EVALUATION OF THE FUNCTIONAL REHABILITATION OUTCOMES OF CLIENTS AFTER RECEIVING PHYSICAL REHABILITATION AT TC NEWMAN COMMUNITY DAY CENTRE

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DECLARATION

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

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ABSTRACT

Introduction: Rehabilitation is an important tool in helping persons with disabilities to recover and attain functional independence as far as possible in achieving a good quality of life. However, scarce rehabilitation services and barriers may prevent full attainment of functional outcomes and impact on quality of life.

Even though guidelines exist for rehabilitation services there remains a need to standardise documentation of outcomes, implementing appropriate outcomes tools and defining expectations for rehabilitation. Headcounts alone cannot fully account for rehabilitation services. The NRP echoes monitoring and evaluation of rehabilitation services, so as to measure its effectiveness and relevance. A lack of clear understanding of rehabilitation outcomes may result in it being overlooked during planning for resources. While on the other hand outcomes can be used to motivate for more rehabilitation services.

Aim of the Study: The aim of the study was to evaluate the functional rehabilitation outcomes of clients after receiving physical rehabilitation at TC Newman Community Day Centre.

Method:

Study Design: A pre-test, post-test descriptive longitudinal study using mainly quantitative methods of data collection was applied.

Study setting: The research was conducted at TC Newman CDC.

Study Population and Sampling method: Study participants were those presenting with one of the five most prevalent conditions at TC Newman CDC, indicated from therapist's data working there, during 2008/2009. Pre-tests were administered to 114 participants adhering to the inclusion criteria. Only 12 participants of the 114, returned for follow up assessments.

The low return rate of participants was a critical concern for the researcher, which led to the inclusion of home visits (8) and telephonic follow up (16), to increase the number of responses from the outcome measures and to determine why participants

did not return for follow up appointments. Only 20 participants completed the pre- and post-tests.

Data collection instruments: Data collection instruments used in the study, on demographics, were designed by the SANPAD research group and validated by rehabilitation experts. The study further used validated functional diagnostic specific outcome measures to answer the research question.

Data collection process: Pre-tests and post-tests were administered at TC Newman CDC by a trained research assistant. The telephonic follow up and data extraction from the patient folders were done by the researcher. Home visits were administered by the research assistant, with support from the researcher.

Data analysis: Quantitative data was analysed by a statistician from the University of Stellenbosch. Qualitative data obtained from the telephonic follow up was thematically analysed, to identify why clients did not return for their follow up appointments.

Results: Despite the low return rate, results indicated an overall improvement in functioning, with mobility, as the one area of functioning demonstrating significant improvement after rehabilitation. Participants that returned for follow up sessions also indicated feeling better after receiving therapy.

In addition to transport and income, environmental factors having the most influence on participants attendance to follow up therapy, were health systems challenges such as appointment systems, poor follow-up and inadequate documentation. Overall participants indicated they experienced their rehabilitation positively.

Conclusion:

Contextual factors should be taken into account when planning rehabilitation services, to ensure optimal access and the best possible outcomes for clients needing rehabilitation. Even though rehabilitation services at TC Newman CDC are available, the extent of accessibility is questionable, thus it is important to look at how rehabilitation services are delivered.

Results will be presented to management of the CWD office, Drakenstein sub-district and therapists employed by the CWD.

KEY TERMS: Physical rehabilitation, functional outcomes, environmental factors, standardised outcome measures

ABSTRAK

Rehabilitasie word erken as 'n belangrike proses om persone met gestremdhede so onafhanklik moontlik te help funksioneer en sodoende die bes moontlike kwaliteit van lewe te hê. Beperkte rehabilitasie dienste en omgewingsfaktore, mag daartoe bydra dat toeganklikheid en uitkomste vir rehabilitasie soms beperk is.

Alhoewel daar riglyne vir rehabilitasie is, is daar 'n behoefte vir gestandardiseerde meetinstrumente, dokumentering van uitkomste en 'n pakket van dienste wat gelewer moet word.

Koptellings, van hoeveel pasiënte gesien word by 'n fasiliteit, is nie 'n aanduiding van wat die uitkomste van dienste is nie.

Die Nasionale Rehabilitasie Beleid, benadruk die belangrikheid van monitering en evaluering van dienste, om sodoende , die effektiwiteit van die rehabilitasie te bepaal. Indien rehabilitasie dienste nie goed geevalueer en verstaan word nie, kan dit 'n negatiewe effek hê, wanneer dienste en hulpbronne vir hierdie dienste beplan word.

Doel van studie: Die evaluering van funksionele uitkomste van deelnemers, nadat hulle rehabilitasie ontvang het, asook om die struikelblokke vir rehabilitasie te help identifiseer.

Metodologie:

Studie ontwerp: 'n Beskrywende metodologie was gebruik. Vraelyste wat vir die navorsing gebruik was, is deur 'n opgeleide veldwerker geadministreer. Dit het 'n voor- en, na-toets wat ongeveer 4-6 weke later geadministreer is.

Plek van studie: Navorsing het plaasgevind by TC Newman Gemeenskap Gesondheid Sentrum (GGS), die enigste buite pasiënte rehabilitasie diens, in die Paarl.

<u>Studie populasie en sampel</u>: Deelnemers in die studie het pasiënte ingesluit, met die vyf (5) mees algemeenste diagnoses wat geïdentifiseer was gedurende 2009, deur terapeute werksaam by TC Newman GGS.

Een Honderd en Veertien (114) deelnemers het aan die aanvanklike evaluering deelgeneem, waarvan net twaalf (12) deelnemers vir die herevaleueirng opgedaag het. Hierdie beperkte (12) getal deelmeners, het daartoe bygedra dat die navorser tuisbesoeke (8) en telefoonopvolg(16) gedoen het, om sodoende die hoeveelheid deelnemers te probeer vermeerder, asook om te bepaal, hoekom pasiënte nie vir hulle opvolg sessies opgedaag het nie.

<u>Instrumente gebruik, met die insameling van data</u>: Instrumente het gefokus op demografiese en funksionele uitkomste van deelnemers. Die demografiese vraelyste was deur die SANPAD navorsingsgroep ontwikkel en die vraelyste vir funksionele uitkomste was bekende instrumente en diagnosties spesifiek.

<u>Proses gebruik in die versameling van data:</u> Die aanvanklike en herevaluering van deelnemers was geadministreer deur 'n opgeleide navorsingsassistent. Telefoniese opvolg en versameling van data uit deelnemers se lêers is deur die navorser self gedoen. Tuisbesoek is deur die navorsingsassistent geadministreer met ondersteuning van die navorser.

<u>Data analise:</u> Kwantitatiewe data was geanaliseer deur 'n statikus by die Universiteit van Stellenbosch. Kwalitatiewe data was volgens temas geanaliseer deur die navorser deur gebruik te maak van die terugvoer vanaf die deelnemers tydens die telefoniese opvolg.

Resultate: Ten spyte van die lae terugkeersyfer, was daar 'n beduidende verbetering in die uitkomste van deelnemers t.o.v hul mobiliteit. Deelnemers wat geherevalueer is, het aangedui dat hulle beter voel nadat hulle terapie ontvang het. Sosio-ekomoniese faktore soos vervoer en inkomste het 'n negatiewe invloed gehad op bywoning. Uitdagings geïdentifiseer in die gesondheidssisteem was: afspraaksisteme, swak opvolg en onvoldoende dokumentasie.

Gevolgtrekking: Omgewings- en persoonlike faktore moet altyd in ag geneem word wanneer rehabilitasie dienste beplan en gelewer word, om sodoende optimale toegang en die bes moontlike uitkomste vir pasiënte te verseker. Ten spyte daarvan dat rehabilitasie dienste by TC Newman GGS beskikbaar is, het hierdie studie bewys dat die mate van toeganklikheid vir dienste bevraagteken kan word en dus is dit belangrik om te kyk hoe word rehabilitasie dienste gelewer.

Resultate van hierdie studie sal bekend gemaak word aan die bestuur van die Kaapse Wynland Distrik kantoor, asook die bestuur van die Drakenstein Sub Distrik en terapeute werksaam by TC Newman GGS.

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What a journey!

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LIST OF ABBREVIATIONS

ADL   Activities of Daily Living

AD   Assistive Devices

AIMS   Arthritis Impact Measurement Scale

AZ   Adapted Zambian

BI   Barthel Index

CBR   Community Based Rehabilitation

CBS   Community Based Services

CDC   Community Day Centre

CHC   Community Health Centre

CHW   Community Health Worker

CMS   Clinical Mobility Scale

COPD   Chronic Obstructive Pulmonary Disease

CP   Cerebral Palsy

CRS   Centre for Rehabilitation Studies

CSI   Caregivers Strain Index

CSP   Comprehensive Service Plan

CVA   Cerebral Vascular Accident

CWD   Cape Winelands District

DASH   Disability of the Arm, Shoulder and Hand

DHS	District Health System
DoH	Department of Health
EQ	Euroqol
GAT	Grip Ability Test
GHS	General Household survey
HBC	Home Based Care
HIV	Human Immunodeficiency virus
HPCSA	Health Professional Council of South Africa
ICF	International Classification of Function
ICIDH	International classification of impairment, disability and health
INDS	Integrated National Disability Strategy
LBP	Lower Back Pain
M&E	Monitoring and Evaluation
NGO	Non-Government Organisation
NRP	National Rehabilitation Policy
OA	Osteoarthritis
OBS	Outcomes Based Study
ODI	Oswestry Disability Index
OT	Occupational therapist
PCE	Patient Centred Experience

PHC	Primary Health Care
PT	Physiotherapist
PWD	Persons with Disabilities
SANPAD	South African Netherlands Research Program on Alternatives in Development
SSA	Sub-Saharan Africa
ST	Speech Therapist
TB	Tuberculosis
UN	United Nations
UNCRPD	United Nation Convention on the Rights of People with Disabilities
US	University of Stellenbosch
UWC	University of the Western Cape
WCRC	Western Cape Rehabilitation Centre
WHO	World Health Organization
YLL	Years Lost To Life

GLOSSARY OF TERMS

Activity: "is the execution of a task or action by an individual".[1(p. 10)]

Activity limitations: "are difficulties an individual may have in executing activities. An activity limitation may range from a slight to a severe deviation in terms of quality or quantity in executing the activity in a manner or to the extent that is expected of people without the health condition".[1(p. 10)]

Assistive devices: "A device that has been designed, made or adapted to assist a person to perform a particular task is known as an assistive device. Many people with disabilities benefit from the use of one or more assistive devices. Some common types of assistive devices are: mobility devices (e.g. walking sticks, wheelchairs), prostheses (e.g. artificial legs), orthoses (e.g. hand splint), visual devices (e.g. glasses, white canes) and hearing devices (hearing aids). To ensure that the assistive devices are used effectively, important aspects of their provision include user education, repair, replacement and environmental adaptations in the home and community".[2]

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".[3]

Community integration: "Community integration is an advanced rehabilitation outcome where the person with the disability has the ability to function in the community. It includes self-directed management of personal affairs, community mobility, social competency, self-directed health monitoring, the ability to manage one's own finances and participation in recreational activities".[4]

Contextual factors: "are factors that together constitute the complete context of an individual's life and in particular the background against which health states are classified. There are two components of contextual factors: Environmental factors and personal factors.[1(p. 10)]

Disability: "The UNCRPD adopts a social model of disability, and defines disability as including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[5]

Environmental factors: "make up the physical, social and attitudinal environment in which people live and conduct their lives".[1(p. 10)]

Functioning: "is an umbrella term encompassing all body functions, activities and participation".[1(p. 10)]

Outcomes: "refer to the effects of treatment, programs or policies on individuals or populations. Outcomes may also be defined as changes in status attributed to a specific intervention or treatment".[6]

Impairment: is loss or abnormality in body structure or physiological function (including mental functions). Abnormality here is used strictly to refer to significant variation from established statistical norms (i.e. as a deviation from population mean within measured standards) and should be used only in this sense.[1 (p. 10)]

Participation: "is involvement in a life situation".[1(p. 10)]

Participation restrictions: "are problems an individual may experience in involvement in life situations".[1(p.10)]

Personal factors: "are contextual factors that relate to the individual such as age, gender, social status, life experiences which are not currently classified in the ICF but which users may incorporate in their applications of the classification".[1(p.10)]

Primary Health Care: "is essential health care based on practical, scientifically sound and socially acceptable methods and technology made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community. It is

the first level of contact of individuals, the family and community with the national health system bringing health care as close as possible to where people live and work, and constitutes the first element of a continuing health care process".[7]

Rehabilitation: "Rehabilitation is a goal orientated and time limited process aimed at enabling an impaired person to reach an optimum mental, physical and social functional level, thus providing one with tools to change one's life when and where necessary".[7] Rehabilitation is also the combined and co-ordinated use of medical, social, educational and vocational measures for training or re-training the individual to the highest possible level of functional activity. Rehabilitation can be achieved through modification of the impairment through medical and surgical methods, compensation for loss of function with assistive devices and techniques, facilitation of social adjustment and acceptance and modification of the environment.[1,8]

South African Netherlands Research Programme on Alternatives in Development (SANPAD): SANPAD is a collaborative research programme financed by the Netherlands Ministry of Foreign affairs and has facilitated and financed research projects, search capacity building and research support activities over the past fifteen years in South Africa.[9]

CHAPTER 1: INTRODUCTION TO THE STUDY

1.1 BACKGROUND

This chapter provides the reader with a background for the study, including the motivation, and the significance of the study.

In 1978 the Alma-Ata declaration on primary health care, affirmed access to basic health services as a fundamental human right, and was ardently perceived as a means of achieving health for all by the year 2000.[10] PHC consists of four pillars, namely: promotive, preventive, curative and rehabilitative services.[8] The South African Department of Health's National Rehabilitation Policy (NRP), 2000, states that the Government of South Africa committed itself to bringing Health Services closer to the people by adopting the Primary Health Care (PHC) approach. In addition the South African Health Act, of 2003 also highlighted that health care services must be provided in line with the District Health Services framework, which emphasises Primary Health Care (PHC) as an approach in service delivery.[10]

Since the advanced outcome of rehabilitation is community integration, this implies that within a PHC delivery health model at district level, rehabilitation should feature strongly. The PHC approach and philosophy of accessibility, affordability and equity should ensure and allow for rehabilitation services to be rendered in communities, thereby becoming more available to the communities it serves.[8]

Primary healthcare is emphasized throughout the NRP. However, the implementation of this approach has posed challenges to the South African government. These challenges included factors such as severe health worker shortages, inequitable resource allocation, a medical model orientated service and a lack of managerial capacity.[11]

Rehabilitation is defined by the World Health Organization (WHO) 2001 as a process to enable a person to reach their optimal physical, sensory, psychological and social functional levels. Furthermore it provides the tools for disabled people to achieve independence, self-determination and community re-integration.[1,4]

Rehabilitation in the context of South Africa as a developing country, with limited resources, is not often seen as a high priority.[11] There are limited resources to meet the current needs for rehabilitation in South Africa.[12] Rehabilitation services should then be delivered on Primary Health Care (PHC) level with a focus on Community Based Rehabilitation (CBR) as a strategy to address the limited resources by involving the family and the community in the rehabilitation process.[13] This decentralisation of rehabilitation services to communities must be followed by the movement of appropriate and equitable resources to this level of care.

Policies guiding rehabilitation services in South Africa includes international policies such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), Community Based Rehabilitation (CBR) and national policies such as the National Rehabilitation Policy (NRP) and Health Care 2010, the strategic plan of the Western Cape Government, Department of Health.[13,14,15,]

Accessibility and affordability to all persons with disabilities are embedded in the above policies. Rehabilitation programs should thus speak to both the needs of individual persons with disabilities and their participation in society and thereby take into account accessibility and affordability of health and rehabilitation services.[14,13,15]

The Western Cape DOH developed a healthcare plan known as Healthcare 2010 that focuses on accessibility and providing healthcare including rehabilitation services at community level incorporating both facility and community based services.[15] PHC may improve access to rehabilitation services as this is often the first point of entry into the health system. Furthermore rehabilitation should be rendered ideally by a multi-disciplinary team and the highest aim is to enable persons with disabilities to return to their communities with the highest possible level of functional independence and the best quality of life.[15] Rehabilitation at PHC level in the HC 2010 document is described as low intensity and proposes an outcome based approach. Despite the scarcity of resources rehabilitation services can still be rendered by at least one rehabilitation professional, not necessarily everyday,[15] thereby facilitating inclusion and participation of persons with disabilities in their communities at their highest level of functioning.

In South Africa different policies as illustrated above have been developed over the past few years to guide rehabilitation service delivery. However, there is little or no evidence that rehabilitation services are aligned with current policies such as the National Rehabilitation Policy and the other policies as mentioned above.

Thus, despite the existence of a number of national policy frameworks for rehabilitation, full implementation of these frameworks in the Western Cape remains a challenge and is hindered by many factors. This may have resulted in underdeveloped rehabilitation services especially in rural areas, and where rehabilitation services are in existence, resources are often not equitable.[8] The general lack of evidence regarding the effect of rehabilitation services and its outcome on the quality of life of clients (disabled persons) more specifically in the Western Cape and generally in South Africa further exacerbate the lack of proper planning for rehabilitation services.[12,13] Thus this study evaluated the functional outcomes of clients after receiving rehabilitation, and highlighted barriers in the rehabilitation process.

1.2 INTRODUCTION

The South African Netherlands Research Program on Alternatives in Development (SANPAD) identified a need to evaluate rehabilitation services in the Western Cape.[9] TC Newman Community Day Centre, in the Drakenstein sub-district in Paarl, previously known as the Elangeni Rehabilitation Centre, was identified as one of the research sites to be evaluated in the SANPAD study, where rehabilitation services are rendered at PHC level in a rural setting.

Rehabilitation services in the Drakenstein sub-district, the largest of five sub-districts in the Cape Winelands District (CWD), are rendered at both Primary (PHC) and Secondary levels of care.

Prior to 2010 rehabilitation services at TC Newman CDC were situated in Elangeni Rehabilitation Centre and was rendered as a vertical program. This meant that rehabilitation services were rendered as an independent program alongside TC Newman CDC and did not form part of the routine primary health care services in TC

Newman CDC. This rehabilitation service was then managed by rehabilitation professionals who were appointed and employed at the centre.

The researcher, at the onset of the study, could not find any written or documented evidence at the research site, relating to how rehabilitation services were offered, the scope thereof and the functional outcomes of clients receiving therapy, other than a few clinical notes made by rehabilitation therapists within patient files. A research study, by Fredericks (2011), on the description and evaluation of the rehabilitation programme for persons with lower limb amputations at Elangeni Rehabilitation Centre, was the only evidence based study found of rehab services at the research site.[16]

With the onset of this research study, rehabilitation headcounts and the issuing of assistive devices were the only data elements that were reported on. Therapists at the research site captured additional data, which reflected the diagnoses seen and treated at the centre. These additional records were developed by rehabilitation professionals at Elangeni Rehabilitation Centre. This research study will report on the functional outcomes of clients after receiving rehabilitation and highlight barriers in the rehabilitation process and. This will assist in initiating the development of a framework that can be used in assessing rehabilitation outcome at TC Newman. This will further assist in understanding the effect of rehabilitation on clients that receive rehabilitation services.

1.3 STUDY PROBLEM

A multi-disciplinary rehabilitation team in the Drakenstein Sub-district has been delivering rehabilitation services at Elangeni Rehabilitation Centre, now known as TC Newman CDC for the past 10 years. There is currently a lack of evidence on programme outcomes for rehabilitation services at TC Newman CDC. Therefore it is not clear how therapy is being offered and the impact of this service on clients accessing the service. A vital component of rehabilitation is continual programme monitoring and evaluation.[8] This may provide information on programme outcomes for rehabilitation and possibly the appropriateness, relevance, effectiveness, efficiency and quality of the services rendered. In addition services, as with

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rehabilitation services cannot improve if feedback on the current performance and barriers is not available.[17,18]

Thus the focus of this study will only be on the functional outcomes of clients after having received rehabilitation at primary health care level so as to determine the extent of improvement if any after receiving rehabilitation as well as identifying barriers or facilitators that may influence the outcomes of rehabilitation rendered.

1.4 MOTIVATION FOR UNDERTAKING THE STUDY, POSSIBLE CONTRIBUTION AND SIGNIFICANCE OF THE STUDY

Rehabilitation services in the DOH have been established, but the effectiveness of these programmes needs to be evaluated. As noted above, one cannot improve a program or service if feedback on its current performance and challenges is not available. Evaluation is essential to improve program potential and to guide the implementation of similar programmes.[17] Thus this research study was done on site, so as to give the researcher the opportunity to get a better understanding of rehabilitation services in the Drakenstein sub-district, how these services are rendered, the utilisation of rehabilitation services, the factors influencing rehabilitation outcomes such as accessibility, cost, waiting times, therapy duration amongst others and create an opportunity to make evidence based changes to improve rehabilitation services. Furthermore, this research will evaluate the functional outcomes of individual clients who receive rehabilitation services currently rendered at TC Newman CDC. In so doing, this may assist in evaluating the outcomes of interventions used in rehabilitation and to inform rehabilitation client treatment goals and service delivery.

The research site was selected, based on the fact that the rehabilitation programme at TC Newman CDC, previously known as Elangeni Rehabilitation Centre, was established more than 10 years ago by the West Coast Winelands District, and is in a rural setting. The purpose for Elangeni was that it should provide a comprehensive rehabilitation service to all its clients. Rehabilitation services at Elangeni were to move from a mainly impairment focused, medical model, individual approach previously used at Paarl hospital. The renewed focus should have moved to include social integration, equalisation of opportunities and collaboration thereby facilitating

accessibility and rendering rehabilitation along a continuum of care. However it was found that Elangeni failed to implement a shift to the social model of disability and rehabilitation, and services were still provided according to the impairment focused medical model.[16] This rehabilitation service is now managed by the Cape Winelands District since 2009 and will give the researcher an opportunity to gain valuable knowledge and evidence based insight of rehabilitation services rendered at TC Newman CDC since its establishment.

Findings may emphasize strengths and challenges of rehabilitation services in a rural setting, and results from this study will be used by other researchers in the bigger SANPAD project to determine the alignment of rehabilitation services at District Health Level with other rehabilitation sites in the Western Cape and will also highlight environmental barriers that need to be addressed.

Furthermore, results from the study will be used to assist with the development of a standardised rehabilitation package of care at TC Newman CDC, identify possible data collection tools for rehabilitation services that are appropriate to the context, identify appropriate monitoring and evaluation guidelines, in ensuring the best possible outcomes for people with disabilities.

To this end, results and lessons learned from this research study will help to develop and guide rehabilitation service delivery in the Cape Winelands District, assist with future planning and adjustment of the rehabilitation service to ensure appropriateness and effectiveness of these services to people with disabilities and the broader community.[8]

1.5 STUDY OUTLINE

This study will follow the outline below:

Chapter 1 provided information on the background of the study, motivation for undertaking the study, study problem and the significance of the study was presented.

Chapter 2 will consist of a literature review relevant to the study. The research design and methodology will be described in Chapter 3. Chapter 4 will present the

results of the study, followed by a discussion of these results in Chapter 5. Chapter 6 will consist of a discussion of the conclusion, possible recommendations and highlight possible areas for further research studies.

1.6 SUMMARY

Rehabilitation is a process of assisting individuals to achieve their optimum quality of life and health within their circumstances. Furthermore, rehabilitation can be viewed as an approach that helps a person who is recovering from illness or injury to regain as much function as possible.[1] Rehabilitation can thus further be seen as an approach in assisting individuals to find ways of reaching optimum functional levels, and in doing so help to improve the quality of life even for the more elementary day-to-day activities that make up an individual's life. Thereby assisting and facilitating performance and participation within, the ability and context of the client.[19]

In the absence of evidence based information on the outcomes of clients receiving rehabilitation at the research site, this research aims to measure and describe the functional outcomes of clients, and to highlight barriers in the rehabilitation process.

CHAPTER 2: REVIEW OF THE LITERATURE

2.1 INTRODUCTION

The emphasis of this study was to look at the functional outcomes of clients after receiving rehabilitation services. The following topics namely: disability definitions, disability models, types of disability, the consequences of disability, the prevalence of disability (both a global and South African perspective) and demographics, were selected for the literature review to provide background and insight into the rehabilitation process, provide the framework for the study, and set the scene for the research.

The literature review will look at the Burden of Disease in the Cape Winelands district, followed by a discussion on rehabilitation, so as to create a better understanding of: what disability and rehabilitation is, the policies that influence rehabilitation, leading causes of disability, measuring disability, the most common diagnostic groups treated and seen for rehabilitation at TC Newman CDC, outcomes based rehabilitation, factors influencing therapy, patient compliance, outcome measurement tools and rehabilitation services delivered at the research site.

2.2 UNDERSTANDING DISABILITY

Disability is complex and not always easy to describe, because of its different dimensions and the different approaches and definitions. The various views and approaches from an individual, medical perspective to a more, social perspective and various policies makes disability complex to describe in trying to encompass and embrace the contribution of each view. These views will be further explored below. The National Rehabilitation Policy (NRP) of South Africa 2000, 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. [7] The World Report on Disability 2011, defines disability as part of the human condition, with almost everyone being temporarily impaired or permanently impaired at some point in their life, with a decrease in functioning, becoming more probable and prominent in old age.[20]

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A curative and mainly medical model approach resonates in both these documents. For the purpose of this study the UNCRPD definition of disability will be used as it not only focuses on a curative or medical approach as with the NRP and WHO 2011 definitions but also encompasses the social model of disability, and thereby acknowledging the role of persons with disabilities in society and hence communities. The UNCRPD defines disability as "including those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others".[5, 20]

Models of disability

Owing to the complexity in defining disability, models have been developed to create a better understanding of disability, how to measure it, and interpret the factors associated with disability.[21] Each model of disability represents a different view on health, functioning, disability and disease. Models of disability can be grouped into two main groups, a medical model and social model.[21,22]

According to Helender 1989, the medical model defines and categorizes disabled people by their impairment and it casts the individual person as the "victim" or 'the problem".[19] This model has been rejected by many disabled people.[23] In the view of the person with a disability, this model is dehumanising, where the focus is on the severity of the impairment. Disabled people further states that this model leads to a "low self-esteem, undeveloped life skills, poor education and consequent high unemployment levels".[22]

The medical model has a strong focus on the individual's health condition. A limitation identified in the medical model lies in its focus being merely on the medical intervention, not taking into account the interaction of the individual with their environment.[24] Historically in South Africa, rehabilitation in the public sector have been mainly institutionally based and focused on one to one therapy with professionals expected to have the ability to provide for the disabled body and alter it for the better.[11, 26]

Thus, this model does not fully take into account the influence of society and that of the environment on the person with a disability. Daniel Mont 2007, in his discussion paper states that disability has often been defined as a physical, mental or psychological condition that limits a person's activities. In the past this was interpreted as a medical model, that is, disability was linked to various medical conditions and was viewed as a problem, residing solely in the affected individual.[25] Therefore disability was previously viewed only as the result of an individual's inability to function. Interventions normally included medical rehabilitation and the provision of social assistance, for example a disability grant.

However, to this end, it seems the aim of the medical model was to eliminate or return impaired bodies to what society perceives as normal. In this view, rehabilitation has been defined as a process aimed at enabling persons with disabilities to reach and maintain optimum levels of functioning by providing them with the tools they need to achieve independence and self-determination.[11] One of the main criticisms of this model is that change is largely the responsibility of the individual with little attention to the barriers that hinder social integration and participation of people with disabilities.[26]

The development of the social model brings another view to disability. The Social Model is more people centred, focusing on understanding the disability, as a problem of exclusion from life/society and not as a medical problem requiring treatment. A difference is made between impairment and disability.[26] Though not denying the necessity for medical intervention the social model recognises disability as a human rights issue and focuses on interventions in the environment in trying to facilitate the full integration of people with disabilities into communities.[11] This could be why the social model is more acceptable to persons with disabilities, as opposed to the medical model.[22] However the social model is largely focussed on removing societal barriers and feminists argue that it ignores the personal experiences of persons with disabilities that includes impairment and pain.[11] The Social Model describes disability as the outcome of the interaction of the person and their environment, and is neither person nor environment specifically.[25]Supporters of the social model recognizes impairments, but do not see them as playing a role in disability.[24]Different views of impairment can lead to different approaches to disability therefore disability should

then be seen as neither medical nor social, but rather as a complex combination of the two models as persons with disabilities may experience problems resulting from their health condition.[27] Discourses about the dualism between impairment and disability resulted in a shift regarding the conceptualization of rehabilitation.[11]

The Biopsychosocial model emerged in 1977, under the development of psychiatrist George Engel. The biospsychosocial framework was proposed by Engel as an alternative to the predominant biomedical model of health. This model was unique in that it presented a holistic approach to health and therefore health care. Like the rehabilitation sciences and services, examines health from a variety of points of view (including the biomedical, the social, and the psychological), and similarly interprets "health" as the interaction of these three perspectives.[21, 24] The first WHO model, the International Classification of Impairments, Disabilities and Handicaps (ICIDH) was published in 1980 and was part of the ICD-10 (International Statistical Classification of Diseases and Related Health Problems). The ICIDH identified three concepts related to disability i.e. impairments, disabilities and handicaps to describe disability. It was based on a directional progression from disease to handicap.[24,22]

After having received much critique, this model underwent an international process of review, coordinated by the WHO. The aim of this review was to provide a more coherent and widely applicable set of classifications, which will be conceptually valid and useful.[65] In April 1997 the review process culminated in the ICIDH-2, which focused more on participation as opposed to its predecessor the ICIDH. However, despite being improved, the ICIDH-2 still was not comprehensive enough and the main critic against it was that it gave little meaning to the role of the environment in disablement. The WHO responded to the criticism and this led to the development of the International Classification of Functioning, Disability and Health (ICF).[22,24]

In recognizing the difference between disability and impairment, the ICF was developed as a way of understanding the interactions of the disease, environment and personal factors impacting on disability.[1, 11]

The ICF which is based the biopsychosocial model, defines disability as the outcome of the interaction between an individual's health condition and the context in which the individual finds themselves.[11] As well as recognising the impact of individual

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bodies and social factors in understanding disability, the main principle of the ICF is to understand disability as a continuum.

