

**PERSONS WITH PHYSICAL DISABILITIES' EXPERIENCES  
OF REHABILITATION SERVICES AT COMMUNITY  
HEALTH CENTRES IN CAPE TOWN**

**BY**

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UNIVERSITY of the  
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**A thesis submitted in fulfilment of the requirements for the degree of Master  
of Science in the Department of Physiotherapy, University of the Western  
Cape.**

**November 2009**

**Supervisor:**

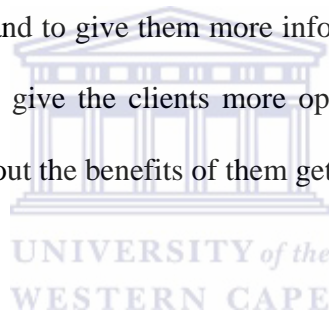
**Mrs. Anthea Rhoda**

## ABSTRACT

According to the United Nations, more than half a billion people (about 650 million) worldwide are disabled. Disability can have a vast impact on both the individual and the family. Rehabilitation is therefore a fundamental need for the persons with disability to achieve functional independence and have an improved quality of life. To enhance the effectiveness of rehabilitation, it is important to seek clients' perspectives of the rehabilitation services and to incorporate these perspectives into the planning and delivery of rehabilitation services.

In areas where rehabilitation services are available in South Africa, minimal research has been done to explore the clients' experiences regarding provision of these services. The aim of this study therefore was to explore the persons with physical disabilities' experiences of the rehabilitation services they received at community health centres (CHCs) in the Cape Town Metro Health District. Data was collected using a mixed methods design in the form of a sequential exploratory strategy. Qualitative data collection was done using in-depth interviews and this was followed by administration of an interview questionnaire. The questionnaire was developed using results from the in-depth interviews together with information from literature. Ten persons with physical disabilities, who had received rehabilitation services at participated in the in-depth interviews and 95 responded to the interview questionnaire. The interviews were tape-recorded and transcribed verbatim and they were analysed using predetermined themes. The SPSS version 16.0 was used to analyse the quantitative data which was presented in frequencies, medians, quartiles and percentages.

The results of the study revealed that the participants experienced problems with getting transport to travel to the community health centres and getting adequate information from the service providers, particularly information regarding disability and support services available for them. Experiences regarding participants' involvement in their rehabilitation were generally positive. Generally, the participants reported positive experiences regarding their interaction with service providers and family support and involvement and this study recommends the staff to maintain their standards regarding these two dimensions of rehabilitation. However most of the participants were not concerned about whether the service providers gave them an opportunity to express their preferences or not. The results indicate the need to improve transport services for persons with physical disabilities and to give them more information regarding support services. The service providers should also give the clients more opportunities to get involved in their rehabilitation and educate them about the benefits of them getting involved.



# **PERSONS WITH PHYSICAL DISABILITIES' EXPERIENCES OF REHABILITATION SERVICES AT COMMUNITY HEALTH CENTRES IN CAPE TOWN**

**CALLISTA KANGANWIRO MATSIKA**

## **KEY WORDS**

Experiences

Disability

Physical disability

Rehabilitation

Rehabilitation services

Community Health Centres

Primary health care

Client

Patient



## ABBREVIATIONS

|         |   |
|---------|---|
| ADLs    | Activities of daily living  |
| CASE    | Community Agency for Social Enquiry   |
| CBR     | Community Based Rehabilitation  |
| CHC     | Community Health Centre   |
| CSP     | Comprehensive Service Plan for the Implementation of Healthcare 2010              |
| CTMHD   | Cape Town Metro Health District   |
| DOH     | Department of Health  |
| DPO     | Disabled People Organisation  |
| ICF     | International Classification of Functioning Disability and Health                 |
| INDS    | Integrated National Disability Strategy   |
| IPDS    | Integrated Provincial Disability Strategy of the<br>WESTERN CAPE                  |
| NGO     | Non-governmental Organisation   |
| NRP     | National Rehabilitation Policy  |
| OT      | Occupational Therapy  |
| PHC     | Primary Health Care   |
| SAHRC   | South Africa Human Rights Commission  |
| UN      | United Nations  |
| UNCRPD  | United Nations Convention on the Rights of Persons with Disabilities              |
| UNDP    | United Nations Development Programme  |
| UNDPSCD | United Nations Department for Policy Co-ordination and Sustainable<br>Development |

UNHCHR United Nations High Commissioner for Human Rights

WHO World Health Organisation

WP Western Cape Province



## DECLARATION

I hereby declare that “**Persons with physical disabilities’ experiences of rehabilitation services at Community Health Centres in Cape Town**” is my own work, that has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references.

**Callista Kanganwiro Matsika**

Signature: ..... November 2009



**Witness: Mrs Anthea Rhoda**

Signature:..... November 2009

## DEDICATION

With deep appreciation and gratitude I dedicate this thesis to my husband Justine and to our son Tamiraishe Will.





## ACKNOWLEDGEMENTS

I give praise and glory to the Lord Almighty for taking me through the peaks and valleys of my research journey, especially for protecting me as I went to different places for my data collection and for giving me strength when the going was tough. I thank him for providing all the people who contributed to making this thesis a success.

I would like to express my sincere gratitude to my supervisor, Mrs Anthea Rhoda for her unwavering support and guidance.

I fail to find the appropriate words to thank my husband Justine for being my pillar of support when times were tough and for helping me to realize my potential. Thank you for taking care of our son, for taking me where I was supposed to be and for always making my burdens lighter.

To Mrs Mlenzana I say thank you for your support towards my stationery and transport and for understanding when I needed extra time to finish my thesis.

I would like to thank all the persons with physical disabilities receiving rehabilitation services at the CHCs who participated in this study.

My appreciation goes to the physiotherapists and occupational therapists at the CHCs where I conducted this study for going out of their way to assist me.

To Cleyson I say thank you for being a source of inspiration and for helping with the lay-out of my thesis. “YES WE CAN!”

I thank my nanny and helper Mbuya Joy for taking care of our son and for all the sacrifices she made for this thesis to be a success.

I extend my gratitude to my family and friends for their encouragement, support and prayers.

Sister Majory and the Mafofos I say thank you all for your support.

To all those whom I have not mentioned by name who contributed to my success I say “May the Good Lord abundantly bless you.



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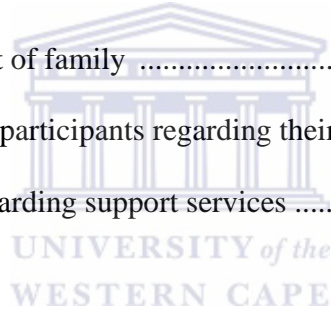
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# CHAPTER ONE

## INTRODUCTION

### 1.0 Background

According to the United Nations, more than half a billion people (about 650 million) worldwide are disabled (UN, 2006). In South Africa, despite the reported lack of reliable information on statistics and nature of disability, it is estimated that about 5% of the national population are moderately to severely disabled (Statistics South Africa, 2005). In the Western Cape Province disability prevalence has been estimated to be about 4.7% of the total provincial population (Statistics South Africa, 2005). These percentages comprise a significant proportion of the population, large enough to be concerned about rehabilitation service provision.

The common types of disability in South Africa, as reported by Census 2001 include hearing, sight, communication, physical, intellectual and emotional disabilities. Of these, sight is the most common disability (32%), followed by physical disability with a national prevalence of about 30% (Statistics South Africa, 2005). The main causes of physical disability in South Africa include traumatic brain injury, spinal cord injury, amputations, stroke, diseases such as diabetes, hypertension, rheumatoid arthritis, poliomyelitis and congenital conditions, injuries due to road traffic, domestic or work accidents, war injuries, poverty and violence (Office of the Deputy President, 1997).

The impact of disability on the individual, their family and the community can be vast (Mont, 2007), hence the need to rehabilitate persons with disabilities so that they can regain functional independence and therefore lead a better quality of life. Despite the relevance of rehabilitation in improving quality of life for persons with disability, Helander (1999) reported that only 3% of those in developing countries are receiving rehabilitation services. Loeb, Eide, Jelsma, Toni and Maart (2008) added that the majority of the persons with disabilities in developing countries, often lack optimal technical, medical or social support that could improve their living conditions.

However, in South Africa, there is evidence that rehabilitation services for persons with disabilities are more developed than in other developing countries. This is despite the fact that there is still a significant proportion of persons with disabilities who are not receiving these services. The worldwide review conducted to investigate access to rehabilitation services in the health sector reported that 21 to 40% of the disabled persons in South Africa were receiving rehabilitation services (WHO, 2002). The survey done in South Africa by Schneider et al. (1999) made an enquiry into the type of services that the persons with disabilities were receiving and found that health care services were the most commonly received when needed, with 76% of those needing these services receiving them. Although rehabilitation services were included within the health care services, this figure does not clearly indicate how many were receiving rehabilitation services.

