins and needles) in your arm, shoulder or hand.	1	2	3	4	5
27. Weakness in your arm, shoulder or hand.	1	2	3	4	5
28. Stiffness in your arm, shoulder or hand.	1	2	3	4	5

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	SO MUCH DIFFICULTY THAT I CAN'T SLEEP
29. During the past week, how much difficulty have you had sleeping because of the pain in your arm, shoulder or hand? (circle number)	1	2	3	4	5

	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
30. I feel less capable, less confident or less useful because of my arm, shoulder or hand problem. (circle number)	1	2	3	4	5

DASH DISABILITY/SYMPTOM SCORE = $\frac{(\text{sum of } n \text{ responses}) - 1}{n} \times 25$, where n is equal to the number of completed responses.

A DASH score may not be calculated if there are greater than 3 missing items.

DISABILITIES OF THE ARM, SHOULDER AND HAND

WORK MODULE (OPTIONAL)

The following questions ask about the impact of your arm, shoulder or hand problem on your ability to work (including homemaking if that is your main work role).

Please indicate what your job/work is: _____

I do not work. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for your work?	1	2	3	4	5
2. doing your usual work because of arm, shoulder or hand pain?	1	2	3	4	5
3. doing your work as well as you would like?	1	2	3	4	5
4. spending your usual amount of time doing your work?	1	2	3	4	5

SPORTS/PERFORMING ARTS MODULE (OPTIONAL)

The following questions relate to the impact of your arm, shoulder or hand problem on *playing your musical instrument or sport or both*.

If you play more than one sport or instrument (or play both), please answer with respect to that activity which is most important to you.

Please indicate the sport or instrument which is most important to you: _

I do not play a sport or an instrument. (You may skip this section.)

Please circle the number that best describes your physical ability in the past week. Did you have any difficulty:

	NO DIFFICULTY	MILD DIFFICULTY	MODERATE DIFFICULTY	SEVERE DIFFICULTY	UNABLE
1. using your usual technique for playing your instrument or sport?	1	2	3	4	5
2. playing your musical instrument or sport because of arm, shoulder or hand pain?	1	2	3	4	5
3. playing your musical instrument or sport as well as you would like?	1	2	3	4	5
4. spending your usual amount of time practising or playing your instrument or sport?	1	2	3	4	5

SCORING THE OPTIONAL MODULES: Add up assigned values for each response; divide by 4 (number of items); subtract 1; multiply by 25.

An optional module score may **not** be calculated if there are any missing items.



ADDENDUM G

CLINICAL MOBILITY

SCALE

Clinical Mobility Scale

Overview:

A Clinical Mobility Scale can be used to assess a patient's degree of mobility over time.

Parameters:

(1) upright posture

(2) walking

(3) gait

(4) sitting

(5) stair climbing

(6) hand-held appliances

(7) wheelchair

(8) time usage

Mobility Parameter	Finding	Rating
upright posture (how patient functions with or without prosthesis)	does not stand	0
	stands only with personal assistance	1
	stands with the assistance of a hand-held appliance (crutch cane walker)	2
	stands without assistance	3
walking (how patient functions with or without prosthesis)	does not walk	0
	walks only with personal assistance	1
	walks with the assistance of a hand-held appliance (crutch cane walker)	2
	walks without assistance	3
gait (how patient functions with or without prosthesis)	walks slowly or not at all	0
	walks at a moderately slow pace	1
	walks briskly	2
	can jog or run	3
sitting (how patient functions with or without prosthesis)	sits only for short periods of time and prefers to lie down	0

	sits without discomfort for short periods of time (1 hour)	1
	sits without discomfort for longer periods of time (over 1 hour)	2
	sits without discomfort	3
stair climbing (how patient functions with or without prosthesis)	cannot climb stairs	0
	climbs stairs with assistance of another person	1
	climbs stairs with assistance of hand rail and/or crutches	2
	climbs stairs unassisted	3
hand-held appliances (crutches and canes)	cannot use crutches or cane	0
	must use crutches	1
	uses single crutch or cane or two crutches intermittently	2
	uses no hand-held appliance	3
wheelchair	moves with the aid of wheelchair most of time	0
	moves with the aid of wheelchair only for long distances	1
	occasionally uses wheelchair	2
	never uses wheelchair	3
time usage	spends most day in bed or on couch at home	0
	spends most of day in chair at home	1
	spends most of day ambulatory but confined to the house	2
	spends most of day ambulatory	3

mobility assessment score = (points for upright posture) + (points for walking) + (points for gait) + (points for sitting) + (points for stair climbing) + (points for hand-held appliances) + (points for wheelchair) + (points for time usage)

Interpretation:

- minimum score 0 = least mobile
- maximum score 24 = most mobile

References:

Barofsky I Cohen SJ Sugarbaker PH. Chapter 16: Selecting a quality of life assessment instrument: Standardized tests clinical assessments or custom-designed instruments. pages 239 - 249. IN:

Wenger NK Mattson ME et al. Assessment of Quality of Life in Clinical Trials of Cardiovascular Therapies. Le Jacq Publishing Inc. 1984.

Sugarbaker PH Barofsky I et al. Quality of life assessment of patients in extremity sarcoma clinical trials. Surgery. 1982; 91: 17-23.