The International Classification of Functioning Disability and Health (ICF) is WHO's framework for measuring health and disability at both individual and population levels. The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001(resolution WHA 54.21). The ICF was endorsed for use in Member States as the international standard to describe and measure health and disability. [1] The International Classification of Functioning Disability and Health (ICF), developed by the World Health Organization (WHO), can be seen as the starting point for measuring functional capacity. The ICF does not identify people as having a disability based on a medical condition, but are classified according to a detailed description of their functioning in society. In the ICF disability and functioning are seen as outcomes of the interactions between health conditions (diseases and injuries) and contextual factors. Contextual factors consist of external environmental factors (attitudes, infrastructure, etc.) and internal personal factors (gender, age, education, etc.).[1, 20,28]

The ICF puts the notions of 'health' and 'disability' in a new light. It acknowledges that every human being can experience a decline in health and thereby experience some degree of disability. Disability is not something that only happens to a minority of people. The ICF thus 'mainstreams' the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact it places all health conditions on an equal footing allowing them to be compared using a common metric – the ruler of health and disability.[1] Furthermore the ICF takes into account the social aspects of disability and does not see disability only as a 'medical' or 'biological' dysfunction. By including Contextual Factors, in which environmental factors are listed the ICF allows one to record the impact of the environment on the person's functioning classification.[1,20,28] The use of the ICF has advantages for the client as well as the treating health professional. The biggest advantage for the client is integrating the social and medical aspects of the client's health condition, thus creating a holistic tool looking at the bio-psychosocial aspects of the person or individual.[28] The ICF provides a framework and common language to the health

professional to identify limitations of function and impairment, which is further used in the planning and implementation of rehabilitation interventions.[1,29]

The ICF will be used as a framework in this study to ensure a common way to present disability and the experience of the person with disability, as this may differ from one person to the next, even if they have the same impairment, the experience may differ.[1]
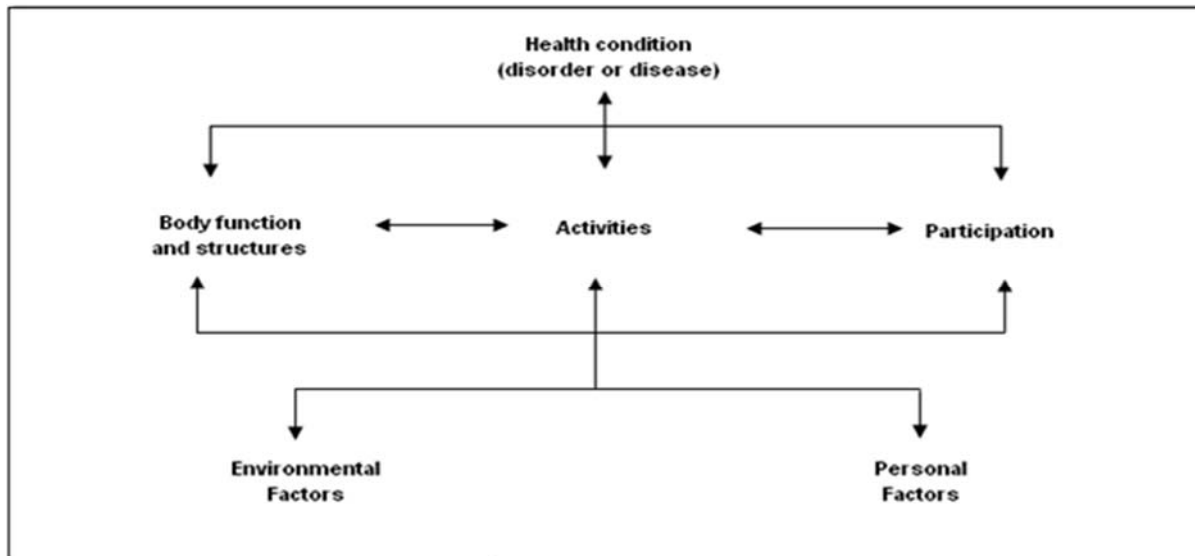
Figure 2.1: The ICF Framework

The ICF consists of three interrelated areas:

- Impairments (problems in body function or changes in body structure)
- Activity limitations (difficulty in executing functional activities)
- Participation restrictions (problems in participation in any area of life)

Experiencing difficulty in any of the above could infer disability. Health conditions refer to the physical manifestation of diseases, injuries or disorders. Impairments are related to specific changes in body functions and structure. The disability results from the interactions of health conditions with environmental and personal factors.[1]

The environmental factors describe the environment in which people live and function. There can be both be facilitators and barriers in the environment e.g. a wheelchair can be seen as a facilitator, but without a ramp, it can be seen as a barrier in terms of accessibility. Knowing the environmental factors in terms of their

level of facilitation or barrier creation, can help therapists in being more practical when planning interventions.[1,28]

The personal factors describe factors influencing the level of participation in society for example motivation and self-esteem. Personal factors also include the capacity to perform and the actual execution of those actions. For example an individual with a law degree, diagnosed with paraplegia, may still have the capacity to practise his profession, despite his disability, in contrast to a farm labourer with minimal education. It highlights the effect of the environment and life roles and how changes in these may influence an individual's performance.[1,28] The ICF provides a universal framework covering human functioning and puts disability on a continuum and does not categorise people with disabilities and it can be used by any profession.[24,30]

2.3 LEADING CAUSES OF DISABILITY

Major causes of disability in South Africa according to the Health Systems Trust appear to be illness, pre and perinatal problems such as birth trauma and injuries, accidents or violence.[31] During 2009 a Burden of Disease study in the Western Cape, highlighted the 10 leading causes of Years Lost to Life (YLL) in the Cape Winelands District (CWD) as: Tuberculosis (TB) (11.3%), Human Immuno-deficiency Virus (HIV) (11.0%), Homicide (6.6%), Road traffic injuries (6.5%), Stroke (5.2%), COPD(4.9%), Ischemic Heart Disease (4.5%), Pneumonia(4.1%), Lung cancer (3.7%) and Diabetes mellitus(3.4%).[32]

The above causes of YLL do not only result in mortality, but may also result in morbidity with disability. For example as HIV progresses, people living with HIV may develop impairments and may be considered to have a disability when participation in society is hindered by social, economic and political barriers.[33] TB may result in lung dysfunction, destruction of joints (skeletal TB) and paraplegia (TB of the nervous system). This may lead to activity limitation or permanent disability.[34] Road traffic injuries is the fourth leading cause of YLL in the CWD, this is similar to South African data, where 30 people are left disabled every day due to road traffic accidents.[35]

Stroke is the fifth leading cause of YLL in the CWD. This burden of stroke may result in up to 50% of survivors being chronically disabled.[36]

Rehabilitation therapists at TC Newman CDC indicated that clients diagnosed with strokes, are one of the common conditions and diagnoses treated by them.[44]

2.4 MEASURING DISABILITY

Evidence assists in making well informed decisions about disability policy and programmes. Understanding the statistics of people with disabilities and their environments can improve efforts to remove disabling barriers and provide services to allow people with disabilities to participate. The collection of appropriate, statistical research data at both national and international levels will help to formulate and implement policies to achieve agreed development goals.[20] This includes planning for comprehensive rehabilitation services for each health service level, however, disability is complex and not easy to measure.[23] Disability measurement varies from country to country, because of the varying definitions, methods of data collection and reporting tools.[20] It is often defined using only one aspect of disability, such as impairments e.g. a mental or physical condition. Sometimes other conditions, such as chronic health conditions, are not always seen as a disability, even though this condition creates a barrier to participation in the environment.[20] Schneider highlighted that using questions that ask about 'difficulty' rather than 'disability' provide more comprehensive and inclusive measures of disability with a clearer understanding of what is being measured.[37]

The continuum approach is becoming more prominent and it allows you to place disability on a scale ranging from minor difficulties in functioning to major impact on an individual's life.[20,23]

Data collection methods influence the type of results obtained e.g. in countries with a low disability prevalence rate, mainly developing countries, data on disability is often obtained by using a census approach (using measures focusing on a narrow choice of impairments). Where higher disability prevalence rates are reported, data is collected through surveys, taking into account and recording activity limitations and participation restrictions as well as impairments. [20]

The ICF provides a common platform for measurement and data collection. As a classification it can provide a standard for health and disability statistics and ensure that data collected encompasses its entire domain. This would ensure that definitions of disability are comparable, uniform methods of data collection and the development of appropriate instruments for rehabilitation.[20]

During the period 2002 - 2004, the WHO did a world health survey, with households in 70 Countries, using the ICF as a framework. Fifty-nine of these countries represented 64% of the global population.[20] The average prevalence rate on disability across these 59 countries, for people 18 and older was 15.6%. This percentage refers to adults who experienced significant functioning difficulties. The average prevalence rate for adults with very significant difficulty in functioning was 2.2%.[20]

In 2004 a Global Burden of Disease study was done to estimate the global disability prevalence. In this study 2.9% of the population was recorded to experience a severe disability and overall 15.3% of the world's population had some form of disability in varying degrees.[20] These findings are similar to the WHO world health survey.[20]

Similar to international studies, South Africa makes use of both a census and survey to determine population demographics, including disability prevalence rates. Censuses are the main means of gathering basic population and housing data required for social and economic development, policy interventions, their implementation and evaluation.[38,39] It covers whole populations, occur at long intervals, and can incorporate only a few disability-relevant questions.[20] Alternatively surveys have the option of providing richer information by means of more comprehensive questions including on institutionalized populations. For example, in developed countries, survey questions recognize people with disabilities for impair-ments in body function and structure, but also progressively more for activities, participation, and environmental factors.[20] In 2001 a Census was carried out in South Africa and data collection on disability was part of this census.[38] This census indicated that 5% of the South African population had a disability. The prevalence rates differed between provinces, with the Western Cape Province prevalence rate being 4.1%, and Gauteng 3.8%.[38] The types of disability recorded and reported on in

the Census of 2001 were: sight, hearing, communication, physical, intellectual and emotional disabilities. The prevalence of sight disability was the highest at (32%) followed by physical disability (30%), hearing (20%), emotional disability (16%), intellectual disability (12%) and lastly communication disability (7%).[38] The results of the data should be viewed with caution as the disabilities showing the highest prevalence are also the most visible types of disabilities.[38]

Census 2011 followed Census 2001 and indicated that >90% of people had "no difficulty or limitation preventing them from carrying out certain functions at the time of the census".[11,38,39] In this Census, questions were also asked relating to the use of assistive devices. These questions were not only asked to people presenting with limitations and resulted in the following data: 14% using spectacles, 12,3% using chronic medication, 3,2% walking sticks, 2,8% using hearing aids and 2,3% using wheelchairs.[39] The 2010 Round of Population Censuses adopted a set of disability questions developed by the Washington Group(WG). Questions related to difficulties people have in performing a series of activities such as; seeing, hearing, walking, communicating, and self-care, remembering and concentrating. Countries that adopted the WG questions believe that this method of measuring disability provides adequate estimates compared to the traditional approach where only severe disabilities are measured, leading to underestimation of people with disabilities.[39]

Data between Census 2001 and 2011 may not be comparable, because the questions related to disability, were asked differently and had different definitions.[39] With Census 2001, disability was defined as a physical or mental handicap which has lasted for six months or more, or was expected to last at least six months, which prevents the person from carrying out daily activities independently, or from participating fully in educational, economic or social activities.[38] In Census 2011, disability was defined as difficulties encountered in functioning due to body impairments or activity limitation, with or without the use of assistive devices.[39] The General Household Survey 2011 (GHS) excluded children under five in the survey and showed that 5.2% of people living in South Africa had a disability.[40]These findings are similar to the prevalence rate of 5% from the Census 2001.

A research paper on measuring disability in censuses: the case of South Africa, reported on findings from the South African census to develop a disability set of

questions for Census 2011. The survey contained three questionnaires: a Household Questionnaire with one member of the household responding for the whole household; a Living Standard Measure (LSM) questionnaire administered to the same person about the whole household; and an adult questionnaire administered to all household members 15 years and older. Analysis of the household survey data shows that the revised questions measures a broader notion of disability than that was measured in Census 2001 and therefore Census 2011 data on disability showed a higher prevalence.[41]

Schneider illustrates that using questions that ask about 'difficulty' rather than 'disability' provide more comprehensive and inclusive measures of disability with a clearer understanding of what is being measured. Asking about 'difficulty' provides an improved measure of disability status for better data collection to promote development, implementation and monitoring of disability-inclusive policies. [42] Thus the wording used in census and surveys should be consistent so as to provide an accurate reflection of disability measurement. This can again be seen with the community survey, 2007, that used different classifications and wording from the previous census.[43]

A community survey was done in 2007, which showed that 3% of the people in the Cape Winelands had a disability. [43] These disabilities were classified according to visual limitations, hearing, communication/speech impairment, physical disability (needs a wheelchair), intellectual (serious difficulty in learning), emotional behaviour and multiple disabilities. The prevalence of physical disabilities in the Drakenstein was highest, with approximately 1927 females and 941 males in need of a wheelchair.[43]

Measuring disability in South Africa is not consistent, but it is evident that people in South Africa and the Cape Winelands District have disabilities or experience limitation in functioning that would require some form of rehabilitation.

The following section will focus on specific conditions, groups of conditions and impairments that can cause disability and require rehabilitation. These relate to the five prevalent conditions of this study. The five prevalent conditions described in this study were identified retrospectively from therapists working at TC Newman CDC.

2.5 DIAGNOSTIC GROUPS

According to the data collection summary on Rehabilitation services at TC Newman CDC, 2008/2009, therapists recorded the 5 most prevalent conditions accessing rehabilitation at CDC, as children with developmental delays, lower back pain, arthritis, strokes and hand injuries.[44] These five most common conditions were used as the sample base for this study. Below is a further description of these five conditions.

2.5.1 Developmental delays

Developmental Delays are defined by the WHO (1980) as the "failure of a function or skill or an ability to perform a function within the normal range for children of that age".[45] Approximately 10–12% of children are affected by developmental disabilities. A research study in South Africa revealed the prevalence of disability among children in rural communities at approximately 6%.[45]

Although most of the world's children live in developing countries and may be at high risk for disability, little is known about the prevalence and causes of developmental disabilities in these countries. Some forms of developmental disability appear to be more common in low-income countries than in wealthier countries, despite the likelihood of higher mortality among children with disabilities in low-income countries.

Low-income countries report prevalence rates greater than 5 per 1,000 children, while prevalence estimations from industrialized countries being consistently below this. Major risk factors for developmental disabilities in some low-income countries include specific genetic diseases, higher frequency of births to older mothers, consanguinity, and specific micronutrient deficiencies and infections.[46]

The Western Cape (DOH) has protocols for developmental screening of children from 6 weeks, 6 months, 9 months and 18 months, beyond this age children need to be routinely weighed and dewormed. The main purpose of the developmental screening is to initiate early intervention so as to lessen the effects of impairment and disability. If 6% of children in South Africa, specifically rural communities have a disability, and there are protocols at PHC level in the Western Cape for

developmental screening and referral, it is concerning if these children are identified at an early age for possible rehabilitation intervention and are not referred for rehabilitation and if so identify possible reasons for this. Similarly this may also have contributed to children with developmental delays not being referred for rehabilitation at TC Newman CDC.

2.5.2 Lower back pain

Lower back pain (LBP) is one of the most common causes of disability and also seen as one of the most prevalent musculoskeletal conditions. Research studies showed that prevalence of LBP among adolescents was 12% and adults at 32%. Findings of this study further reported that the prevalence of LBP appears to be on the increase and becoming a concern when looking at the global burden of disease.[47]

At any one time, about 15% of adults experience LBP. LBP poses an economic burden, mainly in terms of the large number of work days lost. A large number of individuals with chronic LBP also display symptoms of chronic widespread pain. Whilst treatment intervention are aimed at reducing pain and improving activity/participation, including prevention of disability as well as maintenance of work capacity the compliance to attend regular therapy may not be well maintained as this may be impacted by real life demands such as work, caring for households in the absence of additional assistance.[47,48] The Oswestry Disability Questionnaire[74] (Appendix B1), is an outcomes measurement questionnaire that provides information on how clients activity and participation functioning are affected by back and leg pain. This information may assist in developing a treatment plan and outcomes for clients. Treatment guidelines may include fitness programmes; advice to stay active can reduce pain, improve function and can prevent LBP becoming chronic. Analgesics/ anti-inflammatory and muscle relaxants can reduce pain and can improve and maintain function. Multi-disciplinary treatment programmes can also reduce pain and can improve/maintain function in chronic LBP.[48]

From the patient folders and therapists notes it indicates that at TC Newman CDC, therapists manage lower back pain clients in much the same way as described above with the inclusion of exercise groups for clients presenting with chronic lower

back pain. Clients are also referred to Medical practitioners if medication is deemed necessary in the management of the condition.

Another research study on chronic lower back pain in the working aged adult also describes low back pain as an extremely common patient complaint and in most cases should resolve fairly quickly after the acute episode. However, a small number of patients develop chronic low back pain which evolves into a persistent disabling condition. Clients endure unremitting pain and often become functionally impaired.[40,48] Currently, it is difficult to find clinical guidelines on how best to manage chronic low back pain, and it remains a substantial treatment challenge for both physicians and patients.[47,48]

2.5.3 Arthritis

Arthritis is:

> "A disease characterised by joint inflammation. Joint injury can be caused by trauma or by the wear and tear of aging. The general term arthritis includes over 100 kinds of diseases, most of which last for life. In many forms of arthritis, injury is caused by the uncontrolled inflammation of autoimmune disease, in which the immune system attacks the body's own tissues. Common kinds of arthritis include osteoarthritis and rheumatoid arthritis."[42]

In the United States (US) approximately 38% of adults are diagnosed with arthritis, this equals 7.8% of the adult population. It is a major risk factor for disability and the effected population mainly includes men and women 45 years and older".[49]

Osteoarthritis (OA) is one of the most common forms of musculoskeletal disorders resulting in significant economic, social and psychological costs. OA increases in prevalence and also progresses with aging.[50]

It is commonly associated with a limited function characterised by joint pain, crepitus, stiffness after immobility and limitation of movement that can improve with rehabilitative interventions Education and self-management are also important elements in therapeutic intervention.[50]

The effectiveness of interventions in osteoarthritis (OA) is adherence to treatment interventions and advice. It is suggested that adherence to any intervention in OA is between 50 and 95% but many of these estimates are derived from clinical trials but the real levels in clinical practice may be much lower.[49,50] Factors influencing adherence are complex and multifactorial and, although information is available from other diseases, little is known about the relative contribution of these factors in adherence to treatment in OA. Little interventions to improve adherence have been evaluated in OA, and such studies would be limited by the lack of an accurate method for assessing adherence.[51]

The arthritis impact scale (AIMS) is a widely used disease-specific outcomes measurement tool that measures many aspects of health status. It is more responsive in patients with arthritis than any of the generic measures. The revised version, AIMS2 has good psychometric properties and the advantage of including measures of satisfaction with health and patients' priorities for improvement. The full-length versions are however time consuming to complete. The short-form (AIMS2-SF) similar psychometric properties to the full-length versions, may be more appropriate for postal surveys, studies where patients are required to complete several questionnaires, and in clinical practice.

2.5.4 Strokes

Stroke is defined by the WHO as:

> "the interruption of the blood supply to the brain, usually because a blood vessel bursts or is blocked by a clot. This cuts off the supply of oxygen and nutrients, causing damage to the brain tissue. The most common symptom of a stroke is sudden weakness or numbness of the face, arm or leg, most often on one side of the body. Other symptoms include: confusion, difficulty speaking or understanding speech; difficulty seeing with one or both eyes; difficulty walking, dizziness, loss of balance or coordination; severe headache with no known cause; fainting or unconsciousness".[52]

The burden of stroke on a population includes the mortality, the prevalence, the incidence and long term outcomes of these patients. Estimates indicated that more females than males died of strokes and the overall mortality rate was 124.9/100 000. There have been major advances in the treatment of acute strokes over the past few

years in South Africa which includes multi-disciplinary stroke units, the development of protocols and standardisation of care.[53]

The effects of a stroke depend on which part of the brain is injured and how severely it is affected. A very severe stroke can cause sudden death. Stroke is the second most common cause of death worldwide 2/3 of these deaths occur in developing parts of the world, such sub-Saharan Africa (SSA). Strokes also have a high morbidity, leaving 50% of survivors chronically disabled.[36]

The South African guideline for the management of stroke and transient ischaemic stroke supports treatment in a dedicated stroke unit. Dedicated stroke units result in reduced mortality rates and improved rehabilitation outcomes. A multi-disciplinary, interdisciplinary and or transdisciplinary approaches. Bryer advocates the interdisciplinary approach where team members have the experience and knowledge of stroke rehabilitation.[54]

The Barthel Index (BI) (Appendix A) is a functional outcome measurement tool used to measure a client's performance in activities of daily living that have been diagnosed with a stroke. Use of the Barthel Index with stroke clients comes highly recommended by Collin and Wade (1988) in their study on the reliability scale of the Barthel Index.[55]

2.5.5 Disorders of the hand and upper extremities

Disorders of the hand and upper extremity include a wide range of conditions, such as: arthritis, strains and sprains, carpal tunnel syndrome and nerve compression disorders, fractures, joint disorders and other musculoskeletal and neurological conditions.[56] Furthermore, hand impairments arising from injury caused by fracture, laceration and amputation are associated with disability or poor functioning resulting in limitations of activities of daily living such as mobility, self-care and domestic life and restricted participation.[56,57]

Disorders of the upper extremities related to work are a major cause for complaints and disability in worker populations.[57] It consists of a variety of symptoms in the upper extremity, either localised or more widespread, and usually preceded or

affected by exposure to physical activities and/or postures at work. To develop effective management strategies, both from a prevention and treatment perspective, knowledge is needed with regard to the nature, pathophysiological mechanisms and risk factors of this group of disorders.[57]

Persons with these conditions can benefit from rehabilitative care. The Medstar National Rehabilitation Network's outpatient Hand and Upper Extremity Program provides evaluation and treatment services for patients with hand dysfunction resulting from disease, traumatic injury, medical conditions, or surgical conditions. Occupational and physical therapists with training in hand rehabilitation provide interventions designed to restore the patient's hand or upper extremity to optimal function.[58]

Patient reported outcome measures are becoming increasingly utilised for outcome evaluation to gain knowledge on symptoms, health perception, satisfaction and quality of life. Some outcomes measures are impairment specific whilst others such as the patient rated wrist/hand evaluation or regional measures such as the disabilities of the arm, shoulder and hand questionnaire can be used across a spectrum of injuries or disorders.[59]

The Disabilities of the Arm, Shoulder and Hand (DASH) outcome measure was developed to evaluate disability and symptoms in single or multiple disorders of the upper limb at one point or at many points in time. It was found to correlate with other measures ($r > 0.69$) discriminate well between patients who were working and those who were not ($p < 0.0001$). Evidence provided of the validity, test-retest reliability, and responsiveness of the DASH illustrated validity and responsiveness in both proximal and distal disorders, thus confirming its usefulness as an outcomes measurement tool in upper limb conditions.[59]

To conclude this section, the diagnostic conditions namely, lower back pain, arthritis, strokes, conditions of the hand and upper extremity are the main reasons why patients access rehabilitation services at TC Newman CDC. These conditions are managed in the following manner:

- Patients are referred by mostly health practitioners within Department of Health

- A therapist assesses and treats clients based on previous knowledge and guidelines from studies, with no standardised functional assessment and evaluation tools. An inter-disciplinary teamwork approach is followed. The core staff members comprise of a physiotherapist, a physiotherapy assistant, two occupational therapists, a speech therapist,

- Treatment and therapy is mainly based on one-to-one interaction within a health facility

- Follow up appointments are made by the administration clerk

At some point all of these conditions are may result in impairment, activity limitations and participation restrictions and are further influence by an individual's contextual factors. It is generally realised that intervention by professionals in the field of rehabilitation to modify impairments as noted above. Rehabilitation is not only centred on therapeutic intervention but can be used as a tool to facilitate participation and improved quality of life.[54]

2.6 REHABILITATION

The white paper on an Integrated National Disability Strategy defines rehabilitation as a way of assisting people with disabilities to become fully participating members of society with all the benefits and opportunities of that society.[60] So too does the NRP policy promote accessible, affordable and equitable healthcare in communities which includes rehabilitation services.[8] Thereby recognising the constitutional right of access to healthcare and rehabilitation for all citizens.[8]

The National Health Plan was introduced to South Africa in 1994 to restructure health systems in line with the Primary Healthcare approach of which rehabilitation is an important component. The definition of rehabilitation for this study has its foundation from the NRP and is embedded in the South African DOH Comprehensive Service Plan for the Implementation Healthcare 2010.[8,61]

The two main components of this document are centred on facility based and community based services and makes provision for rehabilitation to be provided across both areas.[61]

Health Care 2010 further promotes rehabilitation services to be delivered by a multi-disciplinary team which includes doctors, nurses, physiotherapists, occupational therapists, audiologists, speech and language therapists, social workers, clinical psychologists, dieticians, prosthetists and orthotists, amongst others and emphasises continuity of care from the first point of entry and ultimately reintegration back into the community. Rehabilitation is an integral part of the District Health Services system, and as such being policy it requires that clients requiring rehabilitation are thus able to access these services at PHC level.[61]

Both high and low intensity rehabilitation is required for optimal outcomes of clients. The intensity of rehabilitation would depend on the level of care at which a client is able to access rehabilitation services.[61] At present, the Western Cape Rehabilitation Centre (WCRC) is the only high intensity rehabilitation facility in the Western Cape, whilst low intensity services with rehabilitation professionals are offered at service points such as Booth Memorial Hospital , Maitland Cottage Hospital and Community Health Centres to name but a few and other community rehabilitation services.[61]

Rehabilitation rendered at PHC level is characterised as a low-intensity rehabilitation service, such as the services delivered at TC Newman CDC.

Core package of rehabilitation services for PHC

The core package of rehabilitation services for PHC in the Western Cape has a set of 9 minimum standards for rehabilitation intervention to ensure optimal outcomes and the prevention of secondary complications. These are:

- 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.[61]

Evidence based studies on the management of adult stroke rehabilitation illustrated that patients do better with multidisciplinary treatment methods.[54,69,71] The rehabilitation service plan emphasises the use of multi or interdisciplinary teams in acute and non-acute services at all levels of the healthcare platform. At primary healthcare level, rehabilitation therapists are integral members of the primary healthcare team attached to District health services.[61]

Rehabilitation services at TC Newman CDC offer a low intensity, outpatient rehabilitation service. These services are rendered by a multi-disciplinary team of physiotherapists, occupational therapists and a speech therapist. This team uses a mixture of multi-disciplinary, interdisciplinary and transdisciplinary approaches in rendering rehabilitation services. With a multi-disciplinary approach, team member evaluate and establish treatment plans individually, with the interdisciplinary approach all rehabilitation team members are involved with the assessment and planning ending with a single treatment plan for all.[55] A transdisciplinary approach is when therapists may perform treatment interventions usually allocated to another professions.[54] Additional therapeutic resources are available from a clinical psychologist, dieticians, an oral hygienist, nursing and medical care. Table 2.1 summarises the key rehabilitation levels and appropriate interventions that need to be delivered to the patients' current outcome level, as well as the appropriate health care service delivery points, as illustrated in the Comprehensive Service Plan of the Western Cape.[61.] This also highlights the research focus on a rehabilitation service at a Primary Health Care site. These levels of outcome are based on the levels described by Landrum et al., 1995.[4]

Thus the minimum rehabilitation interventions to ensure optimal outcomes and the prevention of secondary complications which could result in re-entry to the acute health care system together with related outcome levels should be viewed as a guide to facilitate the best possible outcomes for clients at the appropriate level of care.[61] Furthermore it is a useful measure to guide the rehabilitation process and which rehabilitation professionals can be trained to utilise, thus providing a uniform language and understanding of the person's abilities and needs.[54]

Table 2.1 below provides an outline of the rehabilitation outcome levels and related interventions as stated in the Comprehensive Service Plan of the Western Cape.[61]

Table 2.1: Rehabilitation outcome levels and related interventions

Outcome Level	Health care service point	Role of Rehabilitation professionals	Acuity	Rehabilitation Outcome
0 & 1 Physiological instability and Physiological (medical)stability	Hospitals and acute medical facilities (Levels 1, 2 and 3)	Curative services and support to medical professional's medical interventions	High	Planning towards level 2
2 Basic Rehabilitation outcome	• Hospitals and acute medical facilities (Levels 1, 2 and 3) and outpatients departments • Home Based Care • Sub-Acute care	• Basic rehabilitation interventions • Rehabilitation outcome planning towards level 3, e.g. functional training, referrals, training of family and home visits, provision of assistive devices, etc.	Moderate	Planning towards level 3
3 Intermediate Rehabilitation outcome	• Sub-Acute Care • Community-based rehabilitation, e.g. Elangeni • CHCs & home-based care • Rehabilitation OPDs, e.g. all hospitals • Specialised rehabilitation centres, e.g. WCRC	• Functional skills training • Training of care-givers and home visits • Mobilisation of community resources • Provision of assistive devices	Low	Referral for advance rehabilitation
4 & 5 Advance rehabilitation outcome:	• Level 3 hospitals • Specialised Rehabilitation units	• Advanced functional skills training • Vocational assessment and rehabilitation • Mobilisation of community resources • Advocacy and awareness raising • Work-site / school visits • Effecting reasonable accommodations in the work-place		Re-integration to the community

Comprehensive Service Plan of the Western Cape[61] (p.70)

The above allows for patients in any phase of treatment to be operationally described and classified. It indicates the appropriate allocation of resources to the different phases of care and links specific treatment paths to resource utilisation; however, it does not clearly describe and indicate how rehabilitation services should be implemented and evaluated at an operational or clinical level and the functional measures that should be applied.[61] Thus programme monitoring and evaluation is essential in ensuring that a programme is able to meet its objectives. However if these objectives are not or adhered to measurement of a program becomes challenging.