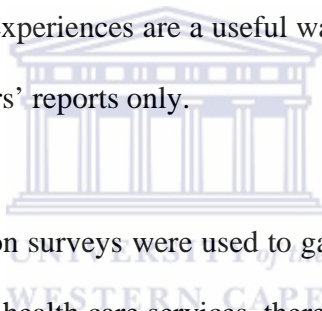
Despite the fact that rehabilitation services in South Africa are more advanced than in other developing nations as mentioned above, information regarding how the persons with disabilities perceive the rehabilitation services they are receiving is lacking. The importance of knowing

how clients experience rehabilitation services cannot be underestimated, especially in rehabilitation of persons with physical disabilities where some of them need long term services. Payton and Nelson (1996) stated that rehabilitation outcomes are likely to be determined by the degree of congruence in perspectives and expectations between health care providers and patients. This congruence can only be determined if the service providers are informed about how their clients perceive the services and if the latter are involved in evaluation of the services. This kind of information may also be used to identify areas that need quality improvement and to inform policy formulation and patient choice (Danielsen, Garrat, Bjertnaes & Pettersen, 2007).

Lund, (2004) carried out a study, investigating the experience of the rehabilitation process in everyday life among persons living with physical disability in Sweden. They concluded that a more comprehensive understanding of how persons with physical disability experience the rehabilitation process is lacking. There is also evidence that the clients themselves express their need to share their experiences of rehabilitation services. For example, in written correspondence submitted for public hearings before the National Centre for Medical Rehabilitation Research in the United States, one patient stated that he was *evaluated, dissected, tested and judged* by everyone on the rehabilitation staff but nobody ever asked how he experienced what they were doing (US Department of Health and Human Sciences in Payton & Nelson, 1996).

Seeking the persons with disabilities' experiences of the rehabilitation process promotes their involvement in promotion, formulation and evaluation of policies affecting their lives. This involvement is emphasised by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (UNHCHR, 2006) to which South Africa is a signatory. The UNCRPD

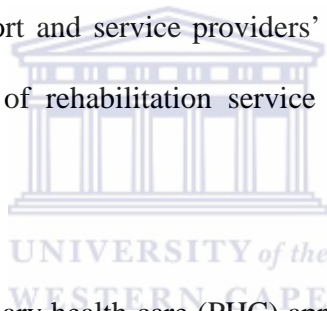
also recognises the importance of the principles of the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UNDPD, 1994), which emphasizes that the client's subjective experiences, preferences and needs should be the base for designing the services provided to persons with physical disabilities. This incorporation of the clients' perspectives enhances partnership between the service providers and the persons with physical disabilities. The former will also be able to target the specific needs and expectations of their clients. South Africa's National Rehabilitation Policy (NRP) also insists on the involvement of persons with disabilities in the planning, implementing and monitoring of rehabilitation services since they are the ones with first-hand experience of the impact of disability on their lives (DOH, 2000). Thus, clients' experiences are a useful way of monitoring the services, rather than relying on the service providers' reports only.



Unlike in the past where satisfaction surveys were used to gather information on the opinions of clients regarding rehabilitation and health care services, there has been movement in recent years to examine their experiences of rehabilitation (Cott, Teare, McGilton & Lineker, 2006). As opposed to satisfaction which is essentially a subjective phenomenon determined in large part by expectations (Jenkinson et al. 2002), experience surveys involve an extensive and more objective research design to find out what patients think about the way they were treated and what the problems were. They also involve asking the patients whether or not certain processes and events occurred during the course of a specific episode of care (The Picker Institute, 2008). This could involve asking whether they were given enough information regarding their rehabilitation or whether they were involved in making decisions. Jenkinson et al. (2002) argued that the study of patients' experiences provides results that can easily be acted upon. Such results have been found

to elicit more critical accounts of what happens in rehabilitation that are less likely to be influenced by expectations.

Studies conducted in Australia, Ireland, United States, Norway, Sweden and the United Kingdom have shown consistency with regard to dimensions of care that clients talk about when reporting their experiences of rehabilitation and health care (Crisp, 2000; Lund, 2004; Ward, 2003; Coulter, 2005; Garrat et al. 2006). The most common among these dimensions of care include accessibility of the services, clients' interaction with service providers, client participation and involvement, family support and involvement, information provision, respect for client, emotional support, physical comfort and service providers' expertise. The clients' experiences regarding some of these aspects of rehabilitation service provision were determined in the present study.



South Africa has adopted the primary health care (PHC) approach in which health care services are delivered within the local community and are centred on the needs of that particular community. The implementation of the PHC approach is mainly guided by two key policies, namely; the National Rehabilitation Policy (NRP) and the Primary Health Care Package (DOH, 2000, 2001). Community health centres (CHCs), which are the foundation of the national health services, were designed to offer primary health care services. These centres, which are the setting for the present study, offer preventative, promotive, curative and rehabilitative care on an out-patient basis (ANC, 1994).

According to the PHC package, rehabilitation is an integral part of the health care services provided at primary care level. Expanding services at PHC level is aimed to improve access for local clients to rehabilitation services which are delivered within their communities, and this is the main function of CHCs. The PHC package advocates for the involvement of communities, particularly people with disabilities in designing, implementing and monitoring rehabilitation services they receive at primary care level (DOH, 2001).

### **1.1 Statement of the problem**

Since the implementation of primary health care facilities in South Africa, minimal research has been done to investigate how the clients experience these services, both in the Western Cape Province and in the country at large. According to Hammell (2007), rehabilitation is perceived by rehabilitation professionals to be of fundamental importance to persons with disabilities and yet few researchers have explored the experiences of rehabilitation from the perspectives of clients. The absence of a significant body of research exploring the clients' perspectives on their rehabilitation services makes it difficult for the service providers to be sure whether the services they are rendering are matching the clients' expectations. Furthermore, lack of this kind of information may hinder implementation of rehabilitation policies that are specifically directed to the clients' preferences and expectations. This study therefore aims to illuminate and enhance the understanding of how persons with physical disabilities experience the rehabilitation services they receive at the Community Health Centres (CHCs) in Cape Town Metro Health District.

## **1.2 Research Question**

What were the experiences of persons with physical disabilities regarding the rehabilitation services they received at Community Health Centres in Cape Town Metro Health District?

## **1.3 Aim of the study**

The aim of this study was to explore the persons with physical disabilities' experiences regarding the rehabilitation services they received at Community Health Centres in Cape Town Metro Health District.



## **1.4 Objectives of the study**

- 1) To determine the rehabilitation services received by the persons with physical disabilities at the Community Health Centres.
- 2) To determine the persons with physical disabilities experiences' regarding accessibility of the Rehabilitation centres.
- 3) To determine the persons with physical disabilities experiences' regarding the service providers' interaction with them.
- 4) To determine the persons with physical disabilities' experiences regarding their involvement and participation in the rehabilitation process.
- 5) To determine the persons with physical disabilities' experiences regarding support and involvement of their families in the rehabilitation process.

6) To determine the persons with physical disabilities' experiences regarding provision of information regarding disability and support services by the service providers.

### **1.5 Definition of terms used in the thesis**

**Experiences** refer to what clients think about the way they were treated and what the problems were from the client's point of view. It involves asking the clients whether certain processes and events occurred during the course of their rehabilitation (The Picker Institute, 2008).

**Disability** is defined as an umbrella term for impairment, activity limitation and participation restriction, created through an interaction between a disease or an injury and contextual factors, including both environmental and personal factors (WHO, 2001).

**Physical disability** in the present study is defined at impairment level (body function/ structure) whereby one has lost or has impaired use of one or more parts of the body that affect their neuromusculoskeletal and movement-related functions (WHO, 2001).

**Rehabilitation** is a process aimed at enabling persons with disabilities to reach and maintain their optimal, physical, sensory, intellectual, psychiatry and or social higher functional levels, thus providing them with tools to change their lives towards a higher level of independence (UNDP, 1994).



**Rehabilitation services** are the services received from physiotherapists, occupational therapists, speech therapists and medical orthotists and prosthetists which are aimed at improving persons with physical disabilities' function and therefore reintegrate them into their communities (DOH, 2000).

**Community Health Centres** are day facilities situated within the clients' communities, which are part of the District Health System in South Africa, providing promotive, preventative, curative and rehabilitative services at primary care level (ANC, 1994).

**Primary health care** is the essential health care based on practical, scientifically and socially acceptable methods and technology made universally accessible to individuals in the community through their full participation. This includes providing the care at a cost that the community and the 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 also the first level of contact of individuals, the family and the community with the national health system bringing health care as close as possible to where people live and work and it constitutes the first element of a continuing health care process (WHO, 1978).

**Client** refers to someone who comes actively and voluntarily to seek help with a problem, taking his or her own responsibility for the situation. The term avoids the connotation that the person is sick or is an object of an experiment (Wressle, 2002). In the present study clients were adults (18-70 years) with physical disability receiving rehabilitation services at the CHCs.

**Patient** refers to any person who receives medical attention, care or treatment (American Medical Dictionary, 2007). In the present study, this term is only used where the referenced authors used it.

## **1.6 Outline of chapters**

As shown above, in Chapter One, the background of the study is described. The prevalence of disability worldwide and locally in South Africa is highlighted. The extent of the availability of rehabilitation services in South Africa is also briefly described. The need to seek the clients' experiences of rehabilitation services that is documented in literature is highlighted, together with a background of research done on this subject. The researcher also gives a background of rehabilitation services at primary health care level in South Africa. The significance of the study, aims and objectives are also presented.

Chapter Two presents a review of the literature relevant to this study. The definition, prevalence and impact of disability are discussed together with the status of rehabilitation service provision in developing countries, with emphasis to the South African situation. The literature regarding experiences of rehabilitation regarding accessibility, service provider interaction with clients, involvement and participation of clients, involvement and support of family and information provision is also reviewed.