ADDENDUM H

EQ5D HEALTH

QUESTIONNAIRE

EQ - 5D

Health Questionnaire

(UK English version)

By placing a tick in one box in each group below, please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in walking about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

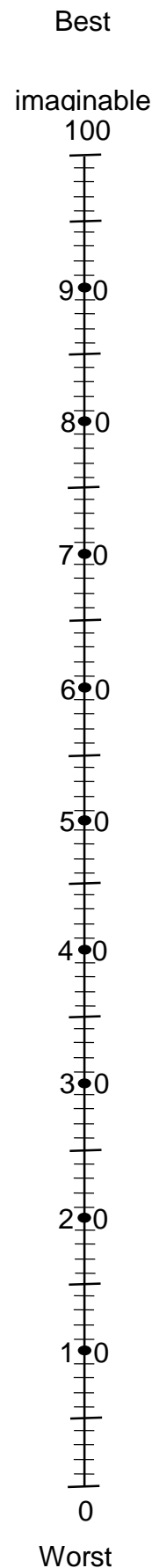
Compared with my general level of health over the past 12 months, my health state today is:

- Better PLEASE TICK
- Much the same ONE
- Worse BOX

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

**Your own
health state**



Because all replies are anonymous, it will help us to understand your answers better if we have a little background data from everyone, as covered in the following questions.

- | | | | |
|--|--------------------------|--------------------------|-------------|
| 1. Have you experienced serious illness? | Yes | No | |
| <i>in you yourself</i> | <input type="checkbox"/> | <input type="checkbox"/> | PLEASE TICK |
| <i>in your family</i> | <input type="checkbox"/> | <input type="checkbox"/> | |
| <i>in caring for others</i> | <input type="checkbox"/> | <input type="checkbox"/> | APPROPRIATE |

2. What is your age in years ?

- | | | | |
|-------------|--------------------------|--------------------------|-------------|
| 3. Are you: | Male | Female | |
| | <input type="checkbox"/> | <input type="checkbox"/> | PLEASE TICK |

- | | | | |
|------------------|--------------------------|--|-------------|
| 4. Are you: | | | APPROPRIATE |
| a current smoker | <input type="checkbox"/> | | |
| an ex-smoker | <input type="checkbox"/> | | PLEASE TICK |
| a never smoker | <input type="checkbox"/> | | APPROPRIATE |

- | | | | |
|--|--------------------------|--------------------------|-------------|
| 5. Do you now, or did you ever, work in health or social services? | Yes | No | |
| | <input type="checkbox"/> | <input type="checkbox"/> | PLEASE TICK |
| | | | APPROPRIATE |
- If so, in what capacity?

- | | | | |
|--|--------------------------|--|-------------|
| 6. Which of the following best describes your main activity? | | | |
| <i>in employment or self employment</i> | <input type="checkbox"/> | | |
| <i>retired</i> | <input type="checkbox"/> | | PLEASE TICK |
| <i>housework</i> | <input type="checkbox"/> | | APPROPRIATE |
| <i>student</i> | <input type="checkbox"/> | | |
| <i>seeking work</i> | <input type="checkbox"/> | | |
| <i>other (please specify)</i> | <input type="checkbox"/> | | |

- | | | | |
|--|--------------------------|--------------------------|-------------|
| 7. Did your education continue after the minimum school leaving age? | Yes | No | PLEASE TICK |
| | <input type="checkbox"/> | <input type="checkbox"/> | APPROPRIATE |

- | | | | |
|---|--------------------------|--------------------------|-------------|
| 8. Do you have a Degree or equivalent professional qualification? | Yes | No | PLEASE TICK |
| | <input type="checkbox"/> | <input type="checkbox"/> | APPROPRIATE |

9. If you know your postcode, would you please write it here

ADDENDUM I

DEPARTMENT OF

HEALTH ETHICS

APPROVAL LETTER



STRATEGY & HEALTH SUPPORT

healthres@pgwc.gov.za
tel: +27 21 483 9907; fax: +27 21 483 9895
1st Floor, Norton Rose House, 8 Riebeeck Street, Cape Town, 8001
www.capegateway.gov.za

REFERENCE: RP 124/2011
ENQUIRIES: Dr V Appiah-Baiden

P O Box 19063
Tygerberg
7505

For attention: Prof M de Villiers, Ms G Mji
Ms S Statham, Ms S Gcaza
Ms A Rhoda

Re: A study to investigate the functional rehabilitation outcomes of patients undergoing physical rehabilitation at the Gugulethu Community Health Center.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research.

Please contact the following people to assist you with any further enquiries.

Gugulethu CHC Ms Mabusela (021) 637 1280

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

A handwritten signature in black ink, appearing to read "T. Naledi".

**DR T NALEDI
DIRECTOR: HEALTH IMPACT ASSESSMENT**

DATE: 18/11/2011

CC DR J CLAASSEN

DIRECTOR: KLIPFONTEIN/MITCHELLS PLAIN

ADDENDUM J

UNIVERSITY OF

STELLENBOSCH ETHICS

APPROVAL LETTER



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

25 July 2011

MAILED

Ms E Pegram
C/O S Statham
Department of Physiotherapy
4th Floor, Teaching Block
Room 4081A

Dear Ms Pegram

A Study to Investigate the Functional Rehabilitation Outcomes of Patients Undergoing Physical Rehabilitation at Gugulethu Community Health Centre.

ETHICS REFERENCE NO: N11/05/144

RE : APPROVAL

A panel of the Health Research Ethics Committee reviewed this project on 13 May 2011; the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 22 July 2011 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 future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds) 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. Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239

The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

July 2011 12:21

Page 1 of 2



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences





UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvenoot • your knowledge partner

Approval Date: 22 July 2011

Expiry Date: 22 July 2012

Yours faithfully

MS CARLI SAGER

RESEARCH DEVELOPMENT AND SUPPORT

Tel: +27 21 938 9140 / E-mail: carlis@sun.ac.za

Fax: +27 21 931 3352

5 July 2011 12:21

Page 2 of 2



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences



Verbind tot Optimale Gesondheid · Committed to Optimal Health
Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352