The NRP of South Africa of 2000, states that the government of South Africa has committed itself to bring health services closer to the people by adopting the Primary Health Care Approach (PHC), of which rehabilitation is an important component.[8] The goal of the national rehabilitation policy is to improve accessibility to all rehabilitation services in order to facilitate the realization of every citizen's constitutional right to have access to health care services. This policy should also serve as a vehicle to bring about equalization of opportunities and to enhance human rights for persons with disabilities, thereby addressing issues of poverty and disparate socio-economic circumstances.[8]

This policy further includes Community-Based Rehabilitation (CBR) as one of its underpinning principles. The policy further expands that CBR for this policy is not only about what we do but how we do it and CBR principles and concepts should underpin how rehabilitation services are delivered in South Africa CBR as an integrated part of Primary Health Care and should ensure accessibility and affordability of appropriate and acceptable services to the disabled population.[7] Community-based rehabilitation is a strategy for the equalization of opportunities and social integration of all children and adults with disabilities. It is a strategy that involves the family and the whole of the community to increase rehabilitation coverage in developing countries at low cost.[3] The focus of rehabilitation professionals at CBR level are to facilitate the utilisation of resources in the community and promote awareness of disability and rehabilitation.[62]

Helender defines CBR as a strategy to improve service delivery to all in need and to promote equal opportunities to all.[23] McColl et al. (2009)[62] also refers to CBR as a

way of delivering rehabilitation services, where there are inadequate material and human resources. Hence the goal for CBR in the NRP is to make rehabilitation accessible to all who need it. Therefore rehabilitation services will also need to be delivered at community level and within communities.[8]

Velema et al. (2008)[17] reported the benefits of CBR to be: "home based training, economic interventions and activities including enhanced family member coping skills, improved school attendance, increased income, enhanced social inclusion and advanced levels of PWD independence, mobility and communication skills".[63]

Supportive of the implementation of CBR, in 1989 the WHO published the CBR manual *Training in the community for people with disabilities.*[112] It played an important role in promoting CBR and changing the quality of life of people with disabilities in developing countries. Furthermore CBR was redefined as a strategy for rehabilitation, equalisation of opportunities, poverty reduction and social inclusion of people with disabilities. In responding to the comprehensive needs in the rehabilitation process, the CBR Matrix evolved and provided a framework to understand the different activities of CBR programmes in a systematic manner in the five domains of health, education, livelihood, social and empowerment.[113]

The outcomes of CBR are difficult to measure, because CBR programmes vary and targets may differ for example: some programmes might measure social participation and others, like the research site, may measure clinical outcomes. Thus to measure the effectiveness of CBR is difficult.[64] CBR programmes are developed to meet specific needs and therefore measure different outcomes.[63,65]

CBR programmes have been found to benefit the lives of individuals as seen in studies conducted in developing countries such as Botswana, India, Guyana, Vietnam, Egypt and Zimbabwe. Success rates of CBR programmes ranged between 40% and 91% in various rehabilitation programme activities which included improvement in self-care activities, mobility, communication, integration into schools, work and family and community participation. The common factor that contributed to the success rates in the CBR programmes included the good relationship with government departments, where support, training and technical assistance was provided.[23,111]

To ensure optimal outcomes of the rehabilitation process minimum standards as mentioned above and guidelines are important so as to determine the appropriate level of care at which rehabilitation services are rendered together with the resources required.

2.7 FACTORS INFLUENCING OUTCOMES OF REHABILITATION

Diagnosis of strokes is commonly used in literature to describe factors influencing the outcome of therapy.

2.7.1 Intensity and availability of rehabilitation

Rhoda et al. (2009)[66], showed that there is inadequate rehabilitation staff at Community Health Centres and this inadequacy of staff, is in contrast to recommendations made by policy documents such as the CSP and NRP.[8,61] According to the CSP the intensity of rehabilitation is determined by frequency and duration of patient-therapist contacts per day.[61]

Rhoda et al. (2009) found that physiotherapy was the service most frequently received at CDCs [66] In ranking order the utilisation of therapy services were firstly, physiotherapy, followed by occupational therapy and then speech therapy. Rhoda further reported that the intensity and frequency of therapy at CDCs in the Western Cape, is less than when compared to developed countries, which can result in many clients not receiving optimal rehabilitation.[66]

A clinical review on rehabilitation after stroke showed that doubling the intensity of therapy significantly improved the functional outcomes of clients. The delivery and the organisation of rehabilitation services is equally as important as the intensity of therapy.[67]

A randomised trial on long term therapy in community dwelling stroke patients found that intermittent high-intensity and continuously low intensity rehabilitation were equally effective in achieving functional outcomes. The therapy intensity was more important than the time or mode of therapy.[68] This article demonstrates that each contact with a client should be utilised effectively, so as to ensure and facilitate the best outcomes, irrespective of the frequency of contacts. In low resource settings,

CBR must be implemented to involve families and communities in ensuring continuity of care and in achieving the best possible outcomes for the client.[3]

However there may also be many confounding factors that impact on the functional outcomes of clients such as age, co-morbidities etc.

2.7.2 Age

Ageing for some groups of people with disabilities begins earlier than usual. Individuals with developmental disabilities display signs of premature ageing in their 40s and 50s and may experience age-related health conditions more frequently.[14] The ageing process and associated changes such as, loss of strength and balance and osteoporosis may have a greater impact on people with disabilities. For example, those with existing mobility impairments may increasingly experience functional loss as they age.[20]

2.7.3 Multi-disciplinary teams

Evidence based studies on the management of adult stroke rehabilitation showed that patients do better with well organised multidisciplinary approaches. Early initiation of rehabilitation and specifically an interdisciplinary versus multidisciplinary setting result in increased functional outcomes with follow up.[69,71]

Teamwork may be multidisciplinary, interdisciplinary or transdisciplinary. The approach will to depend on the availability of human resources and the relevance thereof.

Multidisciplinary approach: each team member does an individual evaluation and sets up an individual treatment programme according to the findings of the evaluation.[54]

Interdisciplinary approach: assessments, goal planning and treatment are done in together with other team members. A single treatment plan is identified in consultation with the client and all team members work accordingly. The team member most suited to perform a particular treatment modality will be allocated the task.[54]

Transdisciplinary approach: with this approach, therapists may perform treatment interventions usually allocated to other professions. Two disciplines may work together on evaluations and treatment, and often consulting with family members.[54,71] An interdisciplinary approach is advocated by Bryer when working with clients affected by a stroke.[53]

2.7.4 Impacts of co-morbidities

Persons with disabilities develop the same health conditions that affect the general population, such as influenza and pneumonia. Some individuals are more susceptible to developing chronic conditions because of the influence of increased physical inactivity. One study showed that adults with developmental disabilities had a similar or greater rate of chronic health conditions such as high blood pressure, cardiovascular disease, and diabetes than those people who do not have disabilities.[20] Co-morbidities are additional conditions independent of and separate to the primary condition. Detection and treatment of co-morbid conditions are often not well managed for people with disabilities and can later have adverse effects on their health.[20]

Co-morbidities often require adaptations in the rehabilitation care plan and may even prevent, interrupt or delay treatment. A systematic approach to the assessment, prevention and management of co-morbidities can improve the patient's chance of receiving maximal benefit from rehabilitation. One of the most common complications of inactivity is thromboembolisms, prevention should part of rehabilitation.[70]

2.7.5 Early initiation of therapy

There are different views on the initiation of rehabilitation in relationship to functional outcomes. It is evident in literature that early initiation of therapy, once clients are medically stable, has better outcomes than compared to late onset of therapy.[71] More importantly continuity of therapy assist in maintaining improved outcomes. For example clients with a stroke for whom rehabilitation intervention is initiated early, experience improved functional outcomes, may lead to patient satisfaction and reduce the cost related to therapy.

2.7.6 Patient, family and caregiver involvement

Patient, family and caregiver involvement of the family and caregivers in the education and rehabilitation process of the client, does not always demonstrate improved outcomes, but has been successful in increasing their knowledge and insight regarding strokes. This may assist patients and caregivers in making informed decisions about treatment. It is important that the education provided should be interactive and in a written format and most importantly documented in the patients folder to prevent conflicting or duplication from different disciplines.[71]

2.7 ENVIRONMENTAL AND PERSONAL FACTORS

A study conducted in the Western Cape showed that environmental factors such as the climate, public buildings, working environment, level of education and housing were barriers to functioning.[72]

Accessibility to appropriate local care including rehabilitation services, among rural populations is reported as a major barrier. A prospective study on the post discharge follow up of stroke patients at Groote Schuur hospital showed that attendance was disappointing and contributing factors included transport, inability of families to provide an escort, depression and loss of insight.[73] Transport is often described as a barrier for accessing services.[72] Adding to the environmental barriers, the Paarl area has a violent crime incidence rate of 12.36%-18.67%.[74] In South Africa high levels of violent crime, make it difficult for health professionals to access disadvantaged and impoverished communities where rehabilitation needs are great.[74] Violence and transport are environmental barriers that should be taking into account when applying a CBR approach.[75]

2.8 PATIENT SATISFACTION

The main theme of Health Care 2020 is centred around the patients experience in health care (PCE).[15] Patients' views are being given more and more importance in policy-making. Understanding patient's perceptions is important in developing measures to increase the utilization of rehabilitation services at PHC level.

Patient satisfaction surveys are used in the department of health to obtain the clients perception of health services. Patient satisfaction is most associated with items that reflect a high-quality interaction with the therapist (e.g. time, adequate explanations and instructions to patients).[76]

A study on patient satisfaction with skill mix in primary care, reported that what matters to patients, included: good communication, time spent with professionals, continuity of care, competence of health professionals, receiving adequate information, accessibility, reduced waiting times and depth relationships with health workers.[76,77]

Fredericks (2011) found that most clients were satisfied with rehabilitation services received at Elangeni. His study reported that clients, perceived the staff at Elangeni as friendly, supportive and well mannered. Clients communicated easily with the staff at the centre. Another aspect that clients were satisfied with and appreciated was that they could make appointments and were seen promptly at that time.[16] However, this issue was in contrast to current study findings in that participants indicated that they waited at least 4-6 weeks before being seen by a rehabilitation professional.

2.9 PATIENT COMPLIANCE

Different studies describe factors influencing therapeutic non-compliance. For example: patient related, therapy related, healthy system, social and economic and disease specific factors.[73,78]

Patient related factors include demographic factors, health literacy and physical difficulties. Therapy related factors included administration and the duration of the treatment period. Health care system factors include lack of accessibility and waiting times. Social and economic factors include inability to take time off work, cost and income and social support. Lastly disease factors include symptoms and severity of the disease.[73,78]

Literature shows that when addressing therapy-related factors it should contribute positively in improving compliance. Healthcare system problems were directly related to compliance. Non-compliance is more common in chronic illnesses, because of the

fluctuation and absence of symptoms. The patient's socio economic status should be taken into account when planning therapy. Personal factors such as beliefs and attitude towards therapy also influence compliance. Inadequate health knowledge regarding therapy and consequences of therapy also influence outcomes. Good communication between healthcare workers and patients enhance compliance.[78]

There are many factors that can influence the compliance of therapy. To give clients indications whether or not there was progress in therapy, the use of measurement tools is important to communicate this to clients so that they are able to understand the treatment rendered, their role and the importance of the treatment.[78] Compliance in therapy is critical in enhancing desired rehabilitation outcomes.

2.10 OUTCOMES BASED EVALUATION

Outcomes-based evaluation is defined as outcomes, namely; personal or organisational changes or benefits that follow as a result or consequence of some activity, intervention or service. The use of outcome based measurement tools is essential to determine the effectiveness of a rehabilitation programme.[79] Some outcomes relate to the organisation and some to the person. Outcomes can be short, intermediate, or long term.[80]

The focus of this study is on the functional outcomes of clients after receiving rehabilitation interventions.

In order to determine if the outcomes of rehabilitation interventions are successful and if interventions are achieving their objectives, the rehabilitation outcome levels and related interventions as stated in the comprehensive service plan of the Western Cape can assist one to develop objectives for rehabilitation and from that identify measuring instruments.[61]

The six clinical outcome levels addressed in the rehabilitation service plan are:[61]

1. Level 0: Physiological instability
2. Level 1: Physiological (medical) stability
3. Level 2: Basic Rehabilitation outcome (physiological maintenance)
4. Level 3: Intermediate Rehabilitation outcome (home/ residential re-integration)

5.   Level 4: Advance rehabilitation outcome (community re integration)

6.   Level 5: Productive activity.

Rehabilitation services at TC Newman CDC, are mainly facility based and in line with the CSP and is classified as low intensity rehabilitation. It includes physiotherapy, occupational therapy and speech therapy. However, the rehabilitation staff is also expected to render an outreach service to other PHC facilities. This could impact on the availability and intensity of therapy, which in turn may have an effect on the outcomes of therapy?[66] Thus it is important to be aware of rehabilitation outcome levels and related interventions which may assist to develop objectives for the clients rehabilitation and ultimately outcomes.

Fredericks' study at Elangeni Rehabilitation Centre (2011) highlighted that despite CBR being propagated in different policies for the past 15 years, it seems that health professionals are still rendering mainly rehabilitation services at clinic and community health centres.[16,54] However, healthcare 2010 was developed to improve the quality of healthcare services to provide financially sustainable health services in the Western Cape. The community-based service approach based on the PHC approach of accessibility advocates the involvement and empowerment of individuals and communities. Thus rehabilitation in the context of CBR can be delivered from health facilities in communities as well as at community based level with a focus on health promotion and prevention and education of caregivers and families.[54,61]

De la Cornillere shared similar findings in that outreach by rehabilitation professionals was mainly from CDCs to PHC facilities in the Western Cape. This may create a perception that CBR is being applied, but rehabilitation services are still mainly facility based.[54,81] Thus there should be a greater shift and renewed focus on home/residential integration and community integration where training of caregivers, home visits, mobilisation of community resources and provision of assistive devices are key in community based rehabilitation and rehabilitation.[61] This can also be seen in the way that rehabilitation is described in the Comprehensive Service plan.[61]

CBR and its advantages in resource limited settings is well described in literature, but in the current health system with more pressing issues, rehabilitation and the advantages of applying a CBR approach is not yet fully applied and realised.

2.11 OUTCOME MEASURES

> "Outcomes refer to the effect of treatment, programs or policies on individuals or populations. Outcomes may also define changes in status attributed to a specific intervention or treatment. Outcomes may be thought of as changes in the lives of clients and their environment (s) as a result of rehabilitation. Outcome measures are tools (e.g. instruments, scales, questionnaires, rating forms etc.) used to uncover or identified the outcome of the intervention for the client. Outcome measures are used to document change in client characteristics, functional abilities or behaviours over time".[6]

When implementing the outcome measurement tools one has to take into account the following criteria: utility, validity, reliability, precision, feasibility and cost.[16,18]

- Utility refers to relevant and useful data generated.
- Validity is the extent to which a tool measure what it is supposed to measure
- Reliability is the extent to which a measurement produces the same result repeatedly
- Precision refers to the ability of a tool to capture incremental changes
- Feasibility is the extent to which outside factors may hinder or prevent the use of a measure
- Cost refers to the cost related to use the tool, which refers to start up and maintenance cost and may also refer to things like copyright, training, etc.[18]

With the folder data extraction, used to obtain demographic information such as diagnosis, age, treatment and referrals etc. from the patient folders, there was no documented or tangible evidence that therapists at the research site make use of standardised outcome measurements in patient assessment and evaluation. Occupational therapists, speech therapist and physiotherapists at TC Newman CDC use their individual skills and knowledge, to plan, assess and treat a client. This may be attributed to the lack of knowledge of these measures, access to measurement

tools, the lack of direction by rehabilitation managers in the service and the lack of measurement appropriate to the consumers of the service.[6,16]

Different types of outcome measurement tools were used in this study. The selection of these tools were based on the five most common conditions seen at the site on the onset of the study.[44]

2.1.1 Selection factors of measurement tools for the current study

1.   Availability and cost of the tool

The tools selected for the study were available and could be accessed at no cost. This is an important factor, because the current research sites has not yet implement the use of standardised outcome measurement tools. Free access and availability of the tools will be a strong motivator for the use of the tools in future. If measurement tools are available at no cost it will increase the likelihood of the organisation to continue using the tool. It will also contribute in comparing data across the rehabilitation field in the CWD.

2.   User-friendliness

The tool and the data must be easy to administer and the data gathered should be relevant and used by all team members.[18] Measurement tools should not be abstract ensuring concepts are carried over in a concrete manner, to ensure reliable data.[82]

3.   Education level of the study population

The education and literacy levels of the participant population should always be taken into account when developing or selecting the measurement tools so that tools are easy to explain and understood by the participants. Thus: not too abstract and beyond participants' abilities.

4.   Time Constraints

The administration of the measurement tools should be not be a lengthy and tedious process so as not to overwhelm, exhaust and demotivate clients coming for therapy. The information required should be just enough.

5.   Reliability and Validity

The tools need to be specific in what they measure. It is important to use tools that are familiar and whose reliability and validity are known so as to ensure accuracy.[82]

2.12 SUMMARY

This chapter looked at the different definitions for disability, the causes of disability and how disability is measured. It shows that disability is complex, not easy to define using a single definition and is not always measured in the same way. Rehabilitation and the way that literature describes how it should be delivered were explored in more depth. Factors influencing rehabilitation outcomes were explored in addition to factors influencing the selection of outcome measurement tools.

Chapter 3 will describe the methodology used for the study and the different measurement tools.

CHAPTER 3: STUDY METHODOLOGY

3.1 INTRODUCTION

Chapter 3 sets the aim of the study and the objectives. It also explains the design of the study and gives an introduction to the study setting. This is followed by a description of the study sample, data collection process, instruments to collect the data, data analysis and the ethical consideration applied in the study.

This study formed part of a bigger SANPAD study on the evaluation of rehabilitation services in the Western Cape.[9,83] The SANPAD study, aimed to describe and analyse the implementation of rehabilitation services, through assessing the capacity of various institutions, using the Kaplan framework. The bigger study further aimed to evaluate the impact of services and determine to what extent rehabilitation services were aligned with the seven key indicators from the NRP and five selected UNCRPD articles.[9,83]

3.2 STUDY AIM

This study aims to describe and evaluate the functional rehabilitation outcomes of clients at TC Newman CDC, after receiving rehabilitation intervention.

3.3 STUDY OBJECTIVES

Objective 1

To describe the demographic factors and from these highlight barriers influencing rehabilitation outcomes.

Objective 2

To evaluate the functional outcomes of clients after receiving rehabilitation intervention at TC Newman CDC during an 8 month period November 2010 to April 2011 using appropriate standardized tools.

Objective 3

To describe the patient's perception of the rehabilitation process and outcomes using a client satisfaction questionnaire.

Objective 4

To make recommendations to key stakeholders regarding rehabilitation services in TC Newman.

3.4 STUDY DESIGN

For the purpose of this study the researcher applied a descriptive longitudinal method, which included the use of a pre and post-test within specific time periods. This will help the researcher obtain feedback about the rehabilitation services offered, the outcomes of these services and factors influencing the outcomes. This method will also allow the researcher to examine the changes or differences, in the client's physical and functional status over a four to six month period. The pre-test post-test design will allow the researcher to identify areas of improvement.[84]

In this study numbers and function scales were used to measure outcomes of participants. Statistics were used to analyse quantitative data. Without statistics quantitative data would only represent numbers. Statistics enabled the researcher to summarise, organise, evaluate and communicate quantitative data. Descriptive statistics summarised and described the data. It converts numbers into visual representation or pictures, to add meaning to the data.[84]

During the data capturing and analysis of the quantitative data, the researcher became aware of the low return rate of clients for their follow up rehabilitation sessions. A need for further investigation was identified.

An additional qualitative phase was added, where the researcher initiated telephonic follow up of clients who had telephone numbers on their folders. The researcher telephoned all clients (N=91) whose telephone numbers were in working order who could be contacted so as determine as to why participants did not return for their follow up rehabilitation sessions. Only 16 participants could be reached

telephonically using the telephone number that was on the folder. Those who could not be contacted telephonically were due to barriers such participants not at home, telephone numbers no longer existing or incorrect telephone numbers.

A semi structured interview questionnaire was developed for the telephonic follow up, where participant's responses were written down as they responded to the questions asked by the researcher. Home visits were initiated whereby twenty patient folders were selected randomly and home visits conducted with support from a community care worker.

 Qualitative data makes use of words, and was used to heighten the quantitative findings in this study.[71] This type of data may also provide subtle explanations and various perspectives, to the evidence gathered with the quantitative data.[85]

3.5 STUDY SETTING

The study was conducted at TC Newman CDC. Rehabilitation services are mainly rendered from TC Newman CDC and rehabilitation therapists rendering these services are based on the staff establishment of TC Newman CDC, thus access to rehabilitation is mainly confined to TC Newman CDC. TC Newman CDC is the only facility that provides an outpatient rehabilitation service in the rural area of Paarl, Drakenstein sub-district (Western Cape). Rehabilitation services offered, as part of the PHC package of care, at TC Newman, were previously rendered from Elangeni Rehabilitation Centre, which was a free standing outpatient rehabilitation centre for persons presenting with physical disabilities.

TC Newman CDC is based in Paarl but provides services to clients from the whole of the Drakenstein area, including the farming communities. The Drakenstein area consists of the following towns: Paarl, Wellington, Saron, Gouda and Simondium.

Patients needing rehabilitation in the Drakenstein enter the service via referrals from health facilities, mainly TC Newman CDC and Paarl hospital, but also from the local community and non-governmental organizations.

Patients are treated at TC Newman CDC by a multi-disciplinary team of qualified occupational, speech and physiotherapists, using an interdisciplinary approach. The

core members of this team are one full time physiotherapist and a community service physiotherapist, a full time occupational therapist and a community service occupational therapist and only one speech therapist. Physiotherapy students from the University of Stellenbosch and the University of the Western Cape also assist in providing rehabilitation services at TC Newman CDC.

The package of care offered at TC Newman CDC by rehabilitation professionals includes: individual and group therapy, back classes, training of community health workers (CHW), outreach to identified primary health care facilities and support to funded Non-Governmental Organizations (NGO) in the Drakenstein. Patients requiring more specialized rehabilitation services are referred to Paarl Hospital (Regional Hospital).

Figure 3.1 maps the different service points where rehabilitation services are offered.
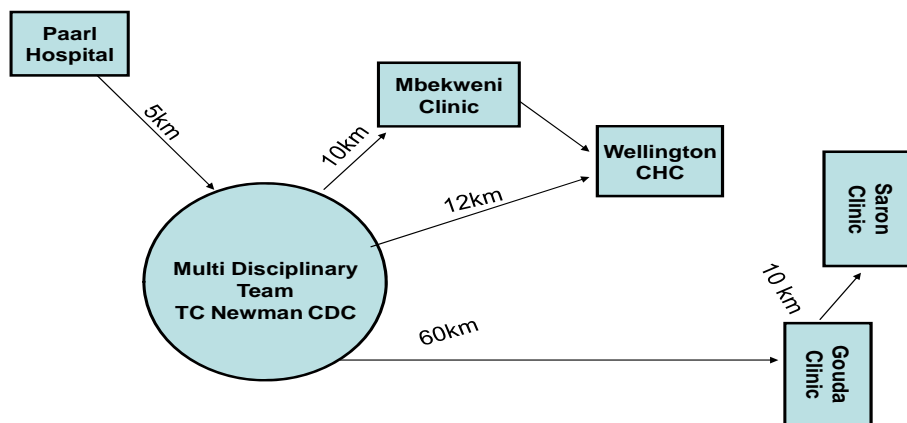
Figure 3.1: Rehabilitation service points

3.6 STUDY POPULATION

The study population consisted of all clients that were referred and treated with the five most prevalent conditions identified at TC Newman CDC during the period November 2010 until April 2011. All new participants who adhered to the inclusion criteria were admitted to the study with their first appointment for rehabilitation.

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The low return rate of participants led to the inclusion of telephoning those participants (N=91) whose telephone numbers were in working order who could be contacted so as determine as to why participants did not return for their follow up rehabilitation sessions. This was followed up by the home visits (N=20) to study participants. A total of 114 clients participated in the study.

- Initial assessments: November 2010 – January/February 2011 (N=114)
- Final assessments: March 2011 – June 2011(N=20)
- Final assessments for home visits: July 2011(N=12)

The five most prevalent conditions were pre-determined and generated from data collated by the health therapists at TC Newman CDC from June to December 2009.

3.7 STUDY SAMPLE

The five most prevalent conditions identified for inclusion in the study were strokes, back pain, arthritis, children with developmental delays and hand/upper limb injuries. These five conditions were specific to each research site and were decided on in the SANPAD group to ensure that data collected could be compared with the other three similar research sites in the SANPAD study. With the onset of the study, no children with developmental delays were referred for rehabilitation at TC Newman CDC, because specialised paediatric services previously at TC Newman CDC had now been relocated to Paarl Hospital, resulting in only four prevalent conditions.

3.7.1 Inclusion criteria

- All patients referred for rehabilitation to TC Newman CDC, for the first time and presenting with one of the five most prevalent conditions, during November 2010 until April 2011.
- All patients who gave consent in writing to participate in the study.

3.7.2 Exclusion criteria

- All patients presenting with a diagnosis outside of the 5 most prevalent conditions presenting at TC Newman CDC.
- Clients who did not give consent to participate in the study.

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3.8 PILOT STUDY

A pilot study on the selected tools was done at Bishop Lavis Rehabilitation Centre (an outpatient rehabilitation centre in the Metro, similar to TC Newman CDC). Criteria used for the pilot study was: Inclusion: all clients in the Bishop Lavis catchment area referred with a diagnoses representing lower back pain, arthritis, CVAs, upper limb injuries and lower limb injuries. Exclusion: clients with a mental health condition and clients younger than 18 years. Children under the age of 18 were not included in the pilot study, study population, because the researcher at the BLRC research site, that did a similar study, excluded this age group from her study. The initial pilot was conducted using the questionnaires and outcome measurement tools and were scored by the researcher at Bishop Lavis Rehabilitation Centre and 3 peer researchers, which included the researcher at TC Newman CDC. This process resulted in discussions and recommendations for amendments to the questionnaires.

3.8.1 Amendments to questionnaires after the pilot study

- With the demographic questionnaire there was a change in wording to make it easier to understand by the field worker and client e.g. "congenital" was changed to "born with".

- The Zambian Survey of living conditions questionnaire was adapted by separating the two columns indicating activity limitations and participation restrictions. This made it easier for the clients and the fieldworker to use.

The pilot study also provided information as to how long the administration of the measuring instruments would take. The study showed that the duration of administering the tools was between 30 – 40 minutes. This was important to determine timeframes in ensuring that adequate time was allowed for the research questionnaires and outcome measurement tools to be completed.

3.9 INSTRUMENTS TO COLLECT DATA

Measurement tools for study were decided on and finalised in the SANPAD group. Data collection tools for demographic information were generic and those measuring functional outcomes were diagnosis specific. The group decided this to ensure that

reliable and valid deductions could be made when comparing data from the other three research sites within the SANPAD study. Table 3.1 below summarises the measurement tools used in the study.