Chapter Three presents the background of the methodology used in the present study followed by a description of the quantitative phase of the research methodology. The research setting, study design, sampling methods, inclusion and exclusion criteria and procedures followed in qualitative data collection are described. The methods of qualitative data analysis are outlined and lastly the chapter describes the ethical considerations.

In Chapter Four, the results from the qualitative phase of the study are presented under the predetermined themes developed according to the objectives of the study and the emerging theme. Within each theme, the participants' experiences of rehabilitation services are presented with inclusion of quotations that support different themes.

Chapter Five presents the quantitative phase of the mixed methods research design used in the present study. The study sample, instrumentation, quantitative data collection and data analysis methods are described.

Chapter Six gives the analysis of results obtained from the quantitative phase of the study. The results are presented in form of percentages, frequencies, medians and inter-quartile ranges which are illustrated in tables and graphs with brief textual descriptions. Like in Chapter Four, the results in Chapter Six are also presented under different themes that correspond with the objectives of the study.

In Chapter Seven the major findings from both phases of the study are summarised and discussed with comparison to previous research in the area. The researcher makes an effort to discuss how

the rehabilitation service providers and other relevant parties could address the negative experiences expressed by the participants. Lastly, within this chapter, the relevance of the findings to rehabilitation service providers is discussed. .

Chapter Eight, which is the final chapter comprises of the summary, conclusion, limitations and recommendations. This chapter wraps up the study, proposing suggestions for future action.

## **1.7 Summary**

Chapter One presented the background of the study. A summary of the prevalence of disability, worldwide and in South Africa was given, followed by a brief discussion of the current situation regarding rehabilitation service provision in South Africa. A background of previous findings on what literature says about seeking clients' perspectives regarding the rehabilitation services they receive is given, highlighting on the knowledge gap in this area. The emphasis given by rehabilitation policies on the need to incorporate clients' perspectives in planning and providing rehabilitation services is also highlighted. This chapter also highlights on the dimensions of rehabilitation that participants in previous studies talked about when reporting their experiences of rehabilitation. The background of primary health care service provision in South Africa is given followed by the problem statement, aims, objectives and definition of terms used in the thesis. Finally an outline of the chapters in this thesis is given. The concepts highlighted in Chapter One will be expanded further in the literature review that is coming in Chapter Two.

## **CHAPTER TWO**

### **LITERATURE REVIEW**

#### **2.0 Introduction**

This chapter presents a review of literature regarding persons with disabilities' experiences of healthcare services with an emphasis on rehabilitation services. Prior to the review, a general background of disability, which includes definition, the disability models, prevalence (both globally and at national level) and the impact of disability is presented. Rehabilitation service provision in developing countries is discussed followed by that in South Africa, with emphasis to the Western Cape Province. The aspects of rehabilitation experiences discussed include accessibility of the services, client participation and involvement, family support, information provision and clients' interaction with the service providers. Most of the literature reviewed in this chapter on clients' experiences of rehabilitation focused on international studies due to paucity of published information on the topic in South Africa.


#### **2.1 Disability**

##### **2.1.1 Definition of disability**

Disability cannot be defined as a uniform concept because the perceptions of what circumstances are disabling and the significance of disabilities vary from one society to the other within different cultures (Bury, 2003; Hammel, 2006). There are several definitions of disability in literature but in the present study, the most widely accepted definition currently is going to be

used. This is the International Classification of Functioning, Disability and Health (ICF) definition, which states that disability, is an umbrella term for impairment, activity limitation and participation restriction, created through an interaction between a disease or an injury and contextual factors, including both environmental and personal factors (WHO, 2001). Human functioning in the ICF is identified as operating at three levels namely the body or body part (impairment), the whole person (activity limitation) and the whole person in a social context (participation restriction). Disability occurs when there is dysfunction at one or more of these levels (Davis & Madden, 2006).

### **2.1.2 Models of disability**

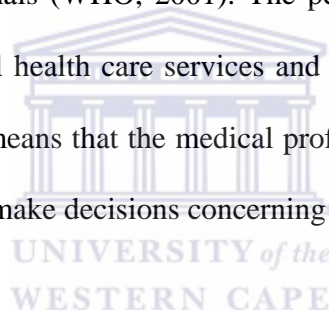


The lack of consistency in definitions of disability led to evolvement of several theoretical models which have been used to define disability and amongst these, the medical model, social model, bio-psychosocial model have been the most dominant. According to Hammel, (2006), these models concern the way in which disabled people are perceived, the allocation of health care resources, including rehabilitation services and, in some instances survival itself. The author went on to add that although these models emerged at different times, they are evident in contemporary societies, demonstrating the persistence of certain patterns of thought in shaping ideas about disability. It is therefore essential for those who offer rehabilitation services to understand how a particular society perceives disability so that planning and implementation of rehabilitation services may be relevant to the targeted group of people.

Two of the theoretical models, the medical (individual) model and the social model, have provided the most dominant but opposite ways of understanding disability. These two models will be discussed in the present study.

### **2.1.2.1 The medical model of disability**

Within the medical model, disability is viewed as a problem of the person, directly caused by disease, trauma or other health condition, which requires medical care provided in the form of individual treatment by professionals (WHO, 2001). The person with disability is expected to enter the sick role, access medical health care services and follow health care worker's advice (Davis and Madden, 2006). This means that the medical professionals plan all interventions and the persons with disability cannot make decisions concerning their rehabilitation.



The medical model of rehabilitation makes persons with disability passive recipients of services, even those not related to healthcare and rehabilitation, with the health professionals making most decisions affecting their lives. This 'medicalisation' of many areas as described by Swain and French (2001) results in doctors becoming involved in decisions and assessments which have little to do with medicine such as housing, education and employment. Even organizations for people with disabilities are controlled by non-disabled people who provide services to people with disabilities. This domination of the disabled persons contributes to the segregation of and discrimination against the latter and produces arguments, usually biological in nature to justify the exclusion of disabled people from mainstream social and economic life (Swain & French, 2001).

Nevertheless, the positive effects of appropriate medical care cannot be ignored since the most urgently required care modalities for persons with disabilities are medical and rehabilitation care (Davis & Madden, 2006). These modalities are important for curing or alleviating the physical or mental conditions of many persons with disability. Swain and French (2001) highlight the positive results of the medical model, which include increased survival rates and higher life expectancy for some disabled individuals for example individuals with insulin dependent diabetes or individuals who receive physiotherapy after spinal cord injury. Despite these positive aspects, the discriminatory nature of the medical model led to its rejection by the persons with physical disabilities, and they instead developed the social model of disability.

In South Africa, the medical model of disability prevailed until the later part of the twentieth century when the government developed the Integrated National Disability Strategy (INDS). The INDS recognises the role of therapeutic and rehabilitative interventions in addressing impairments to ensure maximum independence for persons with disability but on the other hand, promotes the adoption of the social model of disability which promotes recognition of the rights of persons with disabilities and their participation in society (Office of the Deputy President, 1997) as discussed below.

### **2.1.2.2 Social model of disability**

Within the social model, disability comprise of all the things within the society that impose restrictions on disabled people, ranging from individual prejudice to institutional discrimination,



from inaccessible public buildings to unsuitable transport systems, segregated education to excluding working arrangements (Oliver, 1996a). There is need for the society to change and make necessary environmental modifications to be more inclusive if it is to reduce and eliminate disabilities. At the political level this becomes a question of human rights, hence for the social model, disability is a political issue (WHO, 2001).

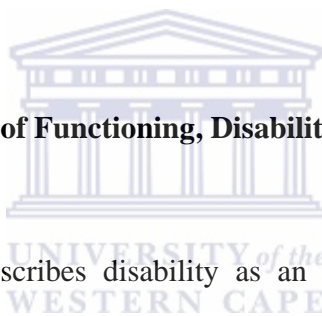
Since 1997, in South Africa, disability and rehabilitation policies have largely been based on the UN Standard Rules, which promote social model practices, beginning with the drafting of the Integrated National Disability Strategy (INDS). The INDS has adopted a socio-political approach to disability, whereby disability is located in the social environment (Office of the Deputy President, 1997). This takes cognizance of disabled people's viewpoint that disability is a social construct and most of its effects are inflicted upon people with disabilities by their social environment for instance, it is neither the disability, nor the wheelchair that disables a person but it is the stairs leading to a building. However McKenzie and Muller (2006) argued that in their experience, service delivery in South Africa is still firmly rooted in the medical model, more so due to the medical bias of the therapists' training. They went on to add that the therapists tend to diagnose the problem in relation to what they are able to offer.

The social model has been criticized for saying that the problems are wholly social, ignoring experiences such as pain, fatigue, paralysis, reduced life expectancy, incontinence and spasticity (Hammel, 2006). The writings of the persons with disability have also reflected the criticism for instance Jenny Morris wrote:

...there is a tendency within the social model of disability to deny the experiences of our own bodies, insisting that our physical differences and restrictions are entirely socially created.

While environmental barriers and social attitudes are a crucial part of our experience of disability – and do indeed disable us – to suggest that this is all there is to it is to deny the personal experience of physical and intellectual restrictions of illness, of fear of dying. (Morris, 1991, p. 10 in Oliver, 1996b)

The absence of a consensus agreement as to which of these two opposing models of disability is more appropriate led to the integration of the perspectives of the medical and social models into a bio-psychosocial approach in the International Classification of Functioning, Disability and Health (WHO, 2001).