Table 3.1: Tools used in the study

Diagnoses	Measuring instrument	Relation to the ICF	Appendix List
Strokes	Barthel index	Activity and participation	A
Back Pain	Oswestry ODI version 2.0	Body functions and structures, activity and participation	B1
	Clinical mobility scale	Activity and participation	B2
Arthritis	Arthritis impact measuring scale	Body functions and structures, activity and participation	C
Hands / Upper Limb	Disability of the Arm Shoulder and Hand	Body functions and structures, activity and participation	D
Demographics	Folder Data extraction tool	Environmental and Personal factors	E
	SANPAD questionnaire 1	Environmental and Personal factors	F
	SANPAD questionnaire 2	Environmental and Personal factors	G
	Adapted Zambian	Activity and Participation	H
Quality of Life	Caregiver strain index	Environmental and Personal factors	I
	European Quality of Life index (EQ5D)	Environmental and Personal factors	J
		Subjective feedback from the client	
	Client Satisfaction	Feedback from clients	K
	Medical records impairment tool	Body functions and structures	L

3.10 INSTRUMENTS TO MEASURE ACTIVITY AND PARTICIPATION

Table 3.1 above illustrates the measuring tools that were used to assess client's activity and participation, presenting with the five most prevalent conditions:

3.10.1 Strokes: Barthel Index

The Barthel Index (BI)[55,86] (Appendix A) was first developed in 1965 and was later modified by Granger. It measures the functional disability by quantifying patient performance in 10 activities of daily life, namely: feeding, bathing, grooming, dressing, bowels, bladder, toilet use, transfers, mobility and stairs.[55,86]

The test takes approximately 5 minutes to complete and shows what a patient does and not what he/she can do. Five point increments are used to score, with a score ranging from 0-100. A score lower than 50 indicates greater dependency and above 75 lesser dependency.[55,86] The BI does not require training or a skilled person to administer. Thus the research assistant was used to administer the tool.

The BI is available in English, Afrikaans and Isi-Xhosa.

Test-retest reliability coefficients r=0.98. The inter-rater reliability of the BI using weighted kappa ranged from 0.53(adequate) to 0.94(excellent). Construct and criterion validity compared to SF-36.[87]

When comparing the Barthel Index to the Care Dependency Scale for rehabilitation, the Barthel Index appears to be more responsive and more appropriate for the assessment of client's changes over time.[88]

The reliability, easy administration and use of the BI in the evaluation of persons with a stroke by a professional or lay person are reiterated by Collin, Wade, Davies and Horne.[86]

A number of researchers in South Africa, including Rhoda et al. (2011), Judy Cawood (2012) and Wendy-Lynne de la Cornillere (2007) used the BI as an outcome measurement tool for clients diagnosed with strokes.[54,66,81]

3.10.2 Back pain: Oswestry Disability Index, V. 2.0

The Oswestry Disability Index[89] (ODI) for lower back pain (Appendix B1) is available at no cost and is seen as a highly recommended tool used for specific outcome measurement in the management of spinal disorders. According to Finch[103] the reliability and validity of the tool is as follows: internal reliability – coefficient alpha values: 0.82 – 0.90 and test re-test reliability: ICC = 0.88 – 0.94.

Version 2.0 was modified in the United Kingdom by a medical research council group. The tool specifically focuses on physical activities and not the psychological consequences of chronic pain. It is designed to provide information as to how a client's back or leg pain affects their ability to function in everyday life.[89]

The tool is divided into 10 sections and focuses on the following areas of activity and participation: pain intensity, personal care, lifting, walking, sitting, standing, sleeping, sex life, social life and travelling. Scoring ranges from 0-5 points per section.

The tool is available in English. The tool was easy to use and could be easily administered by the research assistant.

In an article on the Oswestry Disability Index, authors recommend the use of version 2.0 of the ODI. This instrument has proven usability in a wide variety of applications and reviews as an outcome measure related to spinal difficulties. The instrument remains a valid tool in the measurement of disabling conditions.[90,91]

3.10.3 Clinical Mobility Scale

The clinical mobility scale (CMS) (Appendix B2) is a diagnoses specific questionnaire, which determines the impact of lower limb injuries on activities of daily living (ADL). The clinical mobility scale is divided into eight parameters to measure activity limitations, namely: upright posture, walking, gait, sitting, stair climbing, handheld appliances, wheelchair and gait.

A study on mobility for acute stroke patients, *The Mobility Scale for Acute Stroke Patients: intra-rater and inter-rater reliability* showed that the mobility scale has a high degree of reliability using this testing procedure.[92]

3.10.4 Arthritis Impact Measuring Scale 2-Short Form

The AIMS2–SF[93] (Appendix C) is available at no cost and measures outcomes in arthritis. It specifically measures physical, social an emotional wellbeing. The AIMS2 has nine scales: mobility, physical activity, dexterity, and household activity, and social activity, activity of daily living, depression and anxiety. This measurement also includes arm function, social support and work.[93] The AIMS2-SF has an internal validity of Cronbach alpha = 0.72 – 0.91 and 0.74 – 0.96. It also has a good test, re test reliability. The tools sensitivity to change with pre-test post-test evaluations makes it an ideal tool to use. The tool is available in English.[94]

3.10.5 Disability of the Arm Shoulder and Hand (DASH)

The DASH[95] (Appendix D) is used as an outcome measure for a variety of upper limb dysfunctions. The DASH is a self-administrated questionnaire and can easily be administrated by an unskilled individual. It consists of 30 items related to functional activities and symptoms in activities of ADL. Examples of these items include rating one's ability to open a tight or new jar, write, turn a key, prepare a meal, participate in recreational activities etc. There are two optional parts containing four items relating to the impact of the injury on the clients ability to work and participation in sport for athletes and the ability to use a musical instrument for musicians. It has been extensively investigated with respect to its reliability, repeatability, internal consistency, validity and its degree of acceptance in clinical practice. Reliability and reproducibility have been showed in various studies. Validity has been proven and the correlation with other outcome scales is high. The DASH is also translated in languages other than English. It is also translated into Afrikaans. The dominant language of participants in the study is Afrikaans.[95]

A study on the correlation between upper limb functional ability and structural hand impairment in a rheumatoid population, the DASH questionnaire and the Grip Ability Test (GAT) was used to measure upper limb functionality and ability. It was found that the DASH was a more discriminating measure than the GAT.[96] The test re-test reliability of ICC .0.7 and internal validity of Cronbach's alpha > 0.9 makes it a good discriminating tool to use in data collection.

3.11 GENERAL EVALUATION TOOLS

The general evaluation tools were used with all clients entering the research study.

These tools were developed by a group of professionals in the field of rehabilitation, who also formed part of the bigger SANPAD group. These tools were developed by the group, because no standardized data gathering instruments could be found to record medical, demographic and the socio economic profile of clients.

A specialist in the Rehabilitation field was consulted to format the self-compiled questionnaires, so as to ensure consistency in the data collection process.[44] Once developed, the tools were piloted at a similar site to that of TC Newman CDC.

The translation and back translation of the tools was done by the University of the Western Cape (UWC) Language Centre.

The different tools will briefly be described and as well as the process in developing the tools.

3.11.1 The folder data extraction sheet

The data extraction sheet (Appendix E) was developed to obtain information from the patient folders. There are two sections to the data extraction sheet. Part 1 recorded information relating to the medical profile of the patient which included the diagnoses, referring person, the reason for referral and whether or not a referral form was used. The demographic profile looked at the following elements: age, gender and residence. Part 2 was recorded when the client returned for the post test and looked at reasons for lost to follow up and the number of therapy sessions that the client had. The data extraction sheet was piloted by one of the rehabilitation professionals in the SANPAD group, so as to obtain face and content validity, by means of peer review. This review was conducted at the Western Cape Rehabilitation Centre (WCRC), and facilitated by the researcher at this site.

Recommendations by the reviewers included:

• 'Home address" should change to "Patient's address". This was done to accommodate any clients who might be from another town, country or province. This will enable the researcher to identify the sub-district from where the client comes from.

• Group home and old age home to be added to the discharge list.

3.11.2 SANPAD project: questionnaire 1

Questionnaire 1 (Appendix F) was administered when clients entered therapy. This questionnaire was developed to obtain socio-demographic information from the client and to ascertain whether or not they had received previous rehabilitation. The questionnaire was divided into categories: personal information, where information was recorded on personal demographic factors such as age, gender marital status, education, the client's home environment etc. and medical information, such as diagnosis, onset of injury and an indication of previous rehabilitation. The category on income looked at the client's socio-economic status which included income and activities to generate and income.

The transport category recorded information related to the availability and accessibility of transport as well as the mode of transport that the client used. This was followed by the category, assistance, which looked at assistance in the home. The category on habitat recorded information about the infrastructure of the client's home. The category on community involvement recorded information on participation in community activities such as sport and shopping. The last category recorded information regarding prior involvement in research and if feedback was received.

3.11.3 SANPAD project: questionnaire 2

Questionnaire 2 (Appendix G) was completed after the client received treatment. The Questionnaire recorded information as to the clients income and means of generating an income, any difficulty in making an appointment for rehabilitation, satisfaction with assistive devices issued if needed and use thereof, knowledge of health committees, community participation, whether or not they were referred to

other health professionals and the effect of environmental factors on therapy. The questionnaire was piloted by the researcher at the Western Cape Rehabilitation Centre and the final questionnaire was implemented at all identified research sites.

3.11.4 Adapted Zambian (AZ) survey on living conditions

Since limited participation measures are available, especially generic outcome measures, the Zambian questionnaire (Appendix H) was adapted for the purpose of this study. This questionnaire was adapted from the Zambian survey on living conditions, which was utilised to study the influence of physical disabilities on activity and participation of patients in Zambia.[72,97,98]

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

Each item is described in terms of the relative ease or difficulty that the participant experiences with the execution of the task or action. A four-point scale measuring scale is used. A score of 0 indicates no problem, and a score of 4 indicates the inability to perform the respective activity. It is well known that physical disabilities can cause the inability of a participant to perform a specific task, thus, the score 9, which within the parameters of the scale refers to not specified, can be scored if the patient had refrained from engaging in the specific task or action since the onset of the health condition. Furthermore, some of the items are diverse and not mutually exclusive among patients with similar of different diagnosed health conditions, thus patients are not required to perform a specific task or action in his or her day-to- day

life. For instance, some patients have never driven a car in their lifetime, therefore the score 8 refers to not applicable, thus explicitly inferring that the patient does not need to perform the task or action.

As this questionnaire was adapted it was once again reviewed by the group of researchers in the outcomes base study group for content and face validity. In addition a test retest reliability study was conducted. For the reliability test, the researcher from the Western Cape Rehabilitation Centre the researcher recruited ten chronic stroke patients who were part of a stroke group. Informed consent was obtained from the participants. The participants were interviewed at one point and two weeks later using the questionnaire. Data were captured and analyzed using SPSS version 18. The information for activity was captured separately from those for participation. The Intra-class Correlation Coefficient (ICC) scores for the participation domains ranged from .431 to 1. While the ICC scores for the activity items ranged from .410 to 1. The majority of the items demonstrated good to excellent ICC scores with only the item referring to "lifting" having poor scores in both activity and participation sections. The item referring to lifting was kept in the questionnaire, irrespective of the low ICC score, as with the removal of this item the overall internal consistency would have been reduced.[99] The group of researchers from the outcomes based studies further decided that the removal of the item (lifting) would negatively affect the content validity of the questionnaires, as it was felt that lifting is an essential construct of functioning of both patients with stroke and spinal cord injuries.

Thus the use of the adapted Zambian across all the diagnostic groupings allows for the generic data collection and comparison.

3.11.5 Care Givers Strain Index (CSI)

The CSI[100] (Appendix I) is a standardized tool used when a client is supported and cared for by another person. It is questionnaire with 13 questions measuring strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time. It can be used to assess individuals who have the role of caregiver.

Validity and reliability: Internal consistency reliability is high (alpha = 0.86) and construct validity is supported by correlations with the physical and emotional health of the caregiver and with subjective views of the care giving situation.

This instrument is brief and easy to administer.

3.11.6 European Quality of Life Index (EQ5D)

EQ5D[101] (Appendix J) was developed by a group of international multi-disciplinary researchers to measure health status. It can be used across a range of health conditions and treatments providing descriptive profile for health status. The instrument was developed for self-completion by participants and suited for use in health facilities and face-to-face interviews. It only takes a few minutes to complete, and all instructions are included in the questionnaire. The instrument consists of two parts, the descriptive system and the EQ visual analogue scale (EQ VAS).[101]

The participants had to rate their health status on a vertical, visual scale where the endpoints are labelled 'Best imaginable health state' and 'Worst imaginable health state'. The information obtained can be utilized as a quantitative measure of the participant's health status judged by the participant's response.

The administration of this tool does not require any specific training and therefore was selected for this study.[101]

3.11.7 Client satisfaction questionnaire

A client satisfaction questionnaire (Appendix K) was developed based on questionnaires that were used at the time, to determine patient satisfaction at Primary Health Care facilities in the Cape Winelands District.

The questionnaire consisted of twenty two questions mainly focussing on accessibility and satisfaction with service delivery.

3.11.8 Medical records impairment tool

After reviewing literature the researchers from the outcomes group could not find an instrument suitable to measure impairment and participation restriction of the five

most common conditions selected for the research. The SANPAD group that looked at the outcomes of clients receiving rehabilitation supported each other in developing a measuring tool that measured impairments (Appendix L). A diagnostic specific impairment measure for each of the five conditions was developed by the group of rehabilitation professionals. Literature supporting the development of the impairment measuring tool included the ICF framework1, and various journal articles. (Anderson, 2004; Estores, 2003; Lawrence et al., 2001).This tool was then distributed to ensure face-and content validity. Recommendations were made after the pilot study of this tool, which included; adding a 3 point scale (undocumented, impaired, and not impaired).

3.12 INSTRUMENT TO COLLECT QUALITATIVE DATA

The researcher developed a semi structured questionnaire consisting of three questions to guide the researcher with the telephonic follow up of clients who did not return for their follow up rehabilitation sessions, to determine from the client's perspective why they did not return for therapy.

The patient's replies were written down and later compared, to determine emerging themes.

3.13 DATA COLLECTION

It was important that the data collected was standardised, so that it could be compared to the other three study settings.

The data collection was done by the researcher and a trained research assistant. The research assistant completed all the questionnaires from responses given by participants. Each participant had a unique code and this code was used on all the questionnaires completed for that specific participant. This ensured anonymity and confidentiality.

Research assistants were also used at the other sites in the SANPAD group to minimise bias as far as possible so as to ensure that the completion of the questionnaires/interview process was done without influencing participants

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The training of the research assistant was done by the researcher because at the onset of training for the research assistants at the University of Stellenbosch, the researcher had not yet been able to identify a suitable person. The training for the research assistant at the TC Newman site was a one-to-one training process. The purpose of the training was to explain to the research assistant, the data collection tools, the process of interviewing and documentation and to provide a brief and elementary, background to the study. Role-play was used to familiarize the assistant with the above data collection process. The researcher was able to do this training herself as she formed part of and observed the training session at the University of Stellenbosch presented within the bigger SANPAD group, with the research assistants from the other sites on the process of collecting the data from the study participants. To ensure competency of the assistant, the researcher observed two sessions conducted by the research assistant and gave verbal feedback. The data collection process was then conducted by the research assistant. The research assistant had weekly appointments with the researcher to discuss the process, support her and to do data verification checks.

Data checks were done by scheduling regular appointments with the research assistant to provide support, clarity and to check the completeness of each set of questionnaires using a quality assurance checklist/guide that was provided by the bigger SANPAD group specifically for the group of researchers that looked at the outcomes of clients. The checklist, listed all the questionnaires that were used in the study. Each set of questionnaires were checked in accordance with those elements by both the research assistant and researcher. Once completed, each check list was signed and dated by the researcher and research assistant.

The onset of the data collection process was in TC Newman CDC, in a temporary venue allocated for rehabilitation services. Designated office space was allocated for the research assistant. The area was well ventilated, lighting was adequate, noise was minimal and privacy was ensured.

All new clients, who fulfilled the inclusion criteria, seen at the centre were part of the study population. The initial assessments/ interviews of the clients were conducted by the research assistant. Initial assessments, were done during the time period November 2010 – April 2011. The therapists together with the administrative clerk at

TC Newman CDC were responsible for ensuring that participants within the five categories were referred to the research assistant on the days that she was scheduled to be at the centre. Thus all new participants who attended rehabilitation on the days that coincided with that of the research assistant were included in the study. The total number of patients referred for the pre-assessment was 114 clients. In the first session, the purpose of the study was explained and written consent was obtained from the participants. The participants' language of choice was also obtained in this session, which was predominantly Afrikaans. The informed consent forms were only available in English, but the content of the informed consent forms was explained in detail to the clients in Afrikaans. All clients consented to participate in the study and signed the consent form. Once the consent was obtained the purpose of each questionnaire that followed were explained in detail. The research assistant initiated the interview by using the demographic questionnaires (Questionnaire 1, 2 and the Adapted Zambian Survey on living conditions) which was followed by the administration of the functional questionnaires, appropriate to the client's diagnosis. It took between 30 – 40 minutes to complete one data set.

After the questionnaires were completed by the research assistant, client's proceeded to therapy and follow up visits/appointments were made by the treating therapists and the administration clerk. Follow up appointments were made to coincide with the participants return date together with that of the research assistant's in order for her to complete the follow up assessment at TC Newman CDC.

During the period of the initial assessments and also the onset of the data collection process (November 2010 – January/February 2011), rehabilitation services rendered in TC Newman CDC moved from the allocated venue for rehabilitation services to a temporary venue, while a new dedicated area was being renovated and refurbished. This migration happened during the time period December 2010 – January 2011.

The follow up assessments at TC Newman CDC (N=12) were conducted in the temporary venue from March 2011 – June 2011. Thus the time period between the initial and follow up assessments and data collection period was between two or three months. The follow up assessments were also conducted by the research assistant on completion of the participants rehabilitation. With this assessment the

research assistant completed a second set of forms which included all the above mentioned forms, with the exclusion of Questionnaire 1.

In the event of clients not returning for therapy, the researcher decided to implement a second phase, an alternative means to follow up clients not returning for post testing because of the low return rate. Another procedure was followed. This would include: a telephonic follow up of all clients who had a telephone number that was in working order as well as home visits to clients who had a confirmed address and with whom appointments could be made telephonically. The questionnaires for the follow up assessments were completed at the participants' home with those who were available. All telephonic responses were written down by the researcher, summarised on an excel spread sheet and coded according to common themes/occurrences to identify themes and similarities from responses so as to determine why participants did not return for their follow up appointments.

A second qualitative phase was applied to the study for participants who were lost to the study and those who did not return for their follow up rehabilitation sessions. This would be done by determining who the clients were that did not return for their follow up rehabilitation appointments/sessions inclusive of those who did not complete their post-tests. Addresses and telephone numbers of these participants were obtained from the patient folders at TC Newman CDC. All participants who had a telephone number on their patient folder was contacted (N=91). However not all telephone numbers were in working order, some participants were not at home with the telephonic follow up, telephone numbers were wrong or not existing anymore. A semi structured interview schedule was developed to guide the telephonic follow up.

Because only a few participants could be reached telephonically, home visits were initiated following the telephonic follow up to determine the reasons for participants not returning for their follow up sessions. Due to time constraints participants included in the home visit (N=20) were selected randomly from those participants who only completed the pre-test. The large geographic area of the Drakenstein sub-district resulted in 10 participants living within a 2km radius from TC Newman CDC and the other 10 participants living further than 2km from TC Newman. A total of eight participants were followed up at home. The post-test questionnaires for these participants were administered in their homes by the research assistant.

3.14 DATA ANALYSIS

3.14.1 Quantitative data

With the capturing of the raw data, the researcher ensured that each participant had a complete set of data, that it was in a chronological order and that data captured understood the unique code of each participant. The researcher met with the data capturer on more than one occasion at the centre for rehabilitation studies to provide clarity where needed and to ensure that participant information was captured correct and complete as far as possible. Once all the participant information was captured, this data was then sent to a statistician at the University of Stellenbosch to assist in generating descriptive statistics and to advise on the presentation of the data.

The quantitative data was entered onto a prepared excel sheet with all variables listed as columns. The top row of the excel spread sheet listed the titles of variables. The entries for the different respondents were entered in as rows.

The statistician made use of the Statistica, V. 10 data analysis software, to analyse the data. Variables entered onto the spread sheet were; ordinal variables which represent data which are not continuous but larger numbers give "better" performance, while smaller numbers give "worse" performance and nominal or categorical variables such as gender. This would show the categories into which respondents' fall.[102]

Variables are presented graphically in the form of histograms so as to enable the reader to see the nature of the distribution of the particular variables and in identifying possible outliers. Data is also presented in frequency tables. Even though, both histograms and frequency tables provide similar information, outliers are easier identified in the histograms.[102]

A Wilcoxon Matched Pairs Test and T-test for dependent samples were used to confirm data findings from the descriptive frequency tables.

If the p-value is less than < 0.05, the particular correlation is seen as being statistically significant.

3.14.2 Qualitative data

Qualitative data tool

The researcher developed a semi-structured interview questionnaire for the participants who were followed up telephonically. The questionnaire served as a guide to ensure consistency during the interview.

Qualitative analysis

Participants' responses were written down as they spoke, with the exception of one client who was deceased, and whose daughter answered the questions on behalf of her late mother as she was familiar with her mother's therapy. The responses from the participants were coded firstly according to similarities in responses, these response were summarised and thereafter coded into emerging themes. These themes highlighted barriers and health systems challenges identified in the study.

3.15 RELIABILITY AND VALIDITY OF THE DATA COLLECTION AND OUTCOMES MEASUREMENT TOOLS

Measurement tools used in research must be accurate and reliability and validity are familiar to ensure accurate data is collected. Reliable measures produce the same results repeatedly. According to the common rule, reliability will be higher the more standardised the outcome measure.[18] Validity is the extent to which a measurement tool measures what it is supposed to measure; it must measure actual results.[18]

Reliability and validity was further ensured by participating in the pilot study, to become familiar and confident with administring the tools. The research assistant was trained in the use of the tools to ensure confidence in administering the tools.

3.16 ETHICAL CONSIDERATIONS

Ethical approval to conduct this research study was given by the Committee for Human Research at the US (reference number: NO N09/11/327). Further approval was obtained from the Western Cape Department of Health to conduct the study at TC Newman CDC, which also represents a rural district in the study.

Prior to participating in the research, participants were provided with an explanation of the purpose and process of the research. Written consent (Appendix M) was received from each participant before commencing with the questionnaires (written consent for children was obtained from the primary caregiver). Participants were assured of anonymity and confidentiality. It was also explained that if they did not want to participate in the study, there will be no negative consequences for them..

Confidentiality was ensured by using a unique code instead of the patient's name on the questionnaire, information obtained from the questionnaire was only known to the researcher and the research assistant. The data capturer and statistician were the only other persons who accessed the questionnaire; even then only coding was used to identify patients.

Data collected in the study will be kept at the researcher's office until the researcher graduates. Data will be stored for 5 – 8 years at the University of Stellenbosch.

The results of the study will be made available to all participants and the management of the Cape Winelands District Office (Department of Health).

3.17 SUMMARY

This study aims to describe and evaluate the functional rehabilitation outcomes of study participants at TC Newman CDC, after receiving rehabilitation intervention. A descriptive longitudinal method was used which included the use of a pre and post-test. Questionnaires were administered only to those participants who adhered to the inclusion criteria of the five most prevalent conditions, retrospectively determined by therapist working at TC Newman CDC. Data collection instruments consisted of quantitative questionnaires used to collect demographic data and diagnosis specific questionnaires for the functional outcomes measures and a semi structured interview schedule. A pilot study was conducted at Bishop Lavis rehabilitation centre, a similar setting to TC Newman CDC, prior to the onset of the research to ensure reliability and validity of the questionnaires. A statistician assisted with the data analysis of quantitative questionnaires. Qualitative data was thematically analysed.

CHAPTER 4: RESULTS

4.1 INTRODUCTION

Chapter 4 will present the results of the study. Findings are presented in relation to the objectives of the study. The main objectives were to: To evaluate the physical outcomes of clients receiving rehabilitation, to describe the patient's perception of the rehabilitation process and outcomes using a client satisfaction questionnaire, the physical rehabilitation outcomes and to describe the demographic factors and highlight barriers influencing rehabilitation outcomes.

Chapter 4 commences by describing the demographic details of study participants, followed by the rehabilitation outcomes, the patient's perception of the rehabilitation process and barriers.

4.2 DEMOGRAPHIC DETAILS OF STUDY PARTICIPANTS

4.2.1 Age, gender and race

Figures 4.1 and 4.2 illustrate the age, gender and race distribution of the participants.

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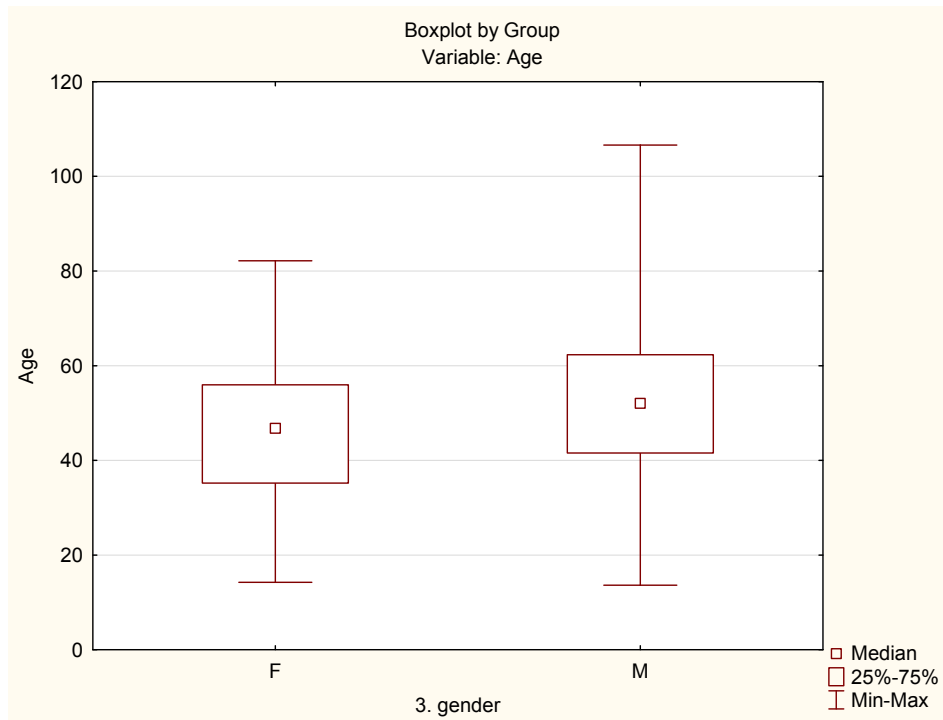
Figure 4.1: Age and gender distribution of participants

Most of the participants were between the ages of 40 and 60 years representing mainly an older population.

C	Coloured
A	African
O	Other
W	White
AS	Asian
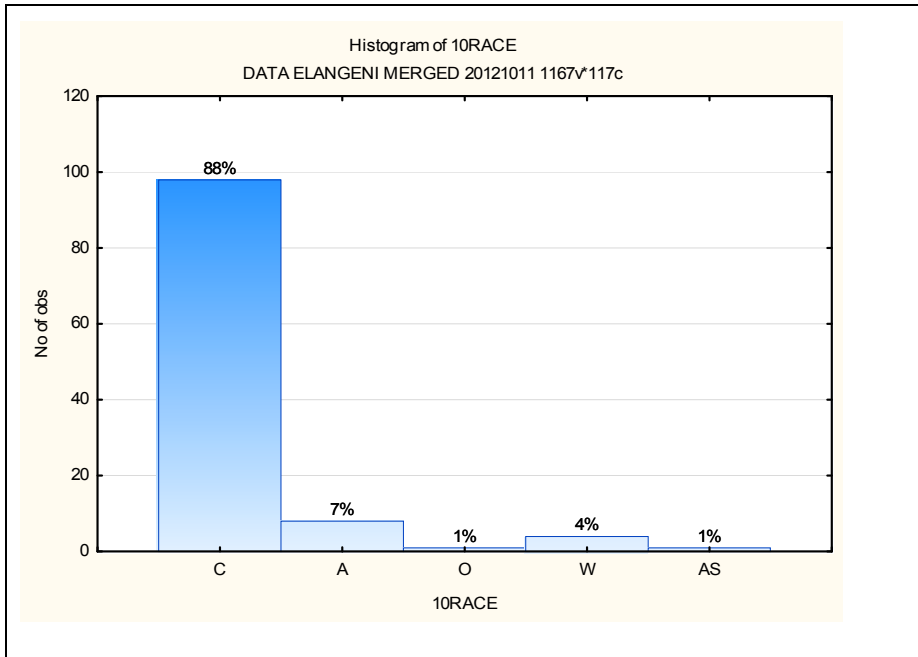
Figure 4.2: Race distribution of participants

The race distribution illustrated in Figure 4.2 shows that the majority of participants were coloured, 88% in total.