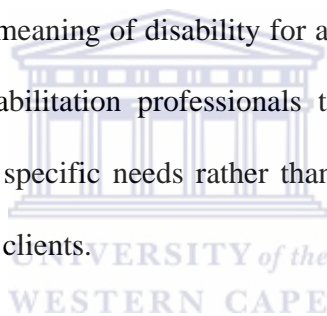
### **2.1.3 International Classification of Functioning, Disability and Health (ICF)**

The ICF is a framework that describes disability as an interaction between the individual (internal factors) and the environment (external factors), (WHO, 2001). This framework has provided the most widely accepted definition of disability worldwide described in 2.1. The interaction between the individual and the environment as described by the ICF indicates the need for one to look at both the individual and the environment if a person's experience of disability is to be described accurately and comprehensively. The ICF refers to this way of thinking as the bio-psychosocial model.

Using the ICF as a framework for rehabilitation ensures that the focus for rehabilitation is not only on the level of impairment and disability but also on the individual's participation in environment and society (Davis and Madden, 2006). It is important to note that in the ICF, the

environment can be either a barrier or a facilitator to the individual's functioning in the society. Environmental factors can be facilitators if they influence in a manner that allows the person to manage with their further deterioration, such as through the use of a walking stick, availability of ramps, positive attitudes and or inclusive policies. On the other hand, environmental factors such as lack of services and assistive technology, inaccessible buildings, negative attitudes and discriminatory policies may create disabling barriers (WHO, 2001).

Within the ICF, the complex interactions between the conditions creating disabilities simply mean that persons with the same disease or injury will always have different experiences of their disabilities, or in other words, the meaning of disability for a person's life can vary dramatically (Lund, 2004). This calls for rehabilitation professionals to attend to every individual with disability differently according to specific needs rather than just using structured programmes that might not be suitable for some clients.



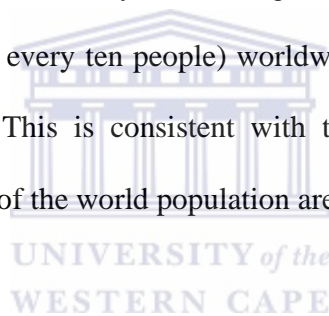
The ICF has become the generally accepted framework within which to describe functioning in rehabilitation, as well as to document health and disability. According to Wade and de Jong (2000) the acceptance of this framework has fostered more consistent communication among professionals from different disciplines and it also brings structure and order to rehabilitation research.

Jelsma (2009) conducted a literature survey to evaluate use of the ICF in research and found that published literature on the use of this framework is limited in developing countries. Only 2.4% of the papers reviewed in this survey (5 in South Africa and 1 in Rwanda) were done in Africa.

In South Africa, census 2001 in part, employed the use of the ICF by adding the dimension of “full participation in life activities” to the questions determining occurrence of disability (Statistics South Africa, 2005). This expanded the concept of disability from a narrow focus on impairments to a broader focus on human functioning in social context.

#### **2.1.4 Prevalence of disability**

The proportion of the world population with disability is huge and it is of growing concern within individual nations and internationally. According to United Nations (2006), more than half a billion people (about one in every ten people) worldwide are disabled because of mental, physical or sensory impairment. This is consistent with the findings by Mont (2007) who reported that between 10 and 12% of the world population are disabled persons.



The reported national prevalence of disability from around the world varies dramatically. This variation is a result of several factors, some of them being: use of different definitions of disability, different methodologies of data collection and variations in the quality of the survey design (Loeb, Eide & Mont, 2008). Higher disability prevalence is reported in developed countries as compared to developing countries. It is likely so because developed countries often use broad survey screening questions that focus on functional or activity limitations, resulting in higher estimates of disability prevalence (Chamie, 1989). On the other hand, developing countries report low prevalence because they rely on censuses due to limited resources for conducting household surveys (Mont, 2007).

The disability prevalence in developed countries is generally above 20% of the country's population. In Sweden in 2002, about one out of every five (21%) of the population in the age range of 16 to 64 years had a disability, with the most common disability being restricted mobility, which accounted for 30% of those with disabilities (Statistiska Centralbyran, 2003). In the US census reports, about 20% of people living in the United States identified themselves as having some type of disability (Hwang et al. 2009). In a survey done by Mont (2007), Canada and Australia were reported to have disability rates of 18.5% and 20% respectively and in this survey, only a few of the developed nations like Italy and Germany recorded prevalence of less than 10%.

In developing countries, national disability prevalence rates are generally below 10%. In Kenya and Bangladesh, Mont (2007) reported disability prevalence rates of 0.7% and 0.8% respectively. The low prevalence is mainly due to use of censuses to determine disability prevalence as opposed to the surveys used in developed countries. A valid example was given in Zambia where the census yielded a disability prevalence of 1%, but a functional based approach using the UN Washington Group Questions in conjunction with a more detailed survey yielded a disability prevalence rate of more than 13% (Mont, 2007).

It is important to note that despite the low prevalence of disability in developing countries, Helander (1999) stated that the majority of the people with disabilities live in developing countries. It was estimated that there were about 234 million moderately or severely disabled people living in developing countries in 2000 and that this number is expected to increase to about 525 million in 2035 (Helander, 2000). These persons with disabilities in developing

countries often live in extreme poverty, as Loeb, Eide, Jelsma, Toni, & Maart (2008) indicated that these nations are very often without optimal technical, medical or social support that could improve their living conditions. Helander (1999) also reported that only 3% of the persons with disabilities in developing countries are receiving rehabilitation services.

In South Africa, the prevalence of disability was determined in two national surveys, namely the Community Agency for Social Enquiry (CASE) (Schneider et al., 1999) and Census, 2001 (Statistics South Africa, 2005) . These two surveys reported slight differences in the national prevalence of disability. The former estimated that there are between 5.7% and 6.1% of the total population with disabilities in South Africa and the latter reported that an estimate of 5% (about 2 255 982 individuals) of the total population is disabled.

In the CASE survey, Schneider et al. (1999) reported that limitations in movement and limitations in daily life activities were the highest reported types of disability while Census 2001, reported that sight was the most prevalent type of disability (32%) followed by physical disability (30%). Both surveys indicate that the proportion of persons with physical disability in South Africa, which is the group that is the focus of attention in the present study, is high.

The two surveys done in South Africa also highlighted on demographic factors that influence disability prevalence rates. Africans had a significantly higher global prevalence rate (6.1%) in both surveys, as compared to other races, more in urban areas than in their rural counterparts and Indians/Asians had the lowest disability prevalence rate (3.7%). Census, 2001 found that there

were generally more females with disability but physical disability was more prevalent among males.

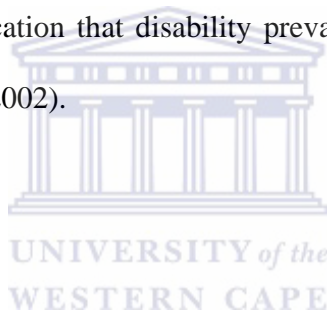
Disability prevalence in South Africa was found to increase with increasing age from 2% in 0-9 year age group to 27% in the 80 years plus age group (Statistics South Africa, 2005). The increasing of disability prevalence with age is a common trend worldwide, which could be due to chronic conditions that come with old age. Jette and Branch (1981), measured the prevalence of physical disability among the elderly (55 years +) in Massachusetts, United States, and in this study the data revealed a consistent increase in physical disability with increasing age. Similarly, the study done by the Netherlands Health Interview Survey found that about 12.6% of the Dutch population aged 16 years and above had a physical disability (seeing and hearing included), which also became more prevalent with increasing age (Picavet & Hoeymans, 2002).

Physical disability has the highest prevalence rates among all the population groups in South Africa except for Africans among whom sight is most prevalent. The coloured population has the highest proportion among persons with physical disability (37.9%). Phillips and Numbissi, (2004), suggested that the racial differences in disability prevalence might be due to cultural differences, differences in access to health facilities and/or the level of development of each sub-population.

In the Western Cape Province, Census 2005 reported a disability prevalence of 4.1%, whilst CASE had reported a prevalence rate of 3.8%. The age groups 25-29 and 30-34 years represent the highest percentages of 8% (11566) and 8.2% (11 886) of the persons with disability in the

province respectively (Office of the Premier, WP, 2002). When comparing the distribution of different types of disability, the trend found in the national prevalence is evident in the Western Cape Province, whereby sight disability has the highest percentage (28%), followed by physical disability (24.2%) (Office of the Premier, WP, 2002).

Mitchell's Plain district has a significantly higher disability prevalence rate (5.7%) as compared to the average rate of Western Cape Province (3.7%) and a survey done by Katzenellenbogen, Joubert, Rendall and Coetzee (1995) found an impairment rate of 12.9% in this district. The Integrated Provincial Disability Strategy (IPDS) document suggests that this high prevalence in Mitchell's Plain could be an indication that disability prevalence is higher in poverty-stricken areas (Office of the Premier, WP, 2002).



### **2.1.5 Impact of disability**

Several economic, psycho-social, and physical consequences of disability have been documented in literature. Of these, the economic impact of disability is a major issue that many writers have documented and the link between disability and poverty is a common subject. Loeb, Eide, Jelsma, Toni, & Maart (2008) reported that most of the persons with disabilities are amongst the poorest of the poor. Mont, (2007) clearly illustrated the link between disability and poverty, stating that disability and poverty are intricately interlinked. Poverty causes disability with its associated malnutrition, poor health services and sanitation and unsafe living and working conditions. Conversely, the presence of a disability can trap people into a life of poverty because



of the barriers the disabled people face in taking part in education, employment, social activities and indeed, all aspects of life (Mont, 2007).