4.2.2 Level of education
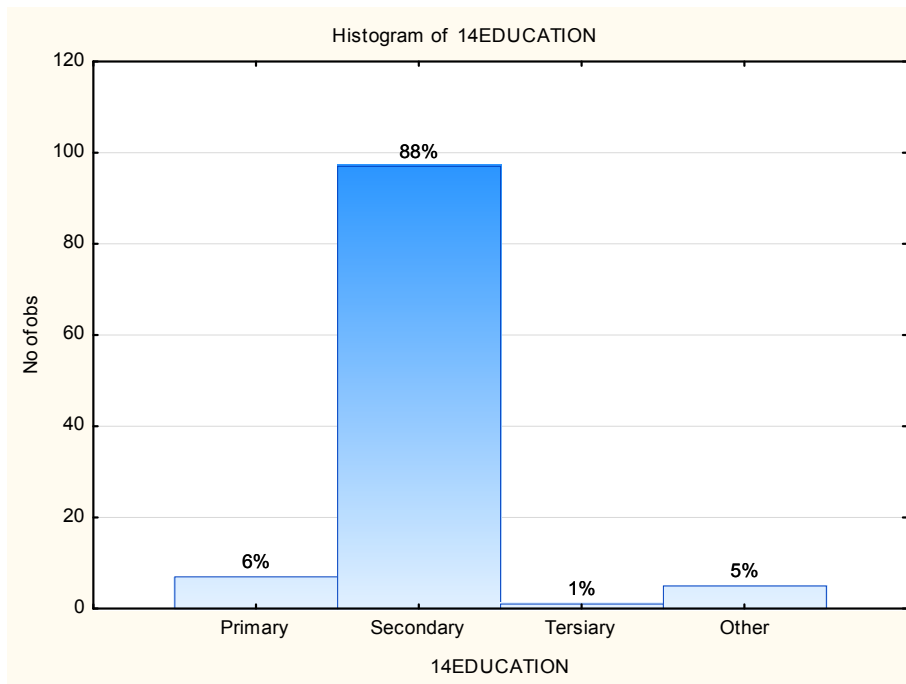
Figure 4.3: Education level

The large majority of participants (88%) had some secondary education. 5% of participants indicated no formal schooling, with 1% of the participants having a tertiary education.

4.2.3 Socio economic profile
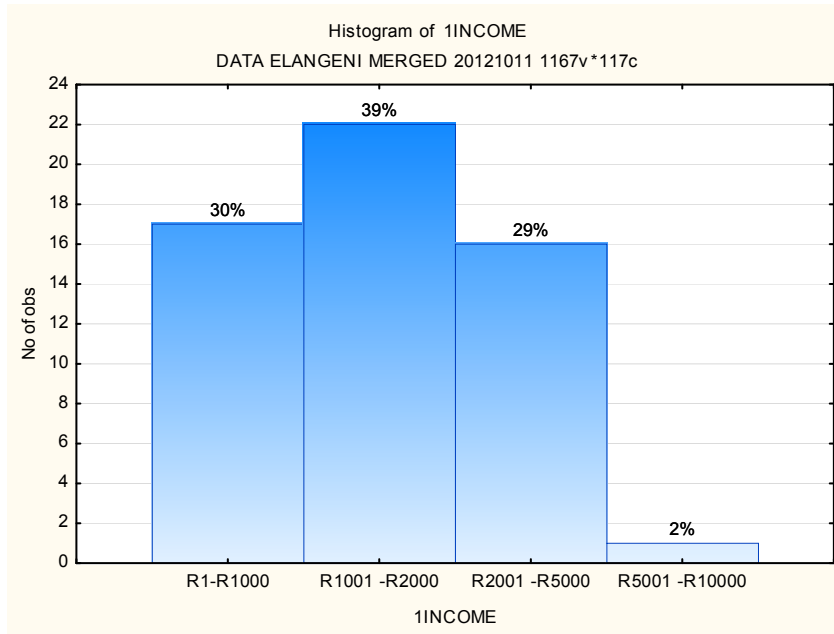
Figure 4.4: Monthly income of participants

Participants indicated a monthly income ranging between R1-R1 000 and R5 000. The majority (39%) had an income of between an R 1 000-R2 000 per month. Only 2% of the participant population received a monthly income more than R5 000.

U	Unemployed
E	Employed
G	Government Grant
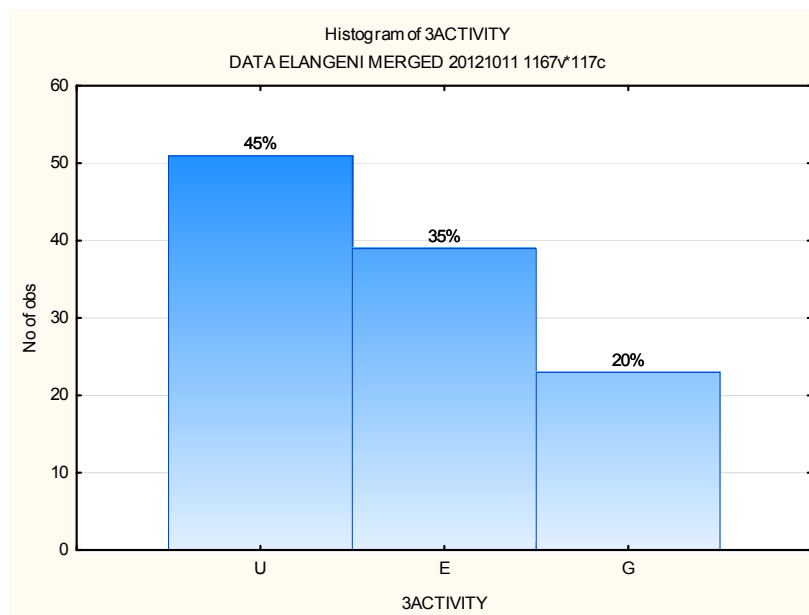
Figure 4.5: Percentage of people unemployed, employed and receiving a government grant

Participants were grouped into three categories based on their activity to generate an income: unemployed, employed (people both formally and informally employed and were able to generate an income) and those receiving government grants, which included old age pensions, disability grants or child care grants. Nearly half the participants (45%) indicated that they were unemployed.

4.2.4 Dwelling

Fifty-eight percent of participants did not specify the type of residence they lived in, but with the options given, indicated other. Eighteen percent indicated that they lived in a flat or a maisonette, while 7% lived in a hut or a traditional dwelling, 5% lived in a room in a backyard and 4% in an informal dwelling (shack). Seven percent indicated that they lived in either a cluster or semi-detached house. Most of the dwellings as indicated in Figure 4.8 had 4 or more rooms.

O	Other
F	Flat
T	Traditional dwelling
R	Room in a backyard
I	Informal dwelling
S	Shack
C	Cluster
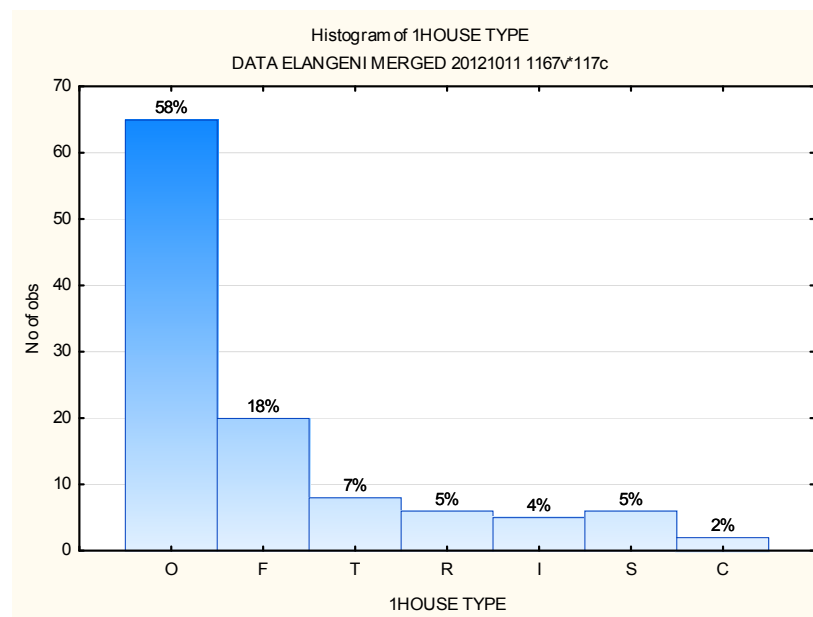
Figure 4.6: Type of housing
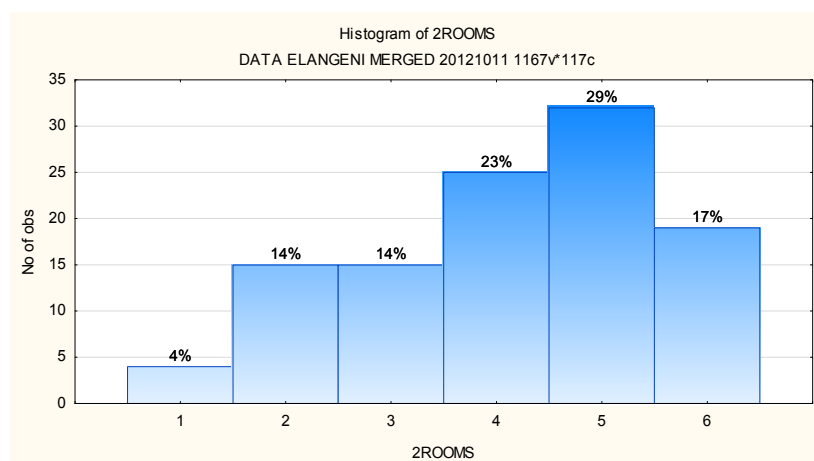
Figure 4.7: Number of rooms per household

69

4.2.5 Access to a phone
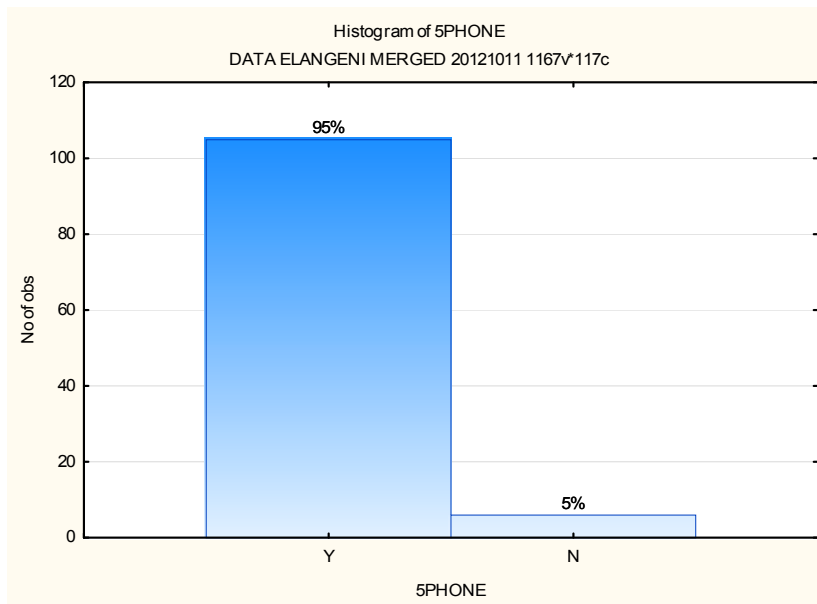
Figure 4.8: Access to phone

Majority of the participants indicated access to a telephone which was either a cell phone or a landline. Only 5% indicated no telephonic access.

4.3 ACCESSING REHABILITATION SERVICES

4.3.1 Referral sources

TC Newman Community Day Centre is based in Paarl and renders PHC services which include rehabilitation services to clients from the whole of the Drakenstein area, including the farming communities. The Drakenstein area consists of the following towns: Paarl, Wellington, Saron, Gouda and Simondium.

Clients are mainly referred from Paarl hospital.

PH	Paarl Hospital
O	Other
GF	GF Jooste
CH	Community Health Centre
T	Tygerberg
WH	Worcester Hospital
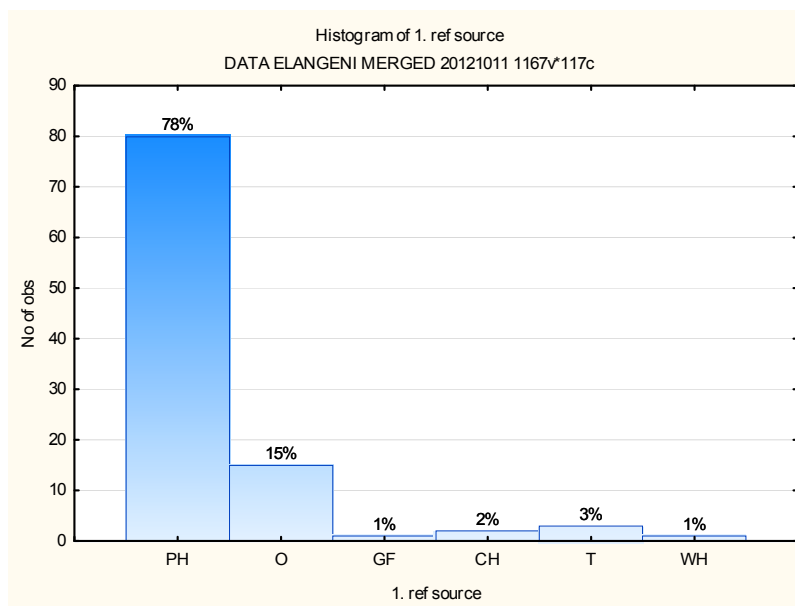
Figure 4.9: Referral source to TC Newman

Figure 4.9 shows that 78% of clients were referred from Paarl Hospital. Other referral sources to the centre included Worcester Hospital, Tygerberg, GF Jooste, other community health centres and 15% were unknown.

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DP	Doctor Private
DH	Doctor Hospital
P	Private
N	Nurse
DC	Doctor Clinic
O	Other

Histogram of 2. ref prof
DATA ELANGENI MERGED 20121011 1167v*117c
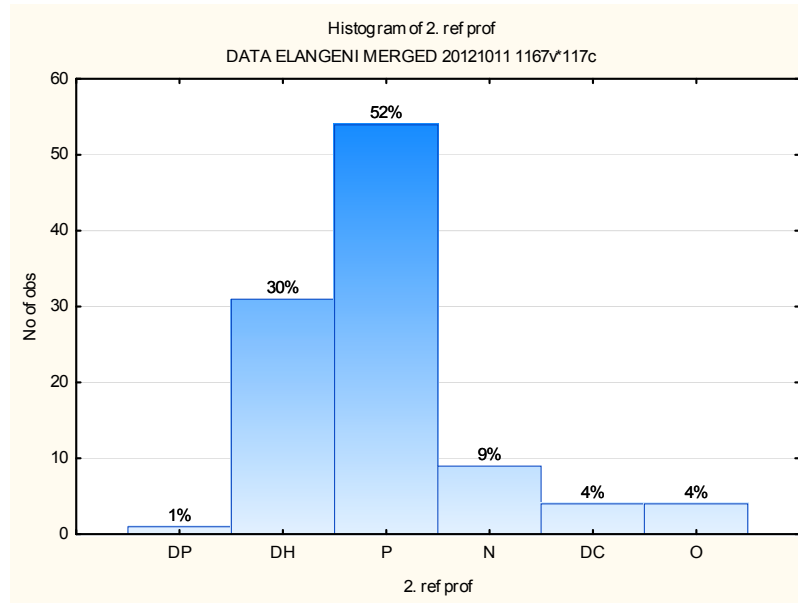
Figure 4.10: Referring professions

Figure 4.10 shows that mainly health professionals referred clients for rehabilitation services. The bulk of referrals were received from physiotherapists (52%) followed by doctors working at hospitals (30%). The nursing profession accounts for 9% of the referring sources, with doctors at PHC clinics, private doctors and other professions accounting for the remaining 9%.

4.3.2 Transport to access services

OM	Own Motor
T	Taxi
W	Walking
H	Hired vehicle
O	Other
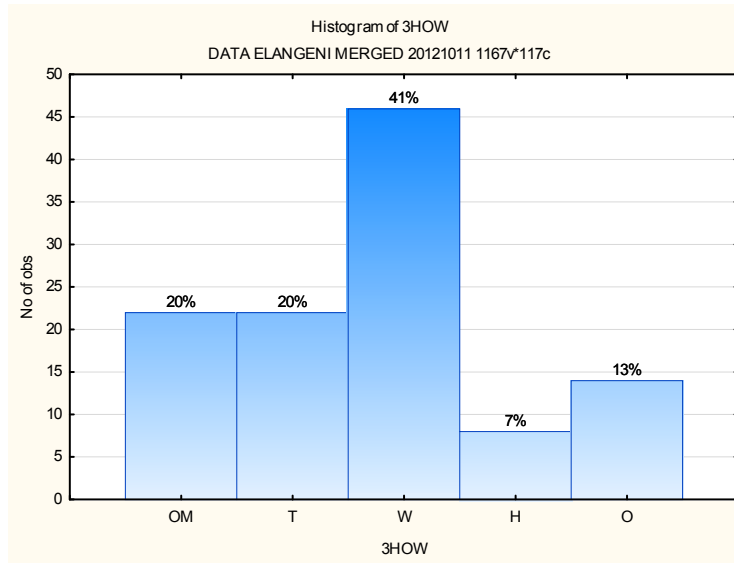
Figure 4.11: Transport used to access rehabilitation services

Figure 4.11 shows the mode of transport most often used by clients to access services at TC Newman CDC: the majority (41%) walked.
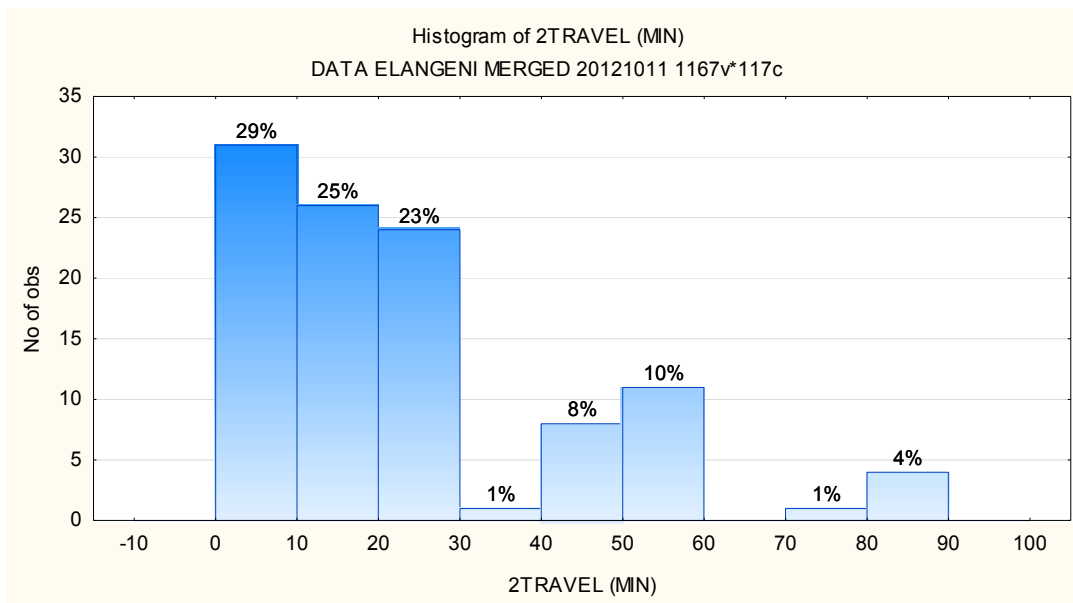
Figure 4.12: Travelling time

The majority of clients (77%) of clients travelled no longer than 30 minutes to get to the centre as shown in figure 4.13. Only 5% travelled more than 60 minutes to the centre.

73
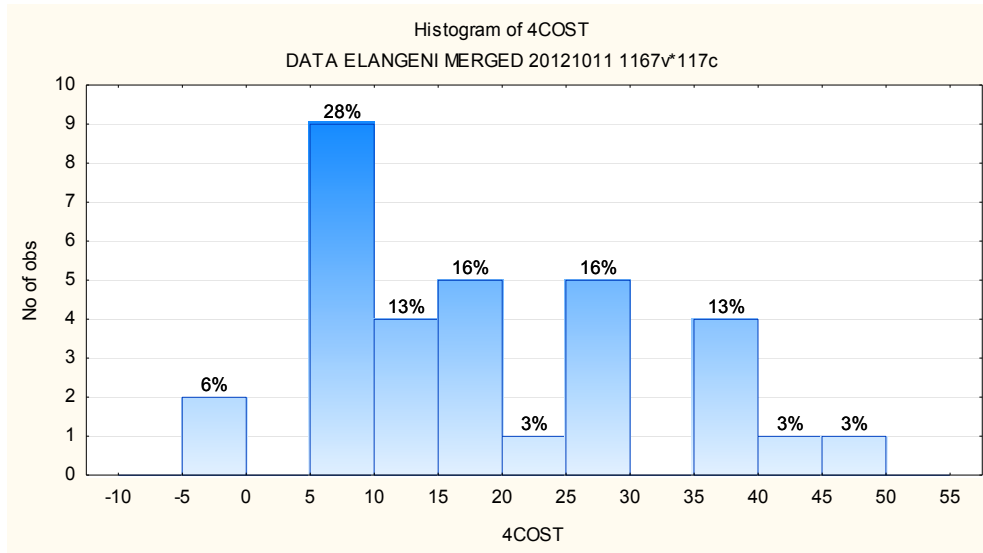
Figure 4.13: Travelling cost

Travelling cost to the centre varied between R5 and R50. Figure 4.13 shows that 57% of clients paid no more than R20, with 6% of the clients indicated no cost.

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4.3.3 Waiting period to get an appointment
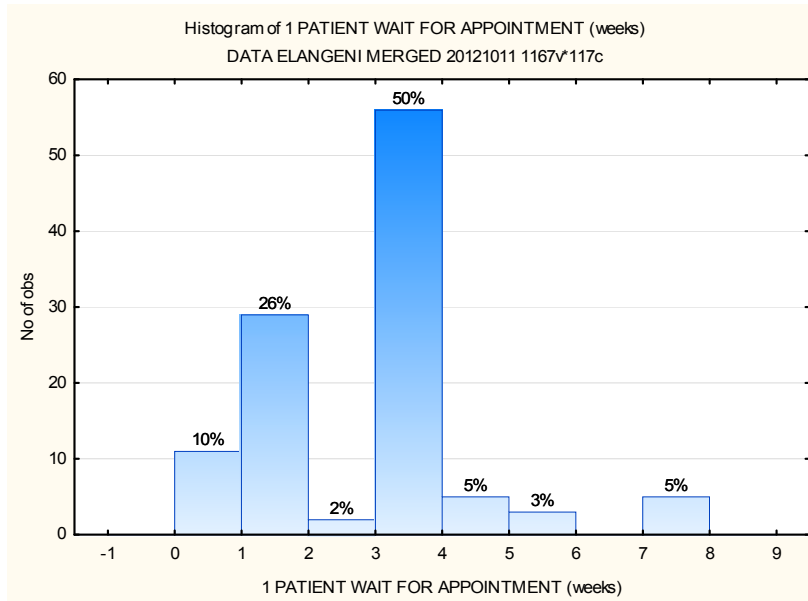
Figure 4.14: Waiting time for an appointment

Participants indicated that they waited between one and eight weeks to get an appointment. Eight-eight percent of participants received an appointment within 4 weeks. Fifty percent of clients waited between three and four weeks before getting an appointment and 5% had to wait between seven and eight weeks before receiving an appointment.

4.4 DIAGNOSTIC GROUPINGS
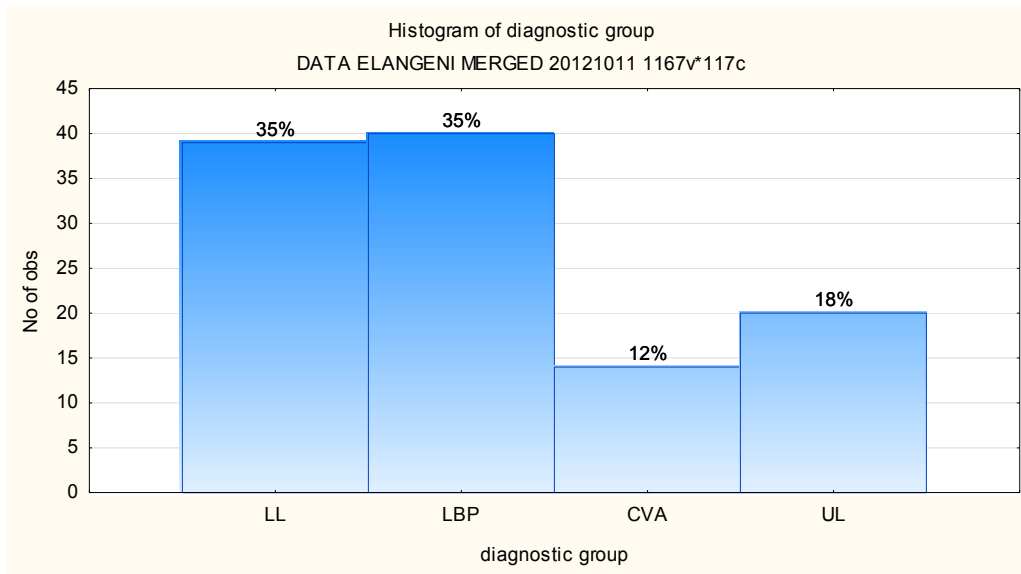
Figure 4.15: Diagnostic grouping

Lower limb and lower back pain accounted for 35% each of the participants seen.

CVAs accounted for the least amount (12%). The lower limb diagnostic grouping was mainly referred for: knee pain and injury, hip pain and injury, arthritis of the knee and hip and a small percentage indicated ankle injuries or fractures of the lower limb. The upper limb grouping the main diagnoses was painful shoulders and upper limb impairments as a result of neurological diagnoses.

4.5 CAUSE OF INJURIES
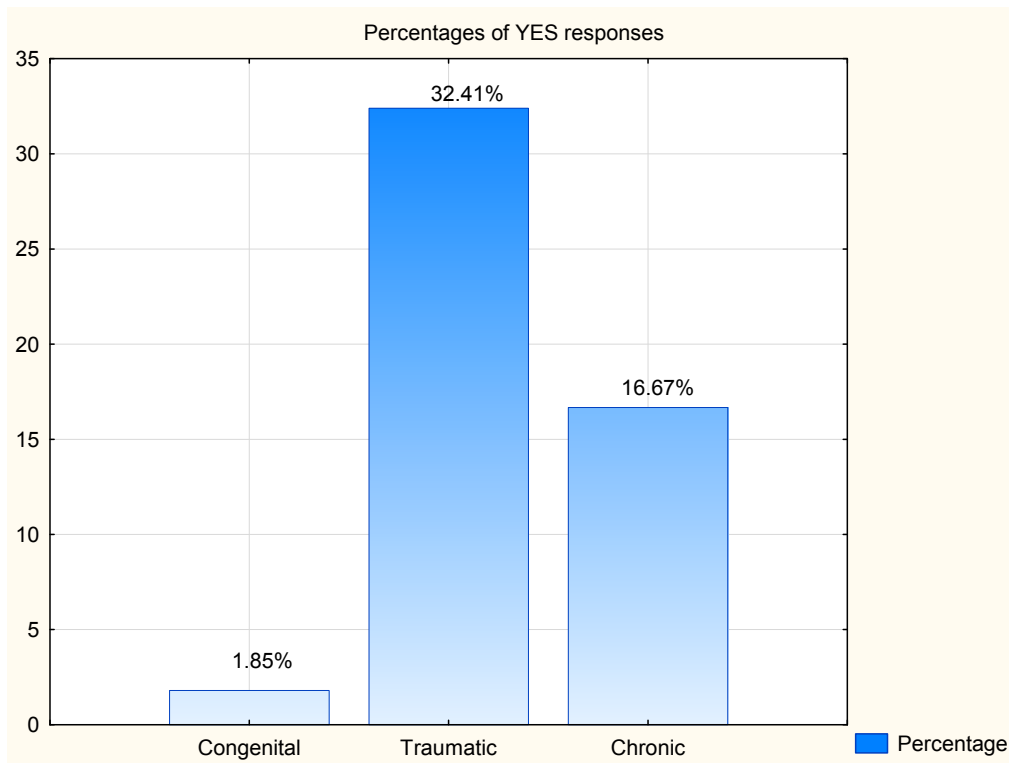
Figure 4.16: Cause of injury

Figure 4.16 shows the causes of injury namely: congenital, traumatic and chronic. Trauma was indicated as the main cause of injury, followed by chronic diseases and lastly, congenital factors. The remaining 13% were unknown. Trauma refers to impairments acquired through violence, road traffic accidents etc. and chronic relates to long standing illnesses or diseases resulting in activity limitations and participation restrictions and congenital refers to an impairment acquired at birth.