The INDS in South Africa also emphasises on the relationship between poverty and disability, stating that not only is there a higher proportion of disabled people amongst the very poor, but also there is an increase in families living at the poverty level as a result of disability (Office of the Deputy President, 1997).

Medical bills, transportation, home adjustments and/or loss of employment can all contribute to financial strain on the person with disability and their family, thus contributing to their poverty. This is always worse when the person with disability was the breadwinner before becoming disabled (Effects of rehabilitation on family, 2007). Although in some countries, including South Africa, a percentage of persons with disability receive social security benefits, these benefits are usually used to pay neighbours and relatives to perform tasks (Office of the Deputy President, 1997).

The marginalization of persons with disability from mainstream society denies them basic services like education and as a result, they are unable to find employment, which drives them deeper into poverty. This was found evident in India, whereby 50% of people with disabilities have never been to school and in Mozambique where 95% of persons with disability are illiterate as compared to 60% in the overall population (Venter, Rickert & Maunder, 2003).

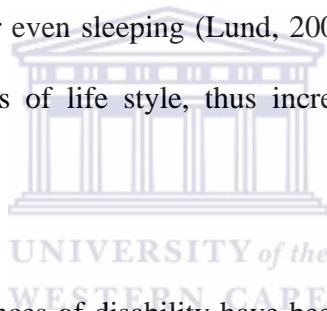
Socially, disability can be isolating to both the person with disability and their family. Ignorance, neglect, superstition and fear are social factors that throughout the history of disability have isolated persons with disabilities and delayed their development (UNDPCSD, 1994). Exclusion and isolation of persons with disability and their families usually begins right from the time one gives birth to a child with disability. Mothers of children with disability often face ostracism from their partners, their families and their communities. This exclusion badly affects other non-disabled siblings, the survival of the family as a unit and the meaningful development of the child with disability (Office of the Deputy President, 1997).

In addition to the isolation and exclusion of persons with disabilities and their families due to occurrence of a disability, care giving is another hurdle that the family of the person with disability has to face. This is worse in cases where one is severely disabled and is in need of assistance with most activities of daily living (ADLs). While motivation for taking care of one's loved ones is often high, the emotional and physical toll of care giving can be overwhelming and most caregivers often feel isolated, anxious and depressed (Effects of rehabilitation on family, 2007). To meet the needs of care, transportation and supervision, nearly one third of caregivers are forced to give up their jobs, increasing the financial strain on the family (Bishop, Degeneffe & Mast, 2006).

The fact that having a disability may comprise changes in a person's ability to engage in activities of daily life and may challenge his/her, participation in society may result in serious emotional turmoil. In the Western Cape Province, Njoki (2004) reported narratives of persons with physical disabilities expressing how the disability affected them emotionally. Sometimes,

persons with disability end up indulging in health risk behaviours like smoking and taking drugs in trying to deal with the emotional pain (Hwang et al. 2008).

In addition to the health risks behaviours reported among persons with physical disability, their loss of ability to engage in daily life activities may lead to them living a sedentary lifestyle. Studies to determine persons with physical disability's involvement in physical activity have provided evidence that a sizeable number of them are not physically active due to certain personal and societal influences (Levins, Redenbach & Dyck 2004; Njoki, 2004; Biggs, 2005). Their leisure time is usually spent on less physically demanding activities in the home such as watching television and reading or even sleeping (Lund, 2004). As a result, some of them may end up acquiring chronic diseases of life style, thus increasing morbidity among them and reducing their quality of life.



However, after all these consequences of disability have been discussed, it is important to note that persons with the same disease or injury will always have different experiences of their disability due to their different circumstances as illustrated by the ICF (WHO, 2001). These variations indicate the need for all sectors involved in rehabilitation to treat the persons with disabilities at an individual level so as to attend to their specific needs.

## 2.2 Rehabilitation

The United Nations Standard Rules on the Equalization of Opportunities for Persons with Disability provided the definition of rehabilitation mainly used worldwide, which states the following.

Rehabilitation is a process aimed at enabling persons with disabilities to reach and maintain their optimal, physical, sensory, intellectual, psychiatric and or social higher functional levels, thus providing them with tools to change their lives towards a higher level of independence. Rehabilitation may include measures to provide and/or restore functions, or compensate for the loss or absence of a function or for a functional limitation. The rehabilitation process does not involve initial medical care. It includes a wide range of activities, from more basic and general rehabilitation to goal-oriented activities, for instance vocational rehabilitation. (UNDP, Vienna, Dec 1994, p. 21).

The INDS in South Africa added that rehabilitation is a holistic and ongoing process which only ends once the individual has fully reintegrated into the society (Office of Deputy President, 1997).

Rehabilitation services can either be in the form of community-based or institution-based services which are offered on inpatient or outpatient basis. Institution-based rehabilitation can be rendered at institutions like special schools, hospitals or training centres. According to the briefing paper for the World Confederation of Physical Therapy written by Bury, (2003), institution-based and outpatient services are models recognisable to most health care professionals. Community-based services can be provided at facilities within the individuals'

communities as those received by the participants in the present study, in form of the community based rehabilitation (CBR) approach or as home based services. These community based services are further described in 2.2.2 below.

For a holistic approach to rehabilitation, which ensures that all the clients' areas of need are catered for, there is need for teamwork from various disciplines of care. The rehabilitation team arises from the compromise between specialisation of disciplines and the need for a comprehensive approach to care when managing chronic illness (Rothberg, 1981). There are various team approaches in rehabilitation, the most popular being multidisciplinary, interdisciplinary and trans-disciplinary teams (Davis & Madden, 2006). In order for rehabilitation to be effective, there is need for collaboration from all the stakeholders involved in the care of the person with disability (Bagwanjee & Stewart, 1999) which means that the person with disability, their family and community should be involved in the planning and implementation of rehabilitation services.

### **2.2.1 Rehabilitation service provision in developing countries**

There is evidence in the literature that despite the fact that about 70% of persons with moderate to severe disability live in developing countries, only about 3% of those who need rehabilitation are receiving meaningful services (Helander, 1999). There is however lack of published information regarding rehabilitation service provision in developing countries and the little that is there mainly focus on Community Based Rehabilitation (CBR). The introduction of CBR services has been useful in improving rehabilitation service provision in developing countries.

Field studies conducted between 1982 and 1997 in developing countries such as Botswana, India, Guyana, Vietnam, Egypt and Zimbabwe found success rates of 26 to 91%. The improvements were found in areas like mobility, communication, integration into schools, social integration and employment (Helander, 2000).

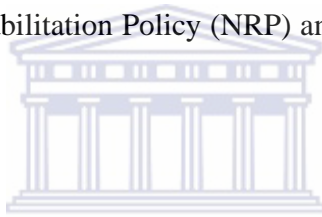
### **2.2.2 Rehabilitation service provision in South Africa**

The South African policy framework for disability and rehabilitation, the Integrated National Disability Strategy, states that few services and opportunities exist for people with disability to participate equally in society (Office of the Deputy President, 1997). The document emphasises the adoption of the social model of disability. South Africa is one of the nations that have ratified the United Nations Convention on the Rights of Persons with Disabilities which also emphasises on a fundamental shift in how we view disabled persons, away from the individual medical perspective, to the human rights and development of disabled people (UNHCHR, 2006). Despite the emphasis on the social model of disability, in South Africa the INDS also recognises the role of therapeutic and rehabilitative interventions in addressing impairments to ensure maximum independence for persons with disability.

Rehabilitation is an integral part of the health care system in South Africa (DOH, 2001). Rehabilitation service provision takes place at various levels of care and at a variety of institutions. All these services fall under each of the three sectors namely: public sector (about 60%), non-governmental organisation/disabled people organisation (NGO/DPO) sector and the

private sector (DOH, 2000). The public sector is going to be discussed below for purposes of the present study.

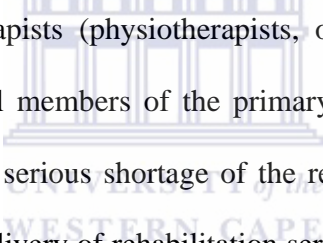
Within the public sector in South Africa, the levels of care include; primary level and step down rehabilitation services, secondary level rehabilitation services, tertiary level rehabilitation services and specialist and academic rehabilitation services. Primary level rehabilitation services, which are the focus of the present study, are limited to certain Community Health Centres (CHCs), district hospitals and primary health care facilities, centred on the needs of the local community and delivered within the community. These services are mainly guided by two key policies namely: the National Rehabilitation Policy (NRP) and the Primary Health Care Package (PHC) (DOH, 2000, 2001).



The principles of the NRP in South Africa are based on the premise that rehabilitation is not only the training of disabled people, but also interventions in the general system of society, adaptations of the environment and protection of human rights (DOH, 2000). This supports the social model of rehabilitation, which strongly emphasizes the persons with disabilities' independence in their own environment. One of the main goals of the policy is to improve accessibility to all rehabilitation services through provision of community based services. The community based rehabilitation services are usually linked to CHCs and these serve as a link between hospital discharge and full community reintegration.