4.6 FUNCTIONAL OUTCOMES OF PATIENTS RECEIVING THERAPY

4.6.1 Perceived health status questionnaire: EQ5D

The EQ5D was used to measure the participant's perception of their health status before and after receiving therapy. The EQ5D was administered to 105 participants as part of the pre-test. The post- was administered to the 20 participants that returned for follow up appointments.
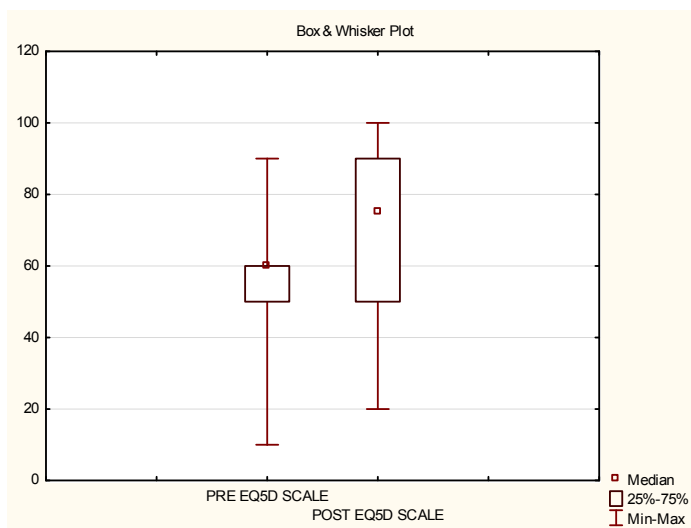
Figure 4.17: Box & Whisker Plot on all participants: pre- and post-EQ5D

The above graph illustrates that 20 participants who completed the post evaluation, compared to their pre-tests felt that their health status improved from the onset of therapy to the point of discharge.

Table 4.1 is the paired T-test for dependent samples where by the 20 participants that completed therapy were compared with each other's pre and post test scores. The results from the paired t-test indicate a significant change in the participant's perception of their health status after receiving therapy, with a p-value of (0.000390), indicating a significant change.

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Table 4.1: Paired T-test: EQ5D

Variable	T-test for Dependent Samples (DATA ELANGENI MERGED 20121011) Marked differences are significant at p < .05000									
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
PRE EQ5D SCALE	53.75000	15.63355								
POST EQ5D SCALE	70.25000	23.08309	20	-16.5000	17.17556	-4.29623	19	0.000390	-24.5384	-8.46159

A Wilcoxon Matched Pairs Test with the 20 participants who completed both their pre and post tests confirmed that the improvement was significant, with a p-value of (0.001696). 2 participants who completed the pre and post-test had the same score with the pre- and post-test, hence the N=19.

Table 4.2: Wilcoxon Test: EQ5D

Pair of Variables	Wilcoxon Matched Pairs Test (DATA ELAN(Marked tests are significant at p <.05000			
	Valid N	T	Z	p-value
PRE EQ5D SCALE & POST EQ5D SCALI	19	17.00000	3.138890	0.001696

4.6.2 Effect of back and leg pain on daily functioning: Oswestry disability index

The Oswestry Disability Index was used to evaluate how the participants back or leg pain affected their ability to manage in everyday life. It was administered to clients with the following diagnoses: lower back pain and lower limb injuries.

As indicated in Table 4.3 the Oswestry was administered to 67 participants, with only 14 from these completing the post test. The table below looking at the mean and the median showed an improvement in scoring, but not significant.

Table 4.3: Descriptive statistics: Oswestry

Variable	Descriptive Statistics (DATA ELANGENI MERGED 20121011)									
	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
PRE OSW TOTAL	67	44.90879	41.36751	48.45007	42.22222	20.00000	102.2222	35.55556	51.11111	14.51826
POST OSW TOTAL	14	44.76190	30.03894	59.48487	32.22222	20.00000	95.5556	26.66667	60.00000	25.49949

The T-test indicated and confirmed that 14 participants that completed the post-test improved, but not significantly with a P value of 0.969740.

Table 4.4: Paired T-test: Oswestry

Variable	T-test for Dependent Samples (DATA ELANGENI MERGED 20121011) Marked differences are significant at p < .05000								
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
PRE OSW TOTAL	44.92063	17.82427								
POST OSW TOTAL	44.76190	25.49949	14	0.158730	15.35807	0.038671	13	0.969740	-8.70876	9.026216

Oswestry results from the paired T-test (dependent samples) only compared the scores with those clients who completed both the pre and post-test. It indicated that the 14 participants who completed the Oswestry pre and post-test showed only a slight improvement in pain. The above results should be interpreted with caution taking into account that only 14 of the 67 were re-tested (both the pre and post-test only).

4.6.3 Establishing the degree of independence (activity and participation) in clients diagnosed with a stroke: Barthel index

The Barthel index was administered to clients who were diagnosed with a stroke (CVA) and was used to establish the participant's degree of independence, however small and for whatever reason. It was administered to 11 clients of whom only 3 of these returned for the post-test. Table 4.5 indicated that there was an improvement in the 3 clients that participated in both the pre and post-test. Results demonstrated an increase in the scores, which could indicate improvement after receiving therapy.

Table 4.5: Descriptive statistics: Barthel Index

Variable	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
Descriptive Statistics (DATA ELANGENI MERGED 20121011)										
PRE BI (Total)	11	63.18182	40.18902	86.1746	70.00000	5.00000	100.0000	#######	90.0000	34.22519
POST BI (Total)	3	96.66667	89.49558	103.8378	95.00000	95.00000	100.0000	#######	#######	2.88675

The Paired T-test for the Barthel index also indicated that there was no significant change in the results which could be attributed to the small number (N=3) that returned for the post test. The paired t-test compared the pre and post test scores of clients who completed both the pre and post-test (N=3).The Wilcoxon also confirmed that improvement was indicated, though not significant.

Table 4.6: Paired T-test: Barthel

Variable	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
T-test for Dependent Samples (DATA ELANGENI MERGED 20121011) Marked differences are significant at p < .05000										
PRE BI (Total)	70.00000	31.22499								
POST BI (Total)	96.66667	2.88675	3	-26.6667	30.55050	-1.51186	2	0.269703	-102.558	49.22499

Table 4.7: Wilcoxon Test: Barthel

Pair of Variables	Valid N	T	Z	p-value
Wilcoxon Matched Pairs Test (DATA El Marked tests are significant at p <.0500				
PRE BI (Total) & POST BI (Total)	2	0.00	1.341641	0.179713

4.6.4 Measurement of physical, social and emotional wellbeing: Arthritis Impact Measurement Scale 2 (AIMS2–SF)

The AIMS was administered to 10 participants presenting with a diagnoses of arthritis. The scale measures physical, social and emotional wellbeing. Only 3 participants returned for the post-test. Results indicated that improvement was visible and that the increase in scores showed improvement in the wellbeing of the participants. The paired t-test and the Wilcoxon were done to confirm findings from the descriptive statistics in Table 4.8 for only those clients who returned for both the pre and post-test. The results showed that change was present, though not significant, which may be because of the small number (N=3), that returned for therapy and to whom both a pre and post-test could be administered.

Table 4.8: Descriptive statistics: AIMS

Variable	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
	Descriptive Statistics (DATA ELANGENI MERGED 20121011)									
PRE AIMS Total	10	71.00000	65.76490	76.2351	69.00000	61.00000	80.00000	67.00000	80.00000	7.318166
POST AIMS Total	3	78.66667	55.58512	101.7482	83.00000	68.00000	85.00000	68.00000	85.00000	9.291573

Table 4.9: Paired T-test: AIMS

Variable	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
	T-test for Dependent Samples (DATA ELANGENI MERGED 20121011) Marked differences are significant at p < .05000									
PRE AIMS Total	75.66667	7.505553								
POST AIMS Total	78.66667	9.291573	3	-3.00000	2.000000	-2.59808	2	0.121690	-7.96828	1.968275

Table 4.10: Wilcoxon: AIMS

Pair of Variables	Valid N	T	Z	p-value
	Wilcoxon Matched Pairs Test (DATA El Marked tests are significant at p <.0500			
PRE AIMS Total & POST AIMS Total	3	0.00	1.603567	0.108810

4.6.5 Symptoms and abilities of the arm/hand to perform activities of daily living: Disabilities of the Arm, Shoulder and Hands (DASH)

The test was administered to 12 participants of whom only 2 returned for the post test. 7 of the participants completed the optional work module, which looked at the impact of the injury/disability on their ability to work. Too few participants with diagnoses of the upper limb returned for the post-test, which made it difficult to compare results between the pre- and the post-test.

Table 4.11: Descriptive statistics: DASH

Variable	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
				Descriptive Statistics (DATA ELANGENI MERGED 20121011)						
PRE UL total symptom score	12	78.83333	58.09787	99.56879	77.50000	36.00000	135.0000	53.00000	101.0000	32.63527
PRE UL work total	7	10.57143	5.92085	15.22201	12.00000	4.00000	18.0000	4.00000	13.0000	5.02849
PRE UL sport total	0									
POST UL total symptom score	2	30.00000	17.29380	42.70620	30.00000	29.00000	31.0000	29.00000	31.0000	1.41421
POST UL work total	2	4.00000			4.00000	4.00000	4.0000	4.00000	4.0000	0.00000
POST UL sport total	0									

4.6.6 Degree of mobility over time for clients with lower back and lower limb injuries: Clinical Mobility Scale (CMS)

The clinical mobility scale was administered to participants presenting with diagnoses of lower back pain or lower limb injuries. It was used to assess a participant's degree of mobility over time. The tool was administered to 99 participants with the pre-test and 21 participants with a post-test. Thus 21 participants completed both the pre and post-tests. Results from the paired t-test indicated that there was improvement in the participant's scores, but not very significant. However the Wilcoxon illustrated that there was a significant change in the participant's scores, which indicated a significant improvement.

Table 4.12: Descriptive statistics: CMS

Variable	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
				Descriptive Statistics (DATA ELANGENI MERGED 20121011)						
PRE CMS Total	99	15.71717	13.99296	17.44138	20.00000	0.000000	24.00000	8.00000	23.00000	8.644971
POST CMS Total	21	22.14286	20.52525	23.76047	23.00000	8.000000	24.00000	22.00000	24.00000	3.553670

Table 4.13: Paired T- test: CMS

Variable	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
	T-test for Dependent Samples (DATA ELANGENI MERGED 20121011) Marked differences are significant at p < .05000									
PRE CMS Total	21.30000	4.117996								
POST CMS Total	22.85000	1.496487	20	-1.55000	3.845366	-1.80264	19	0.087331	-3.34969	0.249687

Table 4.14: Wilcoxon:CMS

Pair of Variables	Valid N	T	Z	p-value
	Wilcoxon Matched Pairs Test (DATA ELANG Marked tests are significant at p <.05000			
PRE CMS Total & POST CMS Total	7	2.000000	2.028370	0.042523

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4.6.7 Care givers strain in the provision of care: Care Givers Strain Index: (CSI)

The CSI was administered to participants who were supported and cared for by another person. It measured strain with the provision of care. The index was administered to 16 participants of whom only 2 participated in the post-test. The small number who participated in the post-test, made it difficult to do a comparison between the pre- and post-results.

Table 4.15: Descriptive statistics: CSI

Variable	Valid N	Mean	Confidence -95.000%	Confidence 95.000%	Median	Minimum	Maximum	Lower Quartile	Upper Quartile	Std.Dev.
Descriptive Statistics (DATA ELANGENI MERGED 20121011)										
PRE CSI TOTAL	16	9.062500	7.2848	10.84015	10.00000	1.000000	13.00000	8.000000	11.50000	3.336041
POST CSI TOTAL	2	6.500000	-63.3841	76.38413	6.50000	1.000000	12.00000	1.000000	12.00000	7.778175

4.6.8 Adapted Zambian survey on living conditions questionnaire

The Adapted Zambian Questionnaire was administered to all participants in the study. The tool measured activity limitations and participation restrictions in the areas of communication, mobility, self-care, domestic life, interpersonal behaviour, major life areas such as attending education, work, economic areas and community and social life. The scoring scale ranged from 0-4. With 0 indicating no problem and 4 indicating that the participant is not able to execute the activity.

The T-test for the pre- and post-test activity limitation scores showed a significant change. The Mean indicated a definite decrease in scoring which indicated that improvement was noted and significant.

Table 4.16: T-test: Zambian: All Groups (Activity limitation)

Variable	All Groups T-test for Dependent Samples (DATA ELANGENI MERGED 20121101) Marked differences are significant at p < .05000									
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE ACT	13.72727	21.42580								
TOTAL POST ACT	10.09091	21.57139	22	3.636364	7.925519	2.152043	21	0.043180	0.122385	7.150342

The results from the T-test for the pre- and post-participation scores also indicate a significant change in the participant's scores, with a P-value of 0.023107.

Table 4.17: T-test: Zambian: All Groups (Participant restriction)

Variable	All Groups T-test for Dependent Samples (DATA ELANGENI MERGED 20121101) Marked differences are significant at p < .05000									
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE PART	14.13636	21.53689								
TOTAL POST PART	10.09091	21.57139	22	4.045455	7.742753	2.450661	21	0.023107	0.612510	7.478399

The above tables indicated that participants showed marked overall improvement in the areas of activity and participation.

Looking at tables 4.18 and 4.19 the lower limb diagnostic group showed the most significant improvement across all 4 diagnostic groups with a P-value of 0.016001.

The lower limb diagnostic group was one of the two categories that were mainly referred for therapy. (Refer: figure 4.17-it refers to all groups)

Table 4.18: T-test: Zambian: Lower Limb (Activity limitation)

| Variable | diagnostic group=LL
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE ACT	15.22222	30.35942								
TOTAL POST ACT	12.22222	31.47133	9	3.000000	2.958040	3.042555	8	0.016001	0.726249	5.273751

Table 4.19: T-test: Zambian: Lower Limb (Participation restriction)

| Variable | diagnostic group=LL
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE PART	15.22222	30.35942								
TOTAL POST PART	12.22222	31.47133	9	3.000000	2.958040	3.042555	8	0.016001	0.726249	5.273751

The lower back pain diagnostic group was the other category that was mostly referred to therapy. Activity limitation before and after receiving therapy, showed a slight improvement as indicated by a mean score of 6.875 with the pre-test compared to a mean score of 6.375 with the post test. The decrease in the mean score showed a slight improvement. When comparing the participation restriction, with the activity limitation there was a greater improvement, than with the mean score, but not significant.

Table 4.20: T-test: Zambian: Lower Back Pain (Activity limitation)

| Variable | diagnostic group=LBP
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE ACT	6.875000	6.401730								
TOTAL POST ACT	6.375000	6.696214	8	0.500000	5.806400	0.243561	7	0.814555	-4.35427	5.354272

Table 4.21: T-test: Zambian: Lower Back Pain (Participation restriction)

| Variable | diagnostic group=LBP
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE PART	8.000000	8.485281								
TOTAL POST PART	6.375000	6.696214	8	1.625000	5.680480	0.809121	7	0.445073	-3.12400	6.374000

The T-test in tables 4.22 and 4.23 showed that participants had the same score in both the pre-and post-tests for activity limitation and participation restrictions. Slight improvement was noted and was similar for both activity limitation and participation restrictions.

Table 4.22: T-test: Zambian: CVA (Activity limitation)

| Variable | diagnostic group=CVA
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE ACT	26.33333	17.61628								
TOTAL POST ACT	20.33333	20.79263	3	6.000000	8.717798	1.192079	2	0.355497	-15.6562	27.65621

Table 4.23: T-test: Zambian: CVA (Participation restriction)

| Variable | diagnostic group=CVA
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE PART	26.33333	17.61628								
TOTAL POST PART	20.33333	20.79263	3	6.000000	8.717798	1.192079	2	0.355497	-15.6562	27.65621

The T-test for the upper limb diagnostic grouping showed similar results as with the CVA group. Improvement noted was equal in both participation restriction and activity limitation, but not significant with the P-value of both at 0.5.

Table 4.24: T-test Zambian: Upper limb (Activity limitation)

| Variable | diagnostic group=UL
T-test for Dependent Samples (DATA ELANGENI MERGED 20121101)
Marked differences are significant at p < .05000 | | | | | | | | | |
	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
TOTAL PRE ACT	15.50000	21.92031								
TOTAL POST ACT	0.00000	0.00000	2	15.50000	21.92031	1.000000	1	0.500000	-181.446	212.4462

Table 4.25: T-test Zambian: Upper limb (Participation restriction)

Variable	Mean	Std.Dv.	N	Diff.	Std.Dv. Diff.	t	df	p	Confidence -95.000%	Confidence +95.000%
	diagnostic group=UL T-test for Dependent Samples (DATA ELANGENI MERGED 20121101) Marked differences are significant at p < .05000									
TOTAL PRE PART	15.50000	21.92031								
TOTAL POST PART	0.00000	0.00000	2	15.50000	21.92031	1.000000	1	0.500000	-181.446	212.4462

Table 4.26: Comparison of the categories from the adapted Zambian, pre and post results on activity limitations and participation restrictions.

Adapted Zambian Activity limitation pre test results		Adapted Zambian Activity limitation post test results				
Variable	Mean	Variable	Mean	Z-score	P-values	Comment
Communication	1.00	Communication	0.82	1.341641	0.179713	no significant impact
Mobility	7.38	Mobility	11.82	2.832748	0.004615	significant impact
Self care	9.90	Self care	1.05	4.014509	0.00006	significant impact
Domestic	3.57	Domestic	10.77	2.52743	0.011491	significant impact
Interpersonal	0.76	Interpersonal	2.55	2.0226	0.043115	significant impact
Major life areas	1.52	Major life areas	14.18	3.91993	0.000089	significant impact
Community	0.76	Community	1.73	1.095445	0.273323	no significant impact
Adapted Zambian Participation restriction pre test results		Adapted Zambian Participation restriction post test results				
Variable	Mean	Variable	Mean	Z-score	P-values	Comment
Communication	1.15	Communication	0.82	1.603567	0.10881	no significant impact
Mobility	7.38	Mobility	11.82	2.832748	0.004615	significant impact
Self care	1.52	Self care	1.05	0.730297	0.456209	no significant impact
Domestic	4.00	Domestic	10.77	2.52743	0.011491	significant impact
Interpersonal	0.76	Interpersonal	2.55	2.0226	0.043115	significant impact
Major life areas	0.76	Major life areas	14.18	4.014509	0.00006	significant impact
Community	1.52	Community	1.64	0.104828	0.916512	no significant impact

Table 4.26 illustrates that participants demonstrated significant improvement in the areas of mobility, self-care, domestic life, Interpersonal behaviour and major life areas. The category community also indicates improvement, though not significant. The scores from communication do not illustrate improvement.

Looking at the fore mentioned results from the different tools used to evaluate the physical outcomes of participants receiving therapy, the overall result indicated an improvement in the functional outcomes of participants.

4.7 PATIENT SATISFACTION
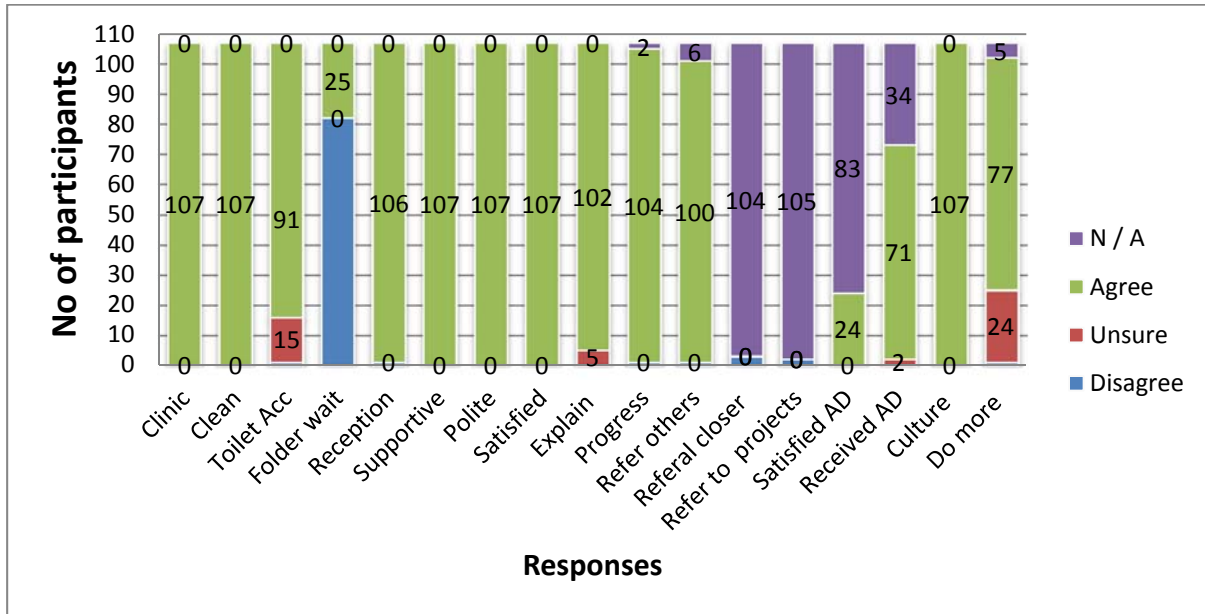
Figure 4.18: Results: Patient satisfaction

A client satisfaction questionnaire was administered to 107 participants. The questionnaire was completed after the first rehabilitation session and again for participants who returned for follow up sessions.

4.8 MEDICAL RECORDS FOR IMPAIRMENT

The medical records impairment tool was used to obtain information from the patient folder regarding the client's body structures and functions after the post test was administered. This tool was completed by the researcher. Documentation in all patient folders (N=114) regarding these aspects were documented incomplete. Clinical notes of did not reflect how rehabilitation clients were evaluated or measured.

4.9 ENVIRONMENTAL FACTORS INFLUENCING REHABILITATION
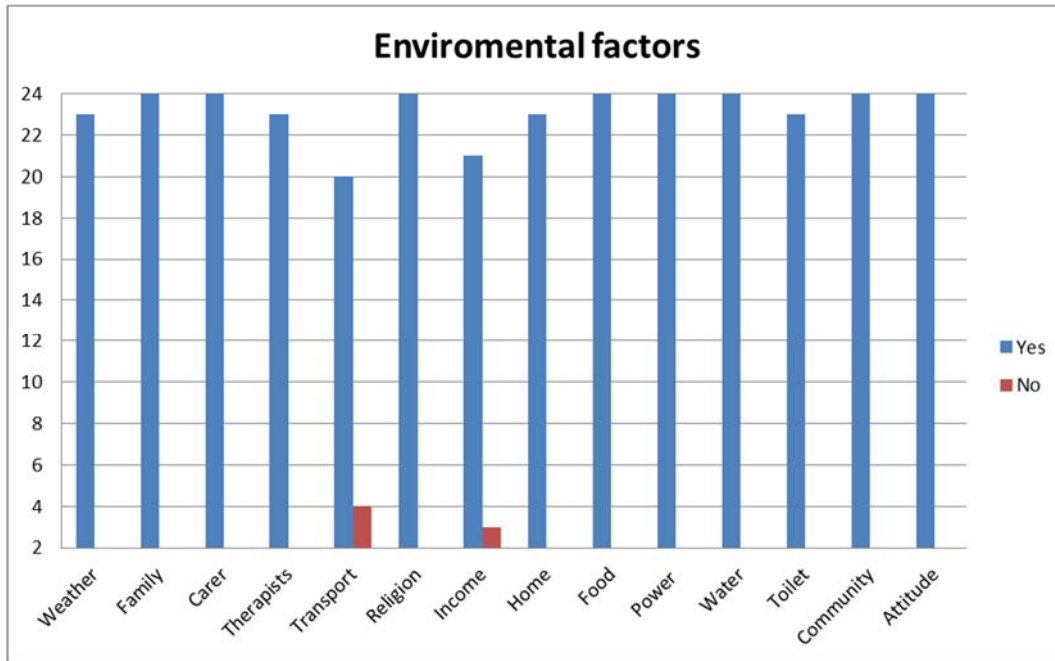
Figure 4.19: Environmental factors as indicated on the questionnaire

Data/information regarding the influence of environmental factors on rehabilitation were obtained from the participants who completed the post test. This information was contained in the SANPAD questionnaire 2 that was only administered to clients completing the post test. The blue bar indicates facilitators in the rehabilitation process and the red bars indicated barriers. There were 6 areas from the 11 responses that were seen as factors that were barriers to rehabilitation. Transport and income appeared to be the two barriers that had the most influence.

4.10 FOLLOW UP OF CLIENTS WHO DID NOT RETURN FOR THERAPY
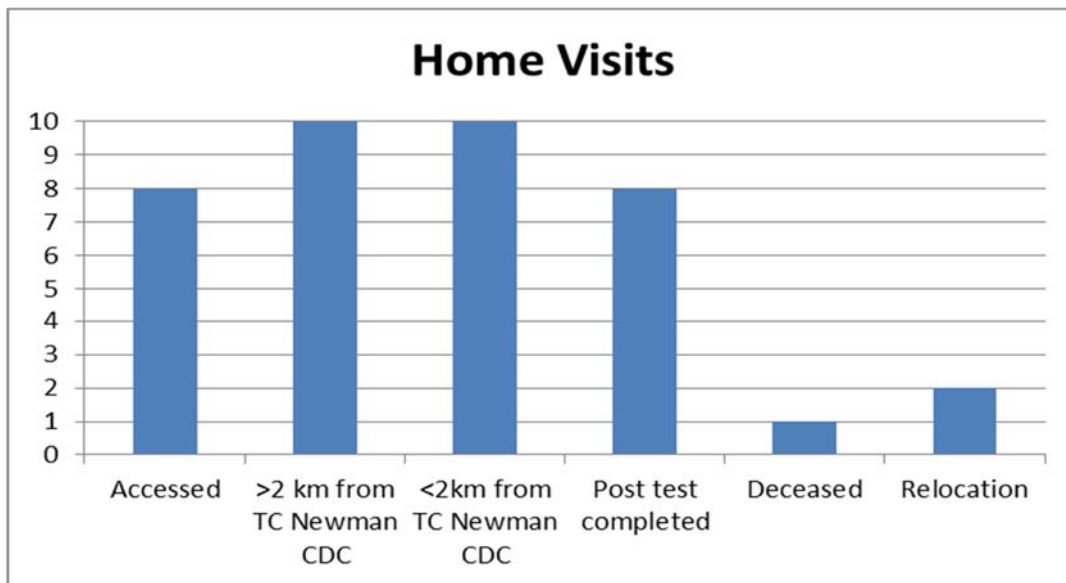
Figure 4.20: Home visits

Of the 20 files that the researcher randomly selected for a follow up home visit, 1 client was deceased and 2 clients relocated, with no follow up address. Ten participants lived within 2 km from TC Newman and the other 10 participants lived further than 2 km from TC Newman. Of the 10 2 clients who lived more than 2 km from TC Newman only 2 completed the post test and 6 participants who lived within 2 km from, TC Newman completed the post test. The 8 clients who completed the post-test with the home visits were those who could be traced, the remaining 12 were either not at home, or the addresses were difficult to locate. Only 1 of the 8 participants gave a reason for not returning for therapy, being distance.

4.11 TELEPHONIC RESPONSES FROM CLIENTS
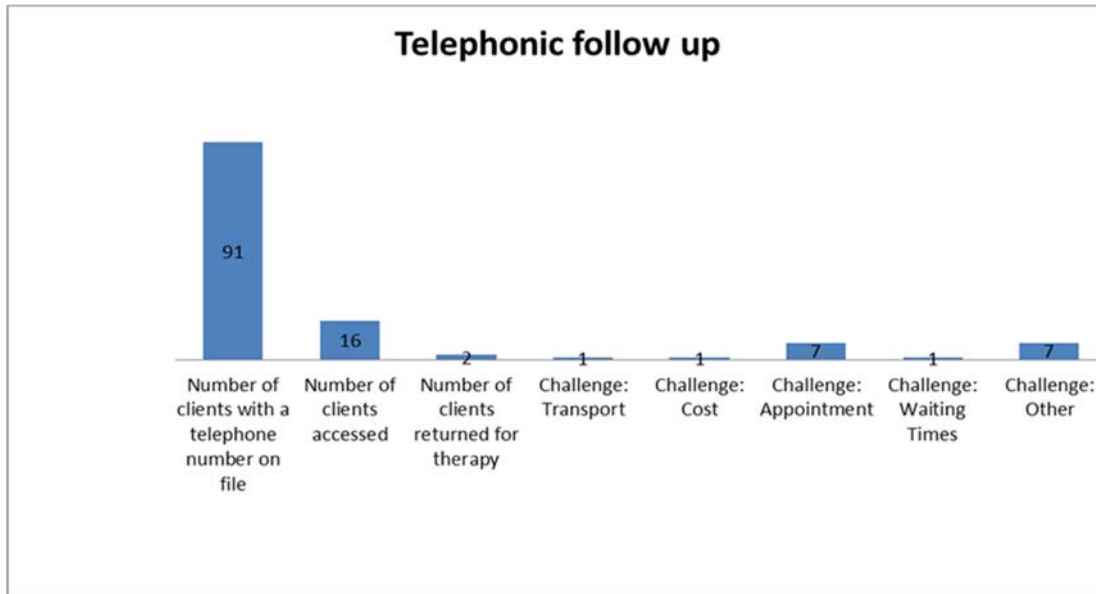
Figure 4.21: Telephonic follow up of participants

Ninety one of the hundred and fourteen patient folders had a telephone number indicated.