In addition to the facility based rehabilitation services offered at the CHCs, community based rehabilitation (CBR) and home based care are the other components of the community based

rehabilitation services in South Africa. CBR is described as a philosophy within community development for the rehabilitation, equalisation of opportunities and social integration of persons with disability which is implemented through the combined efforts of people with disabilities themselves, their families and communities and the appropriate health, education, vocational and social services (UN, 2004) and it is an integral part of the PHC (DOH, 2001). It is an approach to delivering services to the people and not a service itself and it is applicable at all levels of service delivery, from community to tertiary level (DOH, 2000) Home based-care, is a service that is given to the client within their own home environment, especially those who are bedridden and cannot travel to the CHCs.



At PHC level, rehabilitation therapists (physiotherapists, occupational therapists and speech therapists) are regarded as integral members of the primary health care team, attached to the district health services. There is a serious shortage of the rehabilitation professionals in South Africa, which negatively affects delivery of rehabilitation services. The NRP indicated that there were 80 vacancies for OTs and 75 vacancies for physiotherapists within the public sector in the Western Cape Province which needed to be filled at the time the document was published (DOH, 2000). This shortage of rehabilitation personnel is however not a problem in South Africa alone but it is generally affecting all developing countries. Twible and Henley (2000) estimated that the ratio of therapist to clients was 1:550 000 in developing countries as compared to 1:1 400 in developed countries. Ward (2003) also highlighted the shortage of physiotherapists and occupational therapists in Ireland, which indicates that this problem is also affecting some developed countries.



### **2.2.2.1 Rehabilitation service provision in the Western Cape Province**

To enhance the application of the principles encompassed in the INDS, in the Western Cape Province, the Integrated Provincial Disability Strategy (IPDS), was formed (Office of the Premier, WP, 2002). The IPDS aims to apply the principles of the INDS at all levels of service delivery as far as rehabilitation and issuing of assistive devices is concerned. The document also emphasises the shift from institution-based to community-based rehabilitation services supported by secondary and tertiary services.

The Comprehensive Service Plan for the Implementation of Health Care 2010 (CSP) was established in the Western Cape Province to further strengthen the development of community based services. The plan aims for better quality and more accessible care for many people within their communities. The goal of rehabilitation under the CSP is to enable individuals to return home to their communities with the highest possible level of functional independence and the best possible quality of life (DOH, WP, 2007). The plan recommends the following interventions at the primary health care level of rehabilitation:

- Follow-up of all patients discharged from hospitals.
- Screening and assessment (including screening for Disability Grants).
- Education, training and support of the patient, family and primary care- givers/home based carers.
- Low-intensity rehabilitation rendered by, at least physiotherapists and/or occupational therapists for at least 1-2 hours per person/day but not necessarily every day.

- Establishing adequate and safe systems of nutrition, respiration, skin preservation, joint maintenance and bladder and bowel management.
- Therapeutic and support groups.
- Correct prescription and issue of wheelchairs, including correct postural seating, together with the necessary pressure relief cushions.
- 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 and safety (DOH, WP, 2007 p. 71).

It is important to note that the CSP is still in the process of being implemented; therefore some of the aspects of rehabilitation service provision at CHCs are not yet as recommended. Given the shortage of rehabilitation personnel working at the CHCs it is also challenging for the few who are there to meet these recommendations. As of September, 2009 there were 17 physiotherapists and 9 occupational therapists offering services at all the CHCs in the Cape Town Metro Health District (C. M. De Wet, Chief Physiotherapist, CTMHD, personal communication, 12 September, 2009).

### **2.3 Clients' Experiences of Rehabilitation Services**

In the past, persons with disabilities used to be passive recipients of rehabilitation services, with the service providers making all the decisions on their behalf (Swain & French, 2001). However, with the emergence of the social model of rehabilitation, which enhances the control and status

of the client as opposed to control and status of the service provider in rehabilitation, there has been a shift from relying on the service providers' opinions to seeking what the clients think about the services they receive (Wressle, 2002). Getting to know clients' experiences regarding rehabilitation services is important to inform client choice (Danielsen et al. 2007) which in turn might enhance the effectiveness of the services.

Most of the research on persons with disabilities' experiences of rehabilitation and health care services was done in European countries and in the United States with only a few done in Australia, Asia and Africa. However, there is some consistency emerging across studies done within these different continents, with regard to the dimensions of rehabilitation and health care that clients talk about when reporting their experiences.

The Picker Survey Instruments, which were developed from extensive interviews with more than eight thousand patients, family members and caregivers, have become the standard for measuring patients' experiences of rehabilitation and health care in the United States, Canada, Great Britain, Germany and Sweden (Picker Institute, 2008). The instruments measure experiences regarding the following: respect for patient's values, preferences and expressed needs, coordination and integration of care, information, communication and education, physical comfort, emotional support, involvement of patient, family and friends, transition and continuity and access to care. The 56-item Measure of Processes of Care (MPOC) also includes some of the dimensions of care mentioned above but this instrument mainly focuses parent's perceptions of specific behaviours of health care professionals who provide rehabilitation to children with disabilities (King S, King G and Rosenbaum 1995).

In this chapter, the author looked at the clients' experiences regarding dimensions of rehabilitation services that are most common in literature, which also formed the basis of the objectives of the present study. In addition to getting knowledge relating to the participants' experiences of rehabilitation in the setting of the present study, the choice of these dimensions also highlighted on how clients' experiences in other countries compare to those in South Africa. The present study determined clients' experiences of rehabilitation regarding the following dimensions: accessibility of the services, service provider interaction with the clients, involvement of the client in the rehabilitation process, family support and involvement in the rehabilitation process and provision of information.

It is important to note that although presented in a discrete fashion, the aspects of rehabilitation considered in the present study are by no means separate from each other. There is an overlap between most of them, for instance the quality and type of information given by the service providers may determine the degree of involvement of the clients because information can empower the clients to have a say in their rehabilitation. Attitudes of service providers and availability of information may also influence accessibility of the services as discussed later.

### **2.3.1 Accessibility of the services**

Accessibility is the extent to which aspects of society can be equally, easily, safely and appropriately used or reached by people with special needs or impairments. These aspects include buildings, facilities, constructed spaces, transport, information, equipment, services,

activities, resources, utilities, language, communication and technology (SAHRC, 2002). The NRP document in South Africa emphasises on the relationship between accessibility and success of rehabilitation services by stating that the fewer barriers there are, the more successful the rehabilitation process is likely to be (DOH, 2000).

Kroll, Jones, Kehn and Neri (2006) conducted a qualitative exploratory study in the United States of America to investigate access barriers to obtaining preventative health care services for adults with physical disabilities and to identify strategies to increase access to these services. The participants in this study reported a variety of barriers that they experienced in accessing primary preventative services. The authors classified these barriers into two categories, namely: structural/environmental and process barriers. They described the structural/environmental barriers as conditions in the physical and social environment in which services are delivered. These include lack of ramps and parking spaces at buildings where services are held, inaccessible examination rooms and equipment needs (for example; adjustable-height tables, scales that accommodate wheelchairs, inaccessible washrooms), and the unavailability of needed transport services.

Kroll et al. (2006) described process barriers as difficulties that people experience in the course of service delivery, the most commonly cited difficulties being; convenience of care, receipt of preventative teaching, and aspects of communication between providers and clients. In addition to the process barriers mentioned by Kroll et al. (2006), sitting at the facilities waiting for appointments, scheduling appointments (Coughlin, Long & Kendall, 2002) and length of

sessions (Bowers et al. 1996; Iezzoni, Davis, Soukup & O'Day, 2002) have been reported as barriers by persons with disabilities.

Of the two categories of barriers described above, this section of the literature review mainly dwells on the experiences related to structural barriers. Clients' experiences of process barriers, though not directly, are discussed in the subsequent sections namely, interaction with service providers, client involvement in the rehabilitation and information provision.

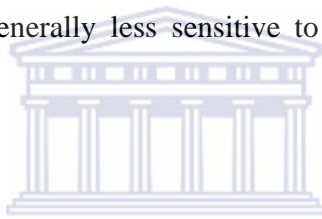
Clients with physical disabilities in previous studies complained about inaccessible environments that hinder them from successfully receiving health care and rehabilitation services (Bowers Esmond, Lutz & Jacobson, 2003; Levins et al. 2004). In the United States of America, Bowers et al. (2003) conducted a qualitative study to determine what persons with physical disabilities think about primary health care services they received. The authors reported that it was common for clients with physical disabilities to receive substandard care because primary health care doctors' offices and clinics often lacked accessible examination tables and scales and because narrow doorways and cluttered exam rooms prevented entry of wheelchairs. This study however made use of in-depth interviews of which some were done face to face and some via the internet with participants recruited via online lists of persons belonging to associations of persons with disability. Use of online interviews might have discriminated against those who did not have access to internet due to their low social status and could have been experiencing the services differently. The research also looked at primary health care facilities offered by general practitioners and specialist physicians whose offices and clinics might have been designed without the persons with physical disabilities in mind.

In South Africa, the main reported barrier to accessing rehabilitation services is transport. At one of the CHCs in Cape Town, De la Cornillere (2007) conducted a study to determine experiences relating to attendance and non-attendance to a stroke group using a mixed methods design. This study found that transport problems were the main negative influence to attending group therapy sessions among the stroke clients. Transport difficulties in this study were mainly related to financial constraints or absence of an attendant to propel the wheelchair. The clients mentioned high cost of transportation charged when they asked for lifts from friends and neighbours. De la Cornillere (2007)'s study is however limited in that it only focused on one CHC and twenty participants. Therefore, the findings cannot be generalised to the whole of the Cape Town Metro Health District. Similarly, Whitelaw et al. (1994) conducted a survey to determine whether a weekly stroke round would determine the rate of referral for rehabilitation at a tertiary hospital in Cape Town. They reported that rehabilitation of stroke patients at this hospital was unsatisfactory because of poor attendance due to transport problems.

The survey by Scheneider et al. (1999) in South Africa found that transport in this country is generally not geared for persons with disabilities. Participants in this survey expressed frustration about being unable to lead a normal life, get to school, hospital or work due to accessibility problems. In support of the findings by Scheneider et al. (1999), the participatory research by Clacherty, Matshai and Sait (2004) in five provinces within South Africa to determine experiences of disability and service provision among children with different types of disabilities and their caregivers, found that use of public transport was problematic among the participants. This was worse among children from rural areas, especially those using wheelchairs. The

mothers of the children with disabilities in this study also complained that the clinics were too far for their children.

Similar to the findings by Clacherty et al. (2004), Iezzoni, Killeen and O'Day (2006) in the United States of America, found accessibility of the rehabilitation and health care services in terms of transport generally more problematic among rural residents than their urban counterparts. The study found that for rural residents with physical, sensory and psychiatric disabilities, available public transport was often inaccessible or unreliable and because most of them could not drive, they faced difficulties getting to their service providers. The interviews perceived that rural areas were generally less sensitive to disability accessibility issues than urban areas.

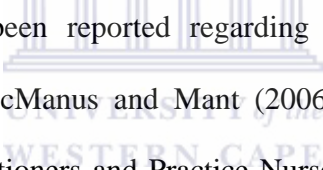


Financial problems were reported in several studies as a hindrance to accessing services among persons with disabilities (Bowers et al. 2003; Levins et al. 2004). Bowers et al. (2003) conducted in-depth interviews with persons with physical disabilities in the United States to investigate how they perceived the primary health care services they received. Sixteen of the interviews were face to face and 19 were done electronically (via internet). The authors reported that persons with disabilities were more than twice as likely as people without disabilities to postpone seeking health care. This was because they lacked the money to pay and they were four times as likely to have health needs that were not covered by insurance. However, Bowers et al. (2003)'s study can be criticised in that 19 of the participants were interviewed online, which could have limited the researcher's chances to probe the interviewees and get a better understanding of their experiences. In South Africa financial problems related to high costs of hiring private transport



were reported which negatively influenced attendance to the rehabilitation services (De la Cornillere, 2007).

Time spent with the service providers was highlighted as an important dimension of care to the clients. Bowers et al. (1996), in the United States conducted interviews to determine persons with physical disabilities' (mostly those with cerebral palsy and spinal cord injuries) perspectives on quality of health care that they received from physicians. Many participants in their study expressed a desire to increase the time that they were allowed to spend with the health care providers, especially due to the fact that some of them had slow speech and needed more time to express themselves.



Positive experiences have also been reported regarding accessibility of the rehabilitation services. Hare, Rogers, Lester, McManus and Mant (2006) conducted a study to determine support needs from General Practitioners and Practice Nurses of patients with stroke and their carers in the United Kingdom. Most of the participants in their study were satisfied with the accessibility of the primary health care services. They reported that they were able to secure appointments without delay and they could arrange home visits without any problems. In their study however, only 27 of the 82 patients who had initially given consent to participate ended up participating which makes it difficult to tell whether those who withdrew were going to give the same experiences as those who participated.

### **2.3.2 Interaction of Service Providers with the Clients**

The manner in which the service providers relate to clients with disability is a major issue that clients talk about when they report their experiences of rehabilitation and health care. Research has shown that in general, patients care more about the quality of their everyday interactions with health care professionals than about how the service is organized (Steine, Finset, & Laerum, 2001; Roush, 1995). Roush (1995) conducted a quantitative study with 81 patients with multiple sclerosis in the United States of America to determine the patients' satisfaction with physiotherapy and occupational therapy using the Therapist Evaluation Form. The participants reported that they valued therapists' rapport issues than their technical skills, and they valued therapists who were friendly and caring. These results indicate the importance of interpersonal aspects of patient therapist relationships for persons with disabilities.

Swain and French (2001) wrote a chapter in Albrecht et al. (2001) on the relationship between persons with disabilities and health and welfare professionals. They state in this chapter that the evidence from research and the writings and recollections of disabled people suggests that relationships between health professionals and persons with disabilities are varied but can be experienced as dehumanizing and abusive by the latter. Swain and French (2001) also cited Ellis (1993) who found that disabled persons with knowledge of their entitlements were frequently viewed as 'grabbing', demanding or fussy. Practitioners preferred disabled persons who accepted with gratitude what was on offer and described those who challenged this as manipulative. Similarly, Barnes and Mercer (2003) stated in their book that disabled people on both sides of

the Atlantic claim that they perceive their relationship with professionals to be hierarchical, with professionals' intent on reinforcing their own power and the powerlessness of disabled people. The existence of these hierarchical relationships negatively influences the clients' involvement in their rehabilitation as discussed in 2.3.3 below.

Poor communication between service providers and clients has been a major complaint from people with disabilities. In the report based on interviews with individuals with physical disabilities and their caregivers, conducted in the United States, persons with physical disabilities identified communication with service providers as an important issue (Bowers et al. 1996). The participants complained that they were not given the opportunity to communicate and the service providers were not ready to listen and to consider the participants' knowledge, experience with and wisdom about their disability. The authors added that the physically disabled participants reported a high level of sensitivity to what they perceived as unspoken cues conveyed by health care professional in reaction to their physical presence. These included distancing behaviours such as avoiding eye conduct, touching only when required by direct bodywork, and sitting at a distance beyond what is perceived as appropriate for social interaction. This report however, did not indicate any procedures followed to ensure trustworthiness of the qualitative research design used.

In addition to the dimensions of rehabilitation mentioned above, lack of emotional support is another aspect that keeps on recurring when clients report their experiences regarding their interaction with service providers. Lerner (1997) in the United Kingdom reported that although the people with severe physical disability had major physical health problems, for example three

out of four had pain every day; their predominant concern was for help with emotional problems. In the same vein, Swain and French (2001) in the United Kingdom reported that the most common complaint from interviews with women with spinal cord injuries was the health and welfare professionals' lack of concern with emotional issues. The women reported little or no help in coming to terms with paralysis and often felt compelled to be cheerful and play a particular role.

Hammel (2007) conducted a meta-analysis of qualitative studies done regarding rehabilitation experiences of clients with SCI and cited a study by Morris (1989) in which complaints about poor communication and lack of emotional support from service providers were common. It is apparent from the literature that although the persons with disability need physical rehabilitation to become functionally independent in society, emotional support is also a pertinent issue to their needs and this is common among persons with disabilities from different countries.

However, contrary to the negative experiences regarding service providers' interaction with persons with disability mentioned above, Morris et al. (2007) reported that patients and carers in their study praised the physiotherapists' positive attitudes and reported high levels of commitment of the latter. In the same study, lack of emotional care was not identified as a problem. This study was however conducted with patients with stroke who were still in the acute phase of rehabilitation delivered in the acute and rehabilitation wards. These participants' experiences could have differed from most of the participants in other studies because the other studies looked at experiences of persons with disabilities who were receiving out-patient services and had long gone past the acute phase. Similarly, Payton and Nelson (1996) in their evaluation

of clients' perceptions of physiotherapy reported very positive responses from some of the participants regarding their interpersonal relationships with therapists. The participants described the therapists as 'absolutely wonderful' with 'lots of compassion'.

In South Africa, De la Cornillere (2007) reported that participants in their study highly commented the therapists' friendliness, politeness and love. Some even mentioned that it was the therapists' positive attitudes that kept them coming to the stroke group. The study however, was conducted by someone who was one of the service providers at the CHCs where the study was conducted. Therefore, the participants could have given the praises in fear of alienating their service providers.



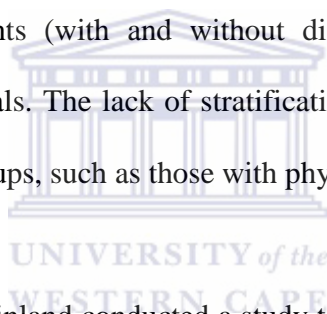
### **2.3.3 Client involvement and participation**

Client participation presupposes that the service providers base all interventions on the wishes and needs of the patient and inform the patient about alternative methods of treatment (Wressle, 2002). The treatment and care should be designed in cooperation with the individual since the clients' perception of their rehabilitation needs sometimes differ from the professional's perception of the clients' needs (Lund, 2004). The individual receiving the services has to be seen as a worthy contributor and perceive a feeling of confidence to be able to participate in planning. However, there can be ambiguity as to how much clients are able to participate and when they need instruction and direction. This gives the service providers responsibility to consciously seek to understand each patient's needs regarding involvement and to plan accordingly (Payton, Nelson & Hobb, 1998).