Of the 91 clients who had a telephone number on their patient folder, only 16 could be reached. 2 of these clients indicated returning for follow up therapy but were never referred to the research assistant. Participants indicated transport, cost, waiting times for appointments as barriers to rehabilitation.

Themes identified from the telephonic follow up responses related to:

- Not receiving a follow up appointment for rehabilitation
- Transport
- Needing to be at work
- Clients felt well enough to stop therapy

Overall from the telephonic follow up, clients responded that they were satisfied with the rehabilitation that they had received.

4.12 SUMMARY

The majority of clients, who access rehabilitation services at TC Newman CDC, were above the age of 40 years and were mainly representative of the Coloured population in the Drakenstein. Most clients indicated a secondary education, with only 2% earning above R5 000 per month. Sixty-five percent of participants were unemployed or were in position of a Government Grant. Ninety-five percent indicated telephone access, but only 16 clients could be contacted telephonically, whilst the remaining telephone numbers did not exist. The main mode of transport to access rehabilitation services was by walking and 20% had their own transport.

The main referral source for rehabilitation services at TC Newman came from Paarl hospital and physiotherapy was the main referring profession. Clients did not wait longer than four weeks for an initial appointment, but follow up appointments appeared to be the biggest challenge of the study. The main conditions treated at TC Newman were diagnoses of the lower limb and lower back pain, with trauma being the main course of injury.

Even though the post test was only administered to a small number of clients, results of the small number indicated an overall improvement after having received rehabilitation.

The client satisfaction done before and after therapy indicated an overall satisfaction with rehabilitation services.

The folder audit indicated overall poor documentation by rehabilitation professionals.

The telephonic follow up confirmed that the lack of a follow up appointment and not knowing when to come back were the biggest barriers for low return rate.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

The findings of the study will be discussed in Chapter 5 in order to identify gaps and challenges, positive aspects and factors that had an influence on the rehabilitation outcomes of participants at TC Newman CDC. The discussion will be structured in relation to the objectives of the study.

5.2 DEMOGRAPHIC PROFILE OF THE STUDY POPULATION

The Drakenstein sub-district is the largest sub-district in the Cape Winelands district, with a population count of 210 801. Eighty percent (168 641) represents an uninsured population who predominantly access health care services from primary health care clinics and hospitals in the public sector.[104] Thus when resources and services are planned for primary healthcare and the population it serves, environmental factors together with contextual factors and therefore the context should always be taken into account in ensuring that health services including rehabilitation is rendered in in equitable manner and at the level of care appropriate and relevant to its users.[8,13,15] The National Rehabilitation Policy highlights the importance of restructuring and strengthening rehabilitation services so as to improve access at PHC level to those who may develop a disability or already have a disability.[111]

The study population illustrated a demographic profile of clients with poor socio economic circumstances, who were largely dependent on government grants and financial support from others as illustrated in the Drakenstein Annual Report.[105] De la Cornillere (2007) at Bishop Lavis Rehabilitation Centre, Fredericks (2011) at Elangeni Rehabilitation Centre and Cawood (2012) shared similar findings that the majority of participants who accessed rehabilitation service at PHC level were from predominantly poor socio economic backgrounds illustrating high levels of unemployment and government grants as a primary source of income.[16,54,81]

5.2.1 Cause of injury

Trauma was highlighted as the main cause of injury and impairment. The Paarl area has a violent crime incidence rate of 12.36%-18.67%.[16,74] Literature shows that social dynamics that support violence includes poverty, unemployment, and income inequality.[74,75]

5.2.2 Age and gender

The illustration of age and gender among participants showed a predominant peak in the age of participants that accessed rehabilitation of between 40 and 60 years of age. Similar findings related to this age group and rehabilitation was shared by Fredericks (2011) also at Elangeni Rehabilitation Centre and Cawood (2012) in the Helderberg basin.[16,54]

5.2.3 Socio-economic circumstances

Re-examining raw data indicated that this group was also mainly unemployed and not everyone receiving a disability grant. Despite these participants presenting with functional impairments, the extent of the impairment might not have been adequately classified or described and therefore not meeting the criteria to access a disability grant. Eligibility for a disability grant in South Africa requires a complex process of assessment. The main criteria that need to be fulfilled includes a means test, age criteria and specifically for the disability grant a medical and functional assessment by a medical officer to determine moderate to severe disability, thus the degree of disability. Thus if the classification of the disability did not meet the set criteria the applicant would not qualify, similarly if documentation was not complete and presents inadequate description of the disability and related impairments, this too may result in an unsuccessful application. This meant that though a majority of the adult sample of participants were struggling with issues of mobility and functionality, they could not access disability grants, that would assist them with resources to alleviate poverty.[106] Having a disability or living with a household member who has a disability generates significant additional costs for the individual and their household. Related costs may include transport for the person with a disability and their caregiver, assistive devices, regular appointments at the health care facility, and

other additional costs related to care.[106] The age of the participants accessing rehabilitation and the rate of unemployment together with those not receiving a disability grant, might be one of the main reasons why participants access rehabilitation services. So as to obtain a classification of the impairment e.g. severe or moderate, which may assist in the application or re-application for a disability grant or in contrast to improve functionality to the extent that they may be able to seek employment.[106]

5.2.4 Transport and follow up

Participants indicated walking as the primary mode of accessing rehabilitation thus if mobility was one of the main reasons that clients accessed rehabilitation it is understandable that participants were not always able to adhere to their appointments for rehabilitation and this could impact on their outcomes, as they would need to be seen at least once or twice a week for therapy. In addition the limited transport system, given that most participants were unemployed and only 20% received a disability grant, one should acknowledge, that this would impact on attendance for rehabilitation. In addition the telephonic follow up, together with the impact of the environmental factors on rehabilitation illustrated that transport was one of the main barriers to access rehabilitation. Transport is often described in literature, as a barrier for accessing services.[72] Participants also indicated with the telephonic follow up that another reason for not attending follow up therapy was that some participants had to return to work. If one looks at the socio economic factors in the Drakenstein it is important for participants to maintain their source of income, so as to ensure sustainability of a source of income. Repeated follow up appointments for therapy would also impact on the cost factor related to attending therapy. Participants indicated from the questionnaire on environmental factors that transport and income were the two barriers that mostly influence attendance to therapy. From the client satisfaction questionnaire participants also indicated that they were not referred to PHC facilities closer to their home, for follow up appointments.

5.2.5 Outreach and support

Outreach was initiated by rehabilitation therapists to a limited number of PHC facilities as described in Chapter 3, but from the response in the above questionnaire

the outreach to PHC facilities need to be re-evaluated and planned according to the Burden of Disease and demographic profile of the clients. Rehabilitation services are predominantly rendered at TC Newman CDC. Clients are also mainly referred from Paarl hospital, thus clients from the Drakenstein mainly access and enter rehabilitation at TC Newman. The vast geographic expanse of the Paarl area should thus be taken into account when rehabilitation is planned so as to ensure that these services are rendered in an accessible and affordable manner. In Chapter 2, reference was made to CBR as an approach to deliver rehabilitation services in low resource setting.[8,13,23] The outreach to PHC facilities indicates that therapists made an attempt to deliver rehabilitation services in communities. Some of the challenges related to delivering outreach and support programmes would include safety and security issues, as the Drakenstein area is known for violence and crime, infrastructure challenges at PHC facilities poses challenges to rehabilitation services as the PHC facilities were previously not designed to accommodate rehabilitation services and the limited data and knowledge of the population and specifically persons with disabilities, in need of rehabilitation services.[16,74] To ensure that people with disabilities are able to access en benefit form rehabilitation services that are affordable and appropriate for the setting, the approach to CBR and the prescribed package of care from Health Care 2010 must be clearly defined within the context of the Drakenstein sub-district.[8,61,62,63,105]

Observations from the home visits confirmed poor socio economic circumstances, crime was not directly observed, but the community care worker shared incidences of robbery and assault, en route to a home visit, feelings of unease and fear were experienced by the home visit team in some of the neighbour hoods, with people just sitting around, drinking alcohol and smoking. Rehabilitation workers need to be sensitized and supported within the socio-political contexts of peri-urban environments they work in. Safety and security are issues for the clients and rehabilitation workers and in planning outreach and support factors related to safety and security should not be excluded when planning rehabilitation services in communities.[74]

5.3 FUNCTIONAL OUTCOMES OF CLIENTS AFTER RECEIVING REHABILITATION AT TC NEWMAN CDC RELATED TO ACTIVITY AND PARTICIPATION

The adapted Zambian outcome measure illustrated that the domain of mobility was the one area of functioning that demonstrated an overall improvement and statistically significant with a p-value of 0.004615. The lower limb diagnostic grouping appeared to be the group that demonstrated overall significant improvement in mobility. Thus enabling greater independence in the area of mobility for the client and thereto facilitate increased participation in there environment.

The functional outcomes domain related to self-care also illustrated significant improvement, specifically in activities of daily living relating to washing, grooming, eating and drinking. This would thus lessen the amount of support and strain by caregivers if there assistance was required.

The domain of domestic also illustrated significant improvement with the pre-test, post–test for both activity limitations and participation restrictions. Improvement in the area of domestic may allow for increased participation in activities such as shopping, preparing meals, active participation with household chores and caring for others. One may also deduce that the significant improvement in mobility would do much to support improvement in independence in the participation of activities of daily living as noted above including the improvement in domestic life.

Interpersonal behaviours and major life areas such as education, getting and keeping a job and handling income and payments also illustrated significant improvement. The significant improvement in this area may lead one to deduce that the importance of greater independence in these areas as mentioned above could have contributed to the adherence to follow up therapy so as to maintain active participation in income generating activities.

Similarly results from the clinical mobility scale and Oswestry confirmed that participants in the lower limb grouping demonstrated the most impact after rehabilitation. Participants with lower back pain and strokes also demonstrated improvement, though not significantly. The outcomes, as noted above, related to

functional independence in the areas of self-care, mobility, safety and communication appear to be in line with the minimum rehabilitation interventions at primary healthcare level in ensuring optimal outcomes and the prevention of secondary complications which could result in re-entry to the health system.[61]

However the domains of communication related to understanding others (spoken or written), producing messages, communicating directly with others and using devices such as phone, sms etc. illustrated no improvement. This is important to note as this could also have been a contributing factor as to why so many participants did not return for their rehabilitation follow up appointments as was scheduled for them. It may be that participants did not understand the manner in which therapy related matters were communicated with them as well as the relevance of the follow up appointment. When information is given to patients and caregivers it is important to ascertain that the relevant information has been understood. The extent to which individuals have the ability to obtain, process and understand basic health information and services to make appropriate health decisions may also be a contributing factor in rehabilitation compliance.[54]

The area of community, social and civic life illustrated only slight improvement. The main aim and advanced outcome of rehabilitation is community integration and productive activity. Thereby assisting persons with disabilities to resume their roles in their family, society and in their work environment as far as possible.[53, 54, 61] It is required of them to be socially competent, have community mobility and be able to function satisfactorily in the community. Results indicate that this area of functioning may not have been fully achieved. Thus revisions in rehabilitation service provision from individualised medical model institution based rehabilitation to social model community based rehabilitation should be advocated for.[16] The researcher suggests that the importance and role of rehabilitation in achieving advanced outcomes is an area of activity and participation that should be further explored.

Lower back pain represented 35% of the participants. Farming, wine and grape culture, factory and domestic labour are seen as the backbone of employment among the uninsured population in the Drakenstein.[105] This type of labour is characterised by physical hands on labour, long standing and repetitive movements. This could be a contributing factor to why lower back pain and other orthopaedic

problems were prominent amongst the study population.[105] As discussed in literature, LBP is a common disability, that poses an economic burden in terms of the number of work days lost and the compliance to therapy may not be well maintained, because it is negatively impacted by demand such as work.[48] The tools used to measure mobility (CMS and the Zambian), indicated that participants with lower back pain improved significantly in the area of mobility. The Oswestry was illustrated improvement in the area of pain and mobility, though not significantly. The literature together with the results from the study indicates that lower back pain is a common condition in the adult population that is referred for rehabilitation, as well as chronic back pain. Treatment interventions are aimed at reducing pain, and improving activity and participation, however the influence of demographic factors should be taken into account when therapist plan therapy, so as to ensure that rehabilitation is initiated as soon as possible, so as to ensure that participants are able to receive a swifter initial response in order to deal with symptoms to be able to continue their life roles and employment, more effectively.[47,48] Furthermore, interventions at PHC level are also aimed at improving primary and secondary prevention and enhanced public and health practitioner awareness or education. Prevention of disease and disability is one of the corner-stones of PHC and is recognized in the CSP for the implementation of Healthcare. Facility-based services and community-based services were the two main components of Healthcare 2010.The role of CBS is to make communities aware of both the burden and cause of diseases and to empower them to become involved in preventative programmes.[15]

Results illustrated that participants waited between 4-6 weeks before being seen by a therapist, and this may have been one of the factors that may have had an influence on follow up attendance. A waiting period of more than 30 days and even more for rehabilitation is an area of concern. According to McColl clients may miss out on important rehabilitation interventions that may be necessary for them to reach an optimal level of functioning.[16,62] In addition, they may also not be informed about the prevention of secondary complications and may lack the knowledge and the skills for proper mobility. Clients may also miss the opportunity to be referred to other health care professionals. Finally, full reintegration into the community may be hindered.[16,62] To effectively manage clients with lower back pain, clients should have

a pre- and post-test using functional outcome scales and treatment guidelines must be revisited and adapted according to the outcome of these scales.[6,89]

Less than one third of the clients with a diagnoses of CVA, returned for follow up. This is concerning to note as the CWD reflects a high CVA burden, especially at community health level.[107] The Barthel Index illustrated that participants with CVAs improved, though not significantly. The low return rate may also not have allowed for an adequate comparison. In pre-determining the diagnostic groups for the research study, strokes were seen as the most prominent diagnoses referred for therapy. The decline in the percentage of stroke patients seen at TC Newman CDC could be as a result of the implementation of the outreach and support by rehabilitation professionals from TC Newman CDC to PHC facilities and the expansion of the Community Based Services in the Drakenstein.[104] This could have made it possible for clients to be accessed in PHC facilities closer to their home. Clients presenting with a stroke are also potentially not mobile and therefore could not walk or access transport. This might need a Community Based Care approach as well as including peers and family as support. Community Based services are delivered by NGO's who receive funding from DOH. Community care workers receive referrals from the respective NGOs. They access the clients' homes by means of walking to the known address. The package of care that is rendered by CBS includes: treatment and care of people with disabilities and adherence and support.[108] Community Based services did not appear to be a source of referral to rehabilitation for clients in need of these services. CBS data showed that strokes formed a big part of clients that were followed up and treated in the home.[107] To ensure that clients access and benefit from rehabilitation services at PHC level, there needs to be a much stronger collaboration and networking between CBS and rehabilitation services, thus ensuring continuity of care and access to rehabilitation services. Bryer promotes an interdisciplinary approach to the management of stroke clients where members of the rehabilitation team have the experience and knowledge of CVA rehabilitation.[54] Thus it is important to ensure that service providers, including the Community Based Services Platform, are equipped with the relevant skill and knowledge to manage CVA clients, at levels of care.

Even though a small number of participants diagnosed with arthritis returned for their follow up therapy, results indicated improvement, though not significantly.

5.4 PARTICIPANTS' PERCEPTION OF THE REHABILITATION PROCESS

The patient satisfaction questionnaire indicated that clients were generally satisfied with therapy received, the environment in which they received therapy and the manner in which therapy was conducted. These findings were further supported by responses from the telephonic follow up that clients did not negatively perceive their therapy. It is positive to note that therapy is not viewed negatively by clients.

The EQ5D is a standardised tool that was used to the measure client's perception of their health status before and after therapy. Results showed that participants experienced a significant improvement in their health status after receiving therapy. These results were based on the opinions of the clients. Although the EQ5D illustrated significant improvement, it was only limited to the small amount of clients returning for therapy. It is concerning that so few clients returned for therapy and that the outcome from the EQ5D could not adequately represent the entire study population. It was positive to note that the few that returned for therapy as well as the post test conducted with the home visit indicated that clients felt that their health status had improved after receiving therapy.

If participants were generally satisfied with therapy received and improvement of outcomes was illustrated in the results, one needs to explore, other factors with the exclusion of demographics, for patients not returning for follow up therapy.

5.5 Possible barriers influencing rehabilitation outcomes.

The data extraction from the folder audits confirmed that administration and documentation were lacking and describes rehabilitation poorly. Fredericks (2011) showed similar findings in his study at Elangeni Rehabilitation Centre.[16] Thus therapy related factors such as administration and documentation is essential in ensuring patient compliance as far as possible.[78]

5.5.1 Accessing rehabilitation services

Most clients that accessed rehabilitation services at TC Newman CDC were referred from Paarl hospital, the Regional hospital, approximately 5-8km from TC Newman CDC. Only 17% of the clients were referred from PHC clinics in the area. It is concerning to note that only a small percentage of clients access TC Newman CDC via PHC referrals. When looking at the district health service model, PHC facilities are the first point of entry to health care and also a leading referral source for clients to community health centres, such as TC Newman CDC which is surrounded by several PHC facilities.[104]

The district health system has a defined referral pathway, where clients are referred from hospital to a CDC and then to PHC.[61] This could be why 78% of clients accessing TC Newman CDC rehabilitation services were referred from Paarl Hospital. Most of the clients were referred by other rehabilitation professionals, predominantly physiotherapy, and medical doctors in Paarl hospital to physiotherapists at TC Newman CDC. The study did not directly focus on rehabilitation program and process inputs such as human and financial resources. This aspect of the study was addressed by the group of researchers that focussed on the organisational capacity within the SANPAD group. The study showed that rehabilitation services at TC Newman CDC were rendered by physiotherapists (2), occupational therapists (2) and a speech therapist. TC Newman CDC thus has a multi-disciplinary team of rehabilitation therapists; it is important in low resource setting to apply an interdisciplinary approach in achieving improved service delivery and outcomes for clients.[54]

5.5.2 Outreach and support

Outreach and support services were implemented which could address accessibility and affordability of rehabilitation services to the broader community of the Drakenstein sub-district. However, the communication regarding outreach and support rehabilitation services may not have been communicated to the community accessing these services. These developments were primarily communicated to health professionals at the facilities where possible outreaches were planned. The lack of communication to the community and only to health staff again highlights the

dominance of mainly a medical model and does not adequately take into account the community at large.

5.5.3 Diagnostic groups

The five most prevalent conditions seen at TC Newman CDC while drafting the proposal for the research were previously: children with developmental delays, CVA's, hands, lower back pain and arthritis. These diagnostic groupings differed from the onset of the data collection for the research. These clients presented with diagnoses in four diagnostic groupings namely: lower limb, lower back pain, upper limb and CVAs. The research had shown that the profile of clients seen for rehabilitation since then had changed to exclude children with developmental delays. This could be partly because of the change in the package of service rendered at TC Newman CDC. Specialist clinics such as Paediatrics and Orthopaedics were re-located to Paarl Hospital. These clinics were previously, a referring source to rehabilitation at TC Newman CDC.

5.5.4 Patient documentation

The research did not specifically assess treatment processes in rehabilitation, however from the data extraction from the patient folders, the researcher observed gaps in the documentation of the treatment processes. The folder audit showed that most clients had a diagnosis, personal details and treatment notes were documented. However, the quality of the documentation was questionable, in that there was no standardised assessment documented, documentation was incomplete and fragmented, there was no use of evaluation tools, treatment plans were lacking and there was a lack of documented treatment process or referral and an absence of discharge notes.[16] From the patient folder it could be ascertained that, patients that was referred with lower back/chronic back pain, in most instances had no clear assessment documented and were in most cases referred directly to a back class for group therapy. To this end, the lack of measuring client status might have impacted negatively on the therapist's ability to set appropriate treatment goals. There is no way of indicating that clients may or may not have progressed and that the services provided were efficient. The measurement of functional progress has the advantage

of motivating clients as they can see their progress. Consequently therapists have no way of measuring the impact of the rehabilitation interventions.[16]

This finding would lead one to wonder how activities for rehabilitation intervention were decided on, and how rehabilitation therapists decided when rehabilitation could be concluded.

The Health Professions Council of South Africa has clear guidelines as to the record keeping by health professionals. As quoted. "Good notes imply good practice" and "A standardised format should be used (e.g. notes should contain in order the history, physical findings, investigations, diagnosis, treatment and outcome)".[109]

The documentation by therapists did not give a clear picture on the treatment and care pathways of rehabilitation clients. The analysis of these findings, made the researcher aware of the importance and legal obligation with regards to patient documentation. In ensuring continuity of care it could become difficult for other health professionals and therapists to further treatment, if clinical documentation is not clear and thorough. The lack of adequate documentation can lead to therapists and other health professionals not being efficient. This highlights a key area, neglected in rehabilitation, namely monitoring and evaluation of rehabilitation services, which is also, one of the objectives of the NRP to ensure quality of care.[8]

The lack of good documentation in the folders did not give a clear picture as to why clients were lost to follow up. With the telephonic follow up participants communicated that they appreciated the contact, they felt valued as a client and also indicated that it was the first time that interest was shown as why they did not return for therapy. The above could indicate that there are poor or no systems in place for tracing participants that did not return for follow up appointments.

5.5.5 Follow up

Only one of the eight clients who could be followed up at home gave a reason why she did not return for therapy. The client indicated that she felt fine, and was happy with the therapy that she received, but commented to the research assistant, from the treating doctor, stating that purchasing a better quality bed, would improve her

chronic back pain, contributed to her not returning to TC Newman. The client also indicated that distance and transport impacted on her adherence. She indicated that she would access therapy if needed. Rehabilitation workers not fully understanding the socio-economic context of the client may in turn impact on the client's therapy and recovery. The remaining seven clients could be found with the home visit, discontinued their therapy, because they felt better and indicated that they too would access therapy if needed. It may seem as if the clients were not part of the planning nor properly informed of the rehabilitation process. They should in essence be aware of the treatment plan and what outcomes they should achieve. These might be the very clients who come back with secondary impairments and chronicity. The remaining twelve that the researcher could not get in touch with, were either not at home, relocated, were at work or the addresses could not be found.

Despite the fact that 95% of the clients indicated that they had access to a telephone, results demonstrated in Figure 4.24, showed that it was not always easy accessing all the clients telephonically as not all the telephone numbers were in working order. Reasons why clients did not return for therapy varied, but seven clients specifically indicated that they were not given an appointment to return and were thus unsure as to whether or not they should return for a follow up session. The researcher also perceived that most clients were not really sure when and why they have to return for therapy. The appointment system for rehabilitation clients appears to be the biggest reason as to why clients did not return. This is supported with evidence or a lack of evidence from the folder audits that follow up appointments were not documented in the patient records.[110]

The relocation of rehabilitation services from Elangeni Rehabilitation Centre (ERC) to TC Newman CDC, could also have contributed to clients not returning for follow up sessions. However it is not known how, or if, rehabilitation professionals communicated the migration from ERC to TC Newman CDC to clients.

5.6 SUMMARY

Poor socio economic circumstances specifically income and transport were highlighted as the demographic factors that had the most influence impacting on rehabilitation outcomes. The evaluation of functional outcomes, despite the low

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return rate for follow up therapy, illustrates an overall improvement in activity and participation, with the areas of mobility showing significant improvement. Participants experienced rehabilitation services positively, but also indicated what they perceived as a barrier in their rehabilitation. Overall, health system challenges e.g. the appointment system, follow up of clients and clear communication on the treatment plan and the duration of therapy, had a profound effect on clients not returning for follow up therapy.

CHAPTER 6: CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION TO THE STUDY

Objective: To describe the demographic factors and highlight barriers influencing rehabilitation outcomes.

Results showed that overall environmental factors did not have a negative impact on the outcome of clients, however two factors that mentioned by clients that had an influence on access to rehabilitation services, were transport and income. Even though this feedback was from a small number of clients, the socio economic profile of the client's context should always be taken into account, when therapy is planned and conducted. The home visits highlighted safety and security issues, environmental factors that cannot be excluded when planning rehabilitation services and specifically looking at access.

Objective: To evaluate the functional outcomes of clients receiving rehabilitation intervention at TC Newman CDC during a four month period November 2010 to April 2011 using appropriate standardized tools.

Objective: To describe the patient's perception of the rehabilitation process and outcomes using a client satisfaction questionnaire.

Results in most areas of functioning showed improvement, some significant.

The 114 participants that access rehabilitation services may give an indication that there is a need for rehabilitation. The significant improvements in participants outcomes and their positive perception of rehabilitation, illustrates that rehabilitation has an impact on client's functioning. In addressing accessibility to rehabilitation at community level, may result in increased follow up visits, and will give a better indication of the impact of rehabilitation services.

6.2 STUDY RECOMMENDATIONS

The study highlighted the importance of demographics, which should be taken into account, when planning therapy and specifically access to rehabilitation. It is not

certain if TC Newman CDC is able to provide accessible rehabilitation services, taking into account the demographic challenges e.g. environmental and personal factors. In attempting to address accessibility to rehabilitation services, it is recommended that therapists expand rehabilitation services to peripheral clinics and the community based platform.

The following should be taking into account when expanding services:

1. The infrastructure at PHC facilities should reasonably accommodate physical therapy. Thus there should be a pre-determined package of care at each level of service e.g. CDC vs. PHC facility vs. Satellite clinic.
2. The Burden of Disease together with the population count at the facility should be considered. This will indicate the type of therapy and frequency of therapy needed at each facility.
3. Community Based Services (CBS) should form part of the care pathway for rehabilitation. Intermediate Care Facilities (ICF) could be a good starting point to involve community care workers in rehabilitation, with outreach and support from therapists.
4. Community Based Rehabilitation (CBR) as an approach should be prioritised and advocated for. In a vast geographic area such as the Drakenstein sub district with limited rehabilitation professionals, CBR as part of PHC service delivery, involving families and the broader community in rehabilitation should form part of the care pathway for clients.[6,7,15]

There should be a renewed and focussed attention on the management of rehabilitation services at TC Newman CDC, which should include the following:

1. A well-coordinated appointment system and follow up system for rehabilitation.
2. Appointments for rehabilitation clients should be registered at all health facilities on the Primary Health Care Information System (PHCIS). This will inform therapists of clients who defaulted on their appointment and facilitate timeous defaulter tracing.
3. Improved documentation of:
    a. The clinical management of clients.

b. The utilisation of standardised measurement tools for pre and post evaluation.

c. Standardised referral document.

d. Standardised data collection tools.

e. On-going monitoring, evaluation and feedback.

f. Annual audit of patient folders, which can include peer review.

g. Annual Report of Rehabilitation services and outcomes for the CWD.

h. Quality assurance.

Specific recommendations for Provincial and District managers in the absence of a Provincial Rehabilitation Policy:

1. The package of care for rehabilitation services should clearly defined what is expected at the level of care

2. Rehabilitation data must form part of the routine data submission and M&E of the District.

3. Resource allocation must be in line with the BOD and the dependent population of a specific facility.

4. Infrastructure recommendations should include the accessibility of persons with disability and reasonable therapeutic space.

6.3 RECOMMENDATIONS FOR FURTHER STUDY

A follow up evaluation of rehabilitation services at TC Newman CDC and other PHC facilities where there is access to rehabilitation. The focus areas or objectives for a study, such the above, should include a critical focus on the rehabilitation process and how this influences outcomes.

6.4 LIMITATIONS OF THE STUDY

1. The low return rate may have had an impact on the outcome of the study and it is recommended as another area for research so as determine reasons for the low return rate and if this occurrence happens at other facilities that offers rehabilitation services.

2. The study only included clients accessing rehabilitation services at TC Newman CDC and excluded clients accessing rehabilitation services at Paarl hospital or the PHC facilities in the Drakenstein sub district.

3. Factors such as the poor appointment system, incorrect telephone numbers and relocation of some the clients was not pre-empted and resulted in inadequate time frames to follow up clients. Therefor 20 files were randomly selected for home visits follow up to obtain information on why clients did not return for their follow up appointments and also to provide more information on the outcomes of clients.

4. The utilisation of a research assistant that has limited knowledge of the rehabilitation process and care pathways. Initially the utilisation of using an independent assistant was as a measure to reduce bias; however in retrospect in the absence of clear procedures and policies the use of rehabilitation professional might have ensured better data collection.

5. Conditions identified for the study was based on previous data, that was not standardised and with the onset of the study, the conditions did not adequately represent the identified BOD e.g. Strokes and children with developmental delays were less prominent as was expected. This was due to changing policy framework

6. Interviews with therapists about the rehabilitation process and physical outcomes as means of triangulation.

6.5 ASPECTS ADDRESSED TO DATE AND DISSEMINATION OF FINDINGS

This research study gave the researcher the opportunity to gain a better evidence-based understanding of rehabilitation, disability and how systems influence the outcomes of therapy.

The following additions were made to improve service delivery:

- A package of care for rehabilitation services (occupational therapy, physiotherapy and speech therapy) at District Health Level for district hospitals and PHC facilities was developed, defined, communicated to therapists and managers of the CWD and implemented in the Cape Winelands District.

- Standardised data collection tools were developed and implemented for occupational, speech and physiotherapy.

- A standardised referral form, based on the ICF was developed in conjunction with the University of Stellenbosch and implemented.

- Reviving of the rehabilitation forum in the CWD to improve communication and feedback.

- Establishment of the CWD allied health forum to facilitate skills development and to ensure the integration of the allied health disciplines.

- An increased focus on the BOD of the CWD and not necessarily conditions related to specific health disciplines e.g. HIV/AIDS focus on developmental screening.

Results from the study will be presented to the management of the CWD office, management of the Drakenstein sub-district and therapists employed by the CWD.

Research questions that arose during the study will be put forward at the District Research Day in 2014.

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APPENDIX A: 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): _____

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APPENDIX B1: OSWESTRY

Oswestry Disability Questionnaire

This questionnaire has been designed to give us information as to how your back or leg pain is affecting your ability to manage in everyday life. Please answer by checking **one box in each section** for the statement which best applies to you. We realise you may consider that two or more statements in any one section apply but please just shade out the spot that indicates the statement **which most clearly describes your problem.**

Section 1: Pain Intensity

☐ I have no pain at the moment
☐ The pain is very mild at the moment
☐ The pain is moderate at the moment
☐ The pain is fairly severe at the moment
☐ The pain is very severe at the moment
☐ The pain is the worst imaginable at the moment

Section 2: Personal Care (eg. washing, dressing)

☐ 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 can 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 me extra pain
☐ Pain prevents me lifting heavy weights off the floor but I can manage if they are conveniently placed eg. on a table
☐ Pain prevents me lifting heavy weights but I can manage light to medium weights if they are conveniently positioned
☐ I can only lift very light weights
☐ I cannot lift or carry anything

Section 4: Walking*

☐ Pain does not prevent me walking any distance
☐ Pain prevents me from walking more than 2 kilometres
☐ Pain prevents me from walking more than 1 kilometre
☐ Pain prevents me from walking more than 500 metres
☐ I can only walk using a stick or crutches
☐ I am in bed most of the time

Section 5: Sitting

☐ I can sit in any chair as long as I like
☐ I can only sit in my favourite chair as long as I like
☐ Pain prevents me sitting more than one hour
☐ Pain prevents me from sitting more than 30 minutes
☐ 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 for more than 1 hour
☐ Pain prevents me from standing for more than 30 minutes
☐ Pain prevents me from standing for more than 10 minutes
☐ Pain prevents me from standing at all

Section 7: Sleeping

☐ My sleep is never disturbed by pain
☐ My sleep is occasionally disturbed by pain
☐ Because of pain I have less than 6 hours sleep
☐ Because of pain I have less than 4 hours sleep
☐ Because of pain I have less than 2 hours sleep
☐ Pain prevents me from sleeping at all

Section 8: Sex Life (if applicable)

☐ 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. sport
☐ 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: Travelling

☐ I can travel anywhere without 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 travelling except to receive treatment

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APPENDIX B2: CLINICAL MOBILITY

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

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APPENDIX C: ARTHRITIS IMPACT MEASUREMENT SCALE

Arthritis Impact Measurement Scales 2 (AIMS2-SF)

During the past four weeks …	All Days	Most Days	Some Days	Few Days	No Days
1. How often were you physically able to drive a car or use public transportation?	☐	☐	☐	☐	☐
2. How often were you in a bed or chair for most of the day?	☐	☐	☐	☐	☐
3. Did you have trouble doing vigorous activities such as running, lifting heavy objects, or participating in strenuous sports?	☐	☐	☐	☐	☐
4. Did you have trouble either walking several blocks or climbing a few flights of stairs?	☐	☐	☐	☐	☐
5. Were you unable to walk unless assisted by another person or by a cane, crutches or walker?	☐	☐	☐	☐	☐
6. Could you easily write with a pen or pencil?	☐	☐	☐	☐	☐
7. Could you easily button a shirt or blouse?	☐	☐	☐	☐	☐
8. Could you easily turn a key in a lock?	☐	☐	☐	☐	☐
9. Could you easily comb or brush your hair?	☐	☐	☐	☐	☐
10. Could you easily reach shelves that were above your head?	☐	☐	☐	☐	☐
11. Did you need help to get dressed?	☐	☐	☐	☐	☐
12. Did you need help to get out of bed?	☐	☐	☐	☐	☐
13. How often did you have severe pain from your arthritis?	☐	☐	☐	☐	☐
14. How often did your morning stiffness last more than one hour from the time you woke up?	☐	☐	☐	☐	☐
15. How often did your pain make it difficult for you to sleep?	☐	☐	☐	☐	☐
16. How often have you felt tense or high strung?	☐	☐	☐	☐	☐

AIMS2-SF   1

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APPENDIX D: DISABILITY 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.

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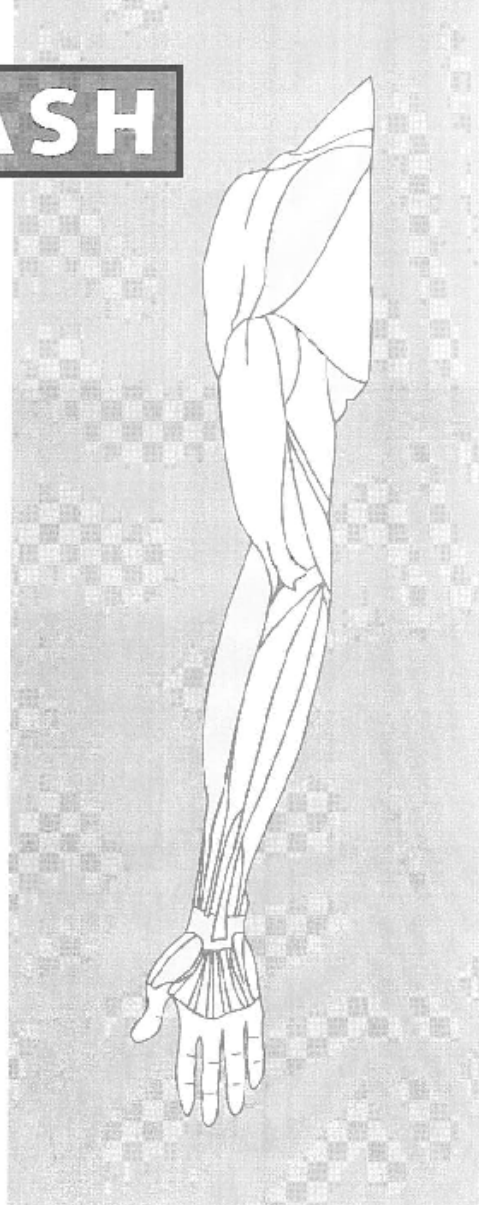
DISABILITIES OF THE ARM, SHOULDER AND HAND

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 = [(sum of n responses) - 1] x 25, where n is equal to the number of completed responses.
                                              n

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

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APPENDIX E: DATA EXTRACTION

REFERENCE NO:

SANPAD PROJECT, Data Extraction Form 1

RESEARCHER'S NAME:

DATE OF DATA EXTRACTION:

FILL IN BEFORE TREATMENT:

PATIENT'S NAME:

DATE OF BIRTH: ………………………………

DATE ON REFERRAL LETTER:………………………………

1. REFERRAL **SOURCE:**

TBH	1	WH	7
GSH	2	PH	8
KBH	3	GFJ	9
CCC	4	NSH	10
Private GP	5	Self Referral	11
CHC	6		
Other	12		

2. REFERRAL PROFESSION:

OT	1
Physio	2
Dr Private	3
Dr. CHC	4
Dr. Hospital	5
Other	6

3. GENDER:

Male	Female
1	2

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4. MAIN DIAGNOSIS:

5. PATIENT'S ADDRESS:

FILL IN AFTER TREATMENT:

6. HEALTH CARE WORKER OR CENTRE THAT PATIENT WAS REFERRED TO BY CENTRE:

Counsellor	**1**	**Prosthetist/Orthotist**	**8**
Psychologist	**2**	**Physiotherapist**	**9**
Nurse	**3**	**Occupational Therapist**	**10**
Pharmacist	**4**	**Speech Therapist**	**11**
Social Worker	**5**	**Dietician**	**12**
Radiographer	**6**	**Doctor**	**13**
Traditional/Faith Healer	**7**	**HBC**	**14**
Other	**15**		

7. Reason for loss to follow up in the event the person does not complete the therapy.

8. How many treatment sessions did the person have?

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APPENDIX F: SANPAD QUESTIONNAIRE 1

SANPAD PROJECT

Questionnaire 1

1. PATIENT NAME AND SURNAME:

2. GENDER: | *1 M* | *2 F* |

3. MARITAL STATUS:

SINGLE	MARRIED	DIVORCED	WIDOW/ER	LIVING TOGETHER	SEPERATED	OTHER

4. DIAGNOSIS:

PERSONAL INFORMATION (PI)

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?**

1YES	2NO

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

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PERSONAL INFORMATION (cont.)

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

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. Teriary	3
4. None	4

INCOME (I)

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	

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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?

TRANSPORT (T)

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	

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1. WHO HELPS YOU AT HOME?

<div style="float:left">ASSISTANCE (A)</div>

	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	7		

2. DO YOU PAY YOUR HELPERS?

1 YES	2 NO

HABITAT (H)

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

HABITAT cont.

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 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	

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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

9. WHAT POWER SOURCES DO YOU HAVE?

Electricity	1
Parafin	2
Gas	3
Generator	4
Solar	5
Other	6
Specify	61

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	

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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**

1 Yes	2 No

RECREATIONAL ACTIVITIES?

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	

COMMUNITY INVOLVEMENT (CI)

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RESEARCH (R)

1. HAVE YOU BEEN INVOLVED IN ANY

1 Yes	2 No

RESEARCH BEFORE THIS?

1 If YES, did you receive any feedback?

1 Yes	2 No

FORM COMPLETED BY:

DATE:

SIGNED BY RESEARCHER:

APPENDIX G: SANPAD 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
Other	7
None	8

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
Voluntary work	7
Other	8

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 Commiteee?	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?		

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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		1 YES	2 NO	
16 None				

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	
16 None	

S = ENVORONMENTAL 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 ATTITTUDE TOWARD YOU AS A DISABLED PERSON?	☺	😐	☹	

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SIGNED BY RESEARCHER: _____

DATE: _____

APPENDIX H: DEMOGRAPHICS QUESTIONNAIRES

Adapted Zambian

ACTIVITY LIMITATIONS:
 	
How difficult is it for you to perform this activity <u>without any</u> kind of assistance at all?
 	
(That is, without the use of any assistive devices – either technical or personal).
 	
PARTICIPATION RESTRICTIONS:
 	
Do you have any difficulty in performing this activity in your current environment?
 	
(*Current environment* refers to the surroundings in which you live, work, and play etc. for the majority of your time).
	Activity limitation score
	
	(A measure of Capacity)
	
	0 no difficulty
	
	1 mild difficulty
	
	2 moderate difficulty
	
	3 severe difficulty
	
	4 unable to carry out
	
	   the activity
	
	8 not applicable
	
	9 not specified
	
	   (level not known)
		Participation restriction
		
		(A measure of Performance in current environment)
		
		0 no problem
		
		1 mild problem
		
		2 moderate problem
		
		3 severe problem
		
		4 complete problem
		
		   (unable to perform)
		
		8 not applicable
		
		9 not specified
		
		   (level not known)

1. COMMUNICATION		
a. understanding others (spoken, written or sign language)		
b. producing messages (spoken, written or sign language)		
c. communicating directly with others		
d. communicating using devices (phone/typewriter/computer/SMS)		
2. MOBILITY		
a. staying in one body position		
b. changing a body position (sitting/standing/bending/lying)		

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c. transferring oneself (moving from one surface to another)		
d. lifting/carrying/moving/handling objects		
e. fine hand use (picking up/grasping/manipulating/releasing)		
f. hand & arm use (pulling/pushing/reaching/throwing/catching)		
g. walking		
h. moving around (crawling/climbing/running/jumping)		
i. using transportation to move around as a passenger		
j. driving a vehicle (car/boat/bicycle/or riding an animal)		
3. SELF CARE		
a. washing oneself		
b. care of body parts, teeth, nails and hair		
c. toileting		
d. dressing and undressing		
e. eating and drinking		

ACTIVITY LIMITATIONS: How difficult is it for you to perform this activity <u>without</u> <u>any</u> kind of assistance at all? (That is, without the use of any assistive devices – either technical or personal). PARTICIPATION RESTRICTIONS: Do you have any difficulty in performing this activity in your current environment? (*Current environment* refers to the surroundings in which you live, work, and play etc for the majority of your time).	Activity limitation score (A measure of Capacity) 0 no difficulty 1 mild difficulty 2 moderate difficulty 3 severe difficulty 4 unable to carry out the activity 8 not applicable 9 not specified (level not known)	Participation restriction (A measure of Performance in current environment) 0 no problem 1 mild problem 2 moderate problem 3 severe problem 4 complete problem (unable to perform) 8 not applicable 9 not specified (level not known)
4. DOMESTIC LIFE		
a. shopping (getting goods and services)		
b. preparing meals (cooking)		
c. doing housework (washing/cleaning)		
d. taking care of personal objects (mending/repairing)		
e. taking care of others		
5. INTERPERSONAL BEHAVIOURS		
a. making friends and maintaining friendships		
b. interacting with persons in authority (officials, village chiefs)		
c. interacting with strangers		
d. creating and maintaining family relationships		
e. making and maintaining intimate relationships		
6. MAJOR LIFE AREAS		
a. going to school and studying (education)		
b. getting and keeping a job (work & employment)		

c. handling income and payments (economic life)		
7. COMMUNITY, SOCIAL AND CIVIC LIFE		
a. clubs/organisations (community life)		
b. recreation/leisure (sports/play/crafts/hobbies/arts/culture)		
c. religious/spiritual activities		
d. political life and citizenship		

APPENDIX I: CAREGIVERS STRAIN INDEX

I am going to read a list of things that other people have found to be difficult. Would you tell me if any of these apply to you? (Give examples)

	Yes=1	No=0
Sleep is disturbed (e.g. because _____ is in and out of bed or wanders around at night)		
It is inconvenient (e.g., because helping takes so much time or it is a long drive over to help)		
It is a physical strain (e.g. because of lifting in and out of a chair; effort or concentration is required)		
It is confining (e.g., helping restricts free time or cannot go visiting)		
There have been family adjustments (e.g. because helping has disrupted routine; there has been no privacy)		
There have been changes in personal plans (e.g., had to turn down a job; could not go on vacation)		
There have been other demands on my time (e.g., from other family members)		
There have been emotional adjustments (e.g., because of severe arguments)		
Some behaviour is upsetting (e.g., because of incontinence; _____ has trouble remembering things; or _____ accuses people of taking things)		
It is upsetting to find _____ has changed so much for his/her former self (e.g., he/she is a different person that he/she used to be)		
There have been work adjustments (e.g., because of having to take time off)		
It is a financial strain		

Feeling completely overwhelmed (e.g., because of worry about _____; concerns about how you will manage)		
TOTAL SCORE (Count yes responses. Any positive answer may indicate a need for intervention in that area. A score of 7 or higher indicates a high level of stress.)		

Why: Caregiver provide the majority of long-term care to the chronically disabled. Caregiving has been recognized as an activity with perceived benefits and burdens; however, they may be prone to depression, grief and changes in social relationships. They may also experience physical health problems and fatigue. Psychological and physical strain on caregivers can lead to premature institutionalization and poor improvement or management of patients. Screening tools are useful to identify families who would benefit from such an assessment.

The Caregiver Strain Index (CSI) is a tool that can be used to quickly identify families with potential caregiving concerns. It is a 13-point questionnaire measuring the strain related to care provision. There is at least one item for each of the following major domains: Employment, Financial, Physical, Social and Time. Positive responses to seven or more items on the index indicate a greater level of strain. This instrument can be used to assess individuals of any age who have assumed the role of caregiver.

APPENDIX J: EQ5D

Figure 1: EQ-5D (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 □

APPENDIX K: PATIENT SATISFACTION QUESTIONAIRE

Elangeni Rehabilitation Centre

Reference number

Datum:_____

Directions: Based on your experiences as a patient at the Elangeni Rehabilitation Centre, please tell us whether you agree, disagree; don't know, with the following statements. Please mark your answer for each question by circling the number. For example, if you disagree with a statement, you would circle 1. If you agree with a statement, you would circle 3. You may only choose one answer per question, and please answer all the questions. The information on this form will be treated confidentially, so please do not place your name on these forms.

If you do not agree with a statement, please comment and give us the reasons, as to allow us to address the problem at the point of origin.

Thank you

Researcher signature:

Field worker signature:

Questions	Disagree	Neutral	Agree	Not applicable
To be completed by all clients				
It takes more than 30 minutes to get to the clinic	1	2	3	4
It costs more than R 20-00 to get to the clinic.	1	2	3	4
The clinic is in good condition.	1	2	3	4
The clinic is clean.	1	2	3	4
The toilets are accessible	1	2	3	4
The toilets are dirty	1	2	3	4
I had to wait a long time to get my folder.	1	2	3	4
There was a chair for me to sit on while I waited.	1	2	3	4
The person who gave me my folder was helpful.	1	2	3	4
The therapist that treated me listened to my problems	1	2	3	4
The staff at Elangeni Rehabilitation Centre was polite and treated me with respect	1	2	3	4
I was pleased with the way I was treated at the clinic	1	2	3	4
The therapist explained my diagnosis to me and the therapy that I will receive	1	2	3	4
The therapist included me in the planning of my treatment and explained to me how it is going to take place	1	2	3	4
I was satisfied with my progress / therapy that I received at Elangeni.	1	2	3	4
I will in future refer other persons for therapy to Elangeni Rehabilitaion Centre.	1	2	3	4
I was referred to a facility/ clinic close to my home for continued therapy.	1	2	3	4
I was referred to other projects/ organisations in my community through my therapist.	1	2	3	4
I am satisfied with my assistive device/ wheelchair that i received.	1	2	3	4
I received my assistive device immediatley	1	2	3	4
I could do more for myself after having received therapy.	1	2	3	4
My culture was respected.	1	2	3	4

Is there anything else that you would like to tell us or help us to make the service better ?

……

……

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APPENDIX L: MEDICAL RECORDS IMPAIRMENT

Patient ID…………………..

DATA GATHERING INSTRUMENT FOR MEDICAL RECORDS REVIEW

DIAGNOSIS: STROKE

I. Swallowing /Dysaphagia:

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 ☐

Impaired ☐

Not Impaired ☐

7. Urination:

Not documented

Impaired

Not Impaired

8. Affection

Not documented

Impaired

 Not Impaired

9. Muscle Power: body part affected (specify)

Not documented

0 = complete problem

1-2 = severe

3 = moderate …………………….

4 = mild …………………….

5 = normal …………………….

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

Impaired ☐

Not Impaired ☐

12.2.2 Dynamic:

Not documented ☐

Impaired ☐

Not Impaired ☐

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

176

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 ☐

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   ☐

    Impaired   ☐

            hot   ☐   cold ☐

    Not impaired   ☐

31.3 Touch

    Not documented   ☐

    Impaired   ☐

    Not impaired   ☐

32. Muscle power   muscles affected

    Not documented   ☐

    0 = complete problem …………☐…………………………

    1+2 = severe …………………☐………………

    3 = moderate …………………☐………………

    4 = mild………………………☐………..

    5 = normal …………………☐………………..

33. Active selective movements

33.1 Upper limb

Not documented ☐

Impaired ☐

Not impaired ☐

33.1.1 Scapula ☐

shoulder ☐

elbow ☐

wrist ☐

hand ☐

33.2 Lower limb

Not documented ☐

Impaired ☐

Not impaired ☐

33.2.1   Pelvis ☐

Hip ☐

knee ☐

ankle ☐

foot ☐

34. Muscle tone

      Not documented

      Impaired

      Not impaired

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

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 muscles affected

Not documented

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 ☐

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

Impaired

Not impaired

Scapula

shoulder

elbow

wrist

hand

43.2.2 Lower limb

Not documented

Impaired

Not impaired

Pelvis

hip

knee

ankle

foot

44. Nerve entrapment

    Not documented   □

    Present   □

    Absent   □

45. Muscle power

    Not documented   □   muscles affected

0 = complete problem ……………………□…………

1-2 = severe   ………………………………□..

3 = moderate   ………………………………□..

4 = mild……………………………………..   □

5 = normal   □   ………………………………………

46. Sensation

    Not documented   □

    Impaired   □

    Not impaired   □

47. Nerve mobility

    Not documented   □

    Impaired   □

    Not impaired   □

48. Pain

Not documented ☐

Impaired ☐

Not impaired ☐

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 ☐

200

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

201

52.1 Pain

Not documented ☐

Present ☐

Not present ☐

52.2 temp

Not documented ☐

Impaired ☐

Hot ☐   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   …………………………☐

DIAGNOSIS: DEVELOPMENTAL DELAY

54. Swallowing/dypsphasia

Not documented

Impaired

Not impaired

55. Speech

Not documented

Impaired

Not impaired

55.1 Aphasia

Not documented

Impaired

Not impaired

55.1.1 Receptive

Not documented

Impaired

Not impaired

55.1.2 Expressive

Not documented

Impaired

Not impaired

55.2 Dysarthria

Not documented

Impaired

Not impaired

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

56.1 Memory

Not documented

Impaired

Not impaired

56.2 Visual

Not documented

Impaired

Not impaired

56.3 Perceptual

Not documented ☐

Impaired ☐

Not impaired ☐

56.4 Attention

Not documented ☐

Impaired ☐

Not impaired ☐

57. Proprioception

Not documented ☐

Impaired ☐

Not impaired ☐

58. Sensation

Not documented ☐

Impaired ☐

Not impaired ☐

59. Defecation

Not documented ☐

Impaired ☐

Not impaired ☐

60. Urination

Not documented

Impaired

Not impaired

61. Muscle power

Not documented   Muscles affected

0 = complete problem   …………………………………

1-2 = severe   …………………………………

3 = moderate   …………………………………

4 = mild…………………………………

5 = normal   …………………………………

62. Active selective movements

62.1 Upper limb

Not documented

Impaired

Not impaired

Scapula

shoulder

elbow

wrist

206

hand ☐

62.2 Lower limb

Not documented ☐

Impaired ☐

Not impaired ☐

Pelvis ☐

hip ☐

knee ☐

ankle ☐

foot ☐

63. Muscle tone

Not documented ☐   Muscle groups affected

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 ☐   ………………………………

64. Balance

Not documented ☐

207

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

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

Not impaired

Pelvis

hip

knee

ankle

foot

65.2 Active ROM

Not documented ☐

Impaired ☐

Not impaired ☐

65.2.1 Lower limb

Not documented ☐

Impaired ☐

Not impaired ☐

Pelvis ☐

hip ☐

knee ☐

ankle ☐

foot ☐

66. Sensation

66.1 Pain

Not documented ☐

Present ☐

Not present ☐

66.2 Temp

Not documented ☐

Impaired ☐

Hot ☐   cold ☐

Not impaired ☐

66.3 Touch

Not documented ☐

Impaired ☐

Not impaired ☐

67. Oedema

Not documented ☐

Present ☐

Absent ☐

68. Muscle power

Not documented ☐   Muscles affected

0 = complete problem ……………………☐……

1-2 = severe ………………☐……….

3 = moderate ……………………………☐

4 = mild……………………………… ☐

5 = normal ……………………☐……

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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 ☐

Impaired ☐

Not impaired ☐

Scapula ☐

shoulder ☐

elbow ☐

wrist ☐

hand ☐

69.2 Active ROM

Not documented ☐

Impaired ☐

Not impaired ☐

69.2.1 Upper limb

Not documented ☐

Impaired ☐

Not impaired ☐

Scapula ☐

shoulder ☐

elbow ☐

wrist ☐

hand ☐

70. Sensation

70.1 Pain

Not documented ☐

Present ☐

Not present ☐

70.2 Temp

    Not documented   ☐

    Impaired   ☐

               Hot   ☐   cold   ☐

    Not impaired   ☐

70.3 Touch

    Not documented   ☐

    Impaired   ☐

    Not impaired   ☐

71. Oedema

    Not documented   ☐

    Present   ☐

    Absent   ☐

72. Muscle power

Not documented   ☐   Muscles affected

0 = complete problem   …………………☐……

1-2 = severe   …………☐………………

3 = moderate   ……………………………☐

4 = mild………………………………   ☐

5 = normal   ☐   ………………………………

APPENDIX M: TELEPHONIC QUESTIONNAIRE GUIDE

Telephonic Questionnaire Guide Administered to Clients Who Did Not Return for Their Follow up Therapy

Introduce researcher to the study participants and provide a review on the research study as well as reminder of the research assistant who administered the questionnaires. Assure participants of anonymity and confidentiality and obtain verbal consent telephonically.

_____

Did you have a follow up appointment for therapy at TC Newman CDC?

_____

_____

Can you please tell me why you did not return for your follow-up appointment?

_____

_____

_____

_____

APPENDIX N: PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TO EVALUATE THE PROGRESS OF CLIENTS AFTER RECEIVING REHABILITATION TREATMENT AT ELANGENI REHABILITASION CENTRE.

REFERENCE NUMBER: N09/11/327

PRINCIPAL INVESTIGATOR: Rochelle Karen Felix

ADDRESS: Department of Health

                                        Cape Winelands District Office

                                        Haarlem Street, Worcester

CONTACT NUMBER: 023-3488133

CONTACT NUMBER – Health Research Ethics Committee (+27 21 938 9677)

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is entirely voluntary and confidential and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee (HREC) at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

The aim of this research study is: To evaluate the physical progress of clients at Elangeni Rehabilitation Centre in the after rehabilitation intervention / treatment.

Why have you been invited to participate?

You were invited to participate in this research study to demonstrate the physical outcomes of your rehabilitation after receiving therapy at Elangeni Rehabilitation Centre.

What will your responsibilities be?

To participate in your rehabilitation / treatment process as prescribed by your treating therapist and give objective and honest feedback of your rehabilitation process.

Will you benefit from taking part in this research?

You will receive therapy and feedback regarding your progress You will have the opportunity to give feedback on your view of the process

Your feedback will help therapists to improve therapeutic service delivery and rehabilitation services to the disabled population.

Are there in risks involved in your taking part in this research?

No personal risks due to taking part in the research.

Will you be paid to take part in this study and are there any costs involved?

There will be no remuneration and your participation in this study is voluntary.

218

Declaration by participant

By signing below, I …………………………….…………. agree to take part in a research study entitled *(insert title of study)*.

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is voluntary and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) ....….......……………. on (*date*) …………...……….. 2010

Signature of participant Signature of witness

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Declaration by investigator

I *(name)* Rochelle Felix declare that:…………………………………...

I explained the information in this document to …………………………………..

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use a interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) ....….........…………….. on (*date*) …………...……….. 2010

Signature of investigator   Signature of witness

Declaration by interpreter

I *(name)* …………………………………………..……… declare that:

I assisted the investigator (*name*) …………………………………………. to explain the information in this document to (*name of participant*) ……………..………………………….. using the language medium of Afrikaans/Xhosa.

We encouraged him/her to ask questions and took adequate time to answer them.

I conveyed a factually correct version of what was related to me.

I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) ....…......……………….. on (*date*) …………..………………..

Signature of interpreter Signature of witness

APPENDIX O: LETTER REQUESTING INFORMATION

Attention: Facility Manager TC Newman

RE: Permission to conduct a research study at Elangeni Rehabilitation Centre.

Herewith Handri Liebenberg and Rochelle Felix, would like to formally request permission to conduct a research study at the above centre.

The study will consist of two parts:

The main focus of Handri Liebenberg's study will be to look at the organisational capacity of the facility to render rehabilitation services

Rochelle Felix study will look at the outcome of clients receiving therapy at the centre.

The research studies have been approved by the committee for Human Research at the University of Stellenbosch.

REFERENCE NUMBER: NO9/11/322 (Handri Liebenberg)

REFERENCE NUMBER: N09/11/327 (Rochelle Felix)

The research studies will provide the DOH with detailed descriptions of:

current rehabilitation services rendered at the centre

how the services are being rendered

effectiveness of these services

and make recommendations based on the outcomes of the study.

As rehabilitation professionals and as part of the management team at the Cape Winelands district office, we believe that these studies will enhance the capacity of rehabilitation services.

Kind regards,

Handri Liebenberg & Rochelle Felix

February 2010

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

11 February 2010   **MAILED**

Ms RK Felix

Centre for Rehabilitation Studies

4th Floor, Teaching building

Stellenbosch University

Tygerberg campus

7505

Dear Ms Felix

"A study to evaluate the functional outcomes of clients after receiving rehabilitation at Elangeni rehabilitation centre."

ETHICS REFERENCE NO: N09/11/327

RE : APPROVED

At a meeting of the Health Research Ethics Committee that was held on 14 October 2009, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 10 February 2010 for a period of one year from this date. This project is therefore now registered and you can proceed with the work. Notwithstanding this approval, the Committee can request that work on this project be halted temporarily in anticipation of more information that they might deem necessary to make their final decision.
Please note add the HREC contact details in the Afrikaans version of the informed consent document and submit it as soon as possible.

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

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