Amongst the studies that looked at clients' experiences of rehabilitation, the reported experiences regarding client participation in rehabilitation vary widely and it is apparent that not all clients worry about their lack of involvement. A study conducted in Sweden by Lund, (2004) using in-depth interviews to explore persons with spinal cord injuries' experiences of rehabilitation, found that some of the clients had surrendered the planning of their rehabilitation to the professionals and some said they shared the planning with the professionals throughout the rehabilitation. On the contrary, some of the participants in the same study complained that they wanted to be involved but they had limited opportunity to influence the planning and decisions.

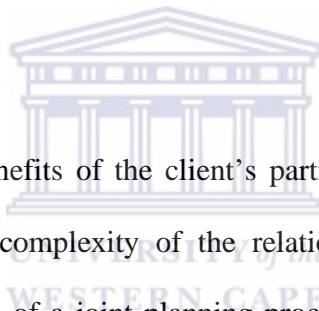
Payton and Nelson, (1996), conducted semi-structured interviews with twenty patients in four physiotherapy clinical settings in United States of America to explore patients' perceptions of their involvement in goal setting, planning treatment and assessing outcomes. The authors reported that most of the patients interviewed liked things the way they were, whether or not they felt involved in the decision-making process. However, the same study discovered that although many patients do not appear to want to be involved, those who are involved are more satisfied with their health care experience and have better therapeutic outcomes. Payton and Nelson (1996) gave a detailed description of the procedure followed to ascertain trustworthiness of their study. Their study included use of private rooms for interviews, tape-recording and peer debriefing and involvement of both researchers in the analysis of data until they reached consensus on the results of the study, all of which could have increased trustworthiness of the study.

There are also studies in which participants reported that they felt as if the service providers were imposing their programmes on them. Oliver et al. (1988), as cited by Hammel, (2007), reported that some of the participants with spinal cord injuries in their study felt that the rehabilitation process was akin to a 'conveyer belt', that there was little opportunity to participate in decision making and that it was standard procedure to do certain things. Similar findings were reported by Payton et al. (1998) whereby several participants complained about lack of involvement in decision-making concerning their rehabilitation. One man in this study reported that he experienced physical therapy as a 'prison camp' in which he was ordered by tough therapists. The study conducted by Payton et al. (1998) however can be criticised in that it involved a wide spectrum of physiotherapy patients (with and without disabilities) receiving physiotherapy services at two community hospitals. The lack of stratification reduces comparability of results with studies involving specific groups, such as those with physical disabilities.



Talvitie and Reunanen (2002) in Finland conducted a study to determine the interaction between physiotherapists and patients in stroke rehabilitation by video-taping nine physiotherapy sessions, which were followed by a discourse analysis. The results of this study showed that physiotherapists typically used oral communication to organise and guide exercises and the patients mostly responded to the instructions given. The physiotherapist scheduled the course of treatment but did not talk to the patients about goals of therapy except for rare occasions on which the patients took the initiative. Unfortunately the physiotherapist had difficulty giving patients the opportunity to express their goals. However, the participants in this study might have lacked confidence to express themselves because of the presence of the video-tapes.

In addition to the reported experiences regarding participants' involvement and participation in rehabilitation, Wressle (2002) mentioned factors that hinder clients from participating in the rehabilitation process, albeit the opportunities given to them to participate. The author argued that sometimes clients may lack confidence or the opportunity to question given information, to disagree with the direction of intervention, or cultural issues may hinder the client from taking advantage of their opportunity to participate. The author went on to add that some elderly people are not used to making demands on care, relying instead on the knowledge of the professionals and simply waiting for treatment. Wressle (2000) concluded that the strategy for overcoming these is to enhance communication, advocacy with and for the client, and moderate the demands for decision-making.



Despite the norms for and the benefits of the client's participation in rehabilitation, evidence from research indicates that the complexity of the relationship between the client and the professional can affect the success of a joint planning process (Lund, 2004) and this has been highlighted in 2.3.2 above. Glueckauf (1993), as cited by Payton & Nelson (1996) argued that most rehabilitation professionals support the notion of facilitating independence, but few include the disabled person directly in the rehabilitation process.

#### **2.3.4 Family support and involvement**

South Africa's Integrated National Disability Strategy states that it is critical to note the impact of disability not only on the disabled individual but also the family and the immediate community (Office of the Deputy President, 1997). The document highlights on the importance



of involving the family in any form of rehabilitation that the disabled individual receives in-order to enlighten the family on the disability and to reduce the burden of care on the latter. There has not been however as much research done on persons with disabilities' experiences regarding family support and involvement in rehabilitation as that done on experiences regarding involvement of the persons with disability. Only a few scholars looked at family support in rehabilitation and in these studies the family members were the informants (Hare et al. 2006; Morris et al. 2007).

In a study conducted by Hare et al. (2006), one caregiver (daughter of the client) described a situation where she had not been told how to manage her mother's incontinence, which left her feeling incompetent, frustrated and extremely stressed. It was recommended in the same study, that the wider primary care team needs to be alert to psychological and emotional problems, particularly anxiety and lack of confidence within the families of persons with stroke and give necessary support. This study however focused on services offered by general practitioners and practice nurses, who might have concentrated on the medical needs of the clients and ignored their disability.

In the focus group by Morris et al. (2007) done with stroke patients and their carers, the carers of patients with stroke expressed their 'burden of care' whereby they had to compensate for the perceived shortfalls in the care of their relatives, for example when the patient needed something and the staff were not there to attend to that need. The carers said this would sometimes bring them into conflict with service providers. Some of the carers in this study also reported that the service providers were not ready to allow them to give insight into the status of the patient, for

example what the patient could or could not do. However, since only six carers participated in Morris et al. (2007)'s study, there is a possibility that more focus group interviews could have given different dimensions of experiences.

Gerteis, Edgman-Levitan, Daley & Delbanco (1994) interviewed over 6000 hospital patients and 2000 care givers from 62 hospitals across the United States of America and most of the patients in this study felt that their families were left out of the information system and they often experienced a poor transition from hospital to community care. This study provided the evidence that lack of family support and involvement can be a barrier to a smooth transition from hospital to the client's home environment. Similar findings were reported in South Africa by Clacherty et al. (2004) in participatory workshops to determine the experience of poverty, disability and service delivery among children with physical disabilities. Mothers in this workshop reported that lack of information was one major problem that made it difficult for them to access poverty reduction programmes like the disability grant. However, Clacherty et al. (2004)'s study focused on children and carers from five provinces, both from urban and rural areas and their report did not give a clear distinction of the informational experiences of participants from different backgrounds.

### **2.3.5 Provision of information**

In rehabilitation of persons with disabilities, the need for information has been reported by the clients as the one least fulfilled by the service providers. This was mainly information about the disability and the services available to improve quality of life for persons with disability (Lui and Mackenzie, 1999; Clacherty et al. 2004; Hare et al. 2006; Morris et al. 2007). Ironically, besides

being the least fulfilled, the need for information appears to be the one most echoed by the clients.

Persons with disabilities have reported that they often struggle to get information about services that are available, support groups, or even information about their disability. Morris et al. (2007) conducted focus groups to explore the experiences of patients, carers and staff of a hospital based stroke service in the United Kingdom. The patients in this study were persons with stroke who were receiving rehabilitation services in an acute stroke unit and in stroke rehabilitation wards. Services were offered by a multi-disciplinary team which included doctors, nurses, physiotherapists, OTs, psychologists and social workers. The patients reported that individual information about the stroke and treatment and what to expect after discharge were highlighted as problem areas and lack of this information engendered anxiety. On the contrary, some of the participants in the same study reported that they received excellent information, though the nature of the information was not specified. Morris et al. (2007)'s study however could be criticised on the basis that they did not distinguish between the clients' experiences regarding information provided by the different service providers, which can be attributed to the differences in the participants' views.

Lui and Mackenzie (1999) interviewed 15 elderly stroke patients in China to identify their rehabilitation needs following stroke and in their setting, the most frequently stated but largely unmet need was information, particularly information about the reasons for stroke and about activities that promote recovery. Some of the patients in this study reported the need for written information that they could use at home. They went on to add that gaining knowledge helps the

clients as a means of controlling their feelings of powerlessness. Similarly, Hare et al. (2006) found that the general consensus in all focus groups and interviews done with stroke patients to identify their needs from community care was the need for more information. In this study the stroke patients wanted information about adaptations to property, benefits advice, appropriate exercises, points of contact, opportunities to network, surviving a stroke and preventing further strokes.

Levins et al. (2004) conducted a qualitative study in the United States of America to determine individual and societal influences in participating in physical activity, which is a crucial component of rehabilitation. In this study, the participants with spinal cord injuries reported lack of information regarding availability of resources to be a hindrance to participation. Similarly in Canada, Pentland, McColl and Rosenthal (1995), found that persons with long term spinal cord injuries reported a lack of information and research available to plan services that are designed to meet their needs.

Garrat et al. (2006) developed a questionnaire to measure psychiatric out-patient rehabilitation experiences among patients attending 90 Norwegian clinics using a literature review, patient interviews and pre-testing of the questionnaire. They found a correlation between the reported experiences of rehabilitation and the patients' perceptions of the quality of information received. In this study, patients who did not think they were informed about the complaints procedure or access to their records had poorer experiences than their counterparts did. Steine et al. (2001) in the United Kingdom also found that the direction and rating of experiences of healthcare were mainly influenced by the information received from service providers which they referred to as

the 'take home message.' This included information regarding insight, knowledge, results and feelings after meeting with service providers. However, there is minimal information in literature on studies of this nature that look at the relationship between information received by the clients and the latter's general experiences of the services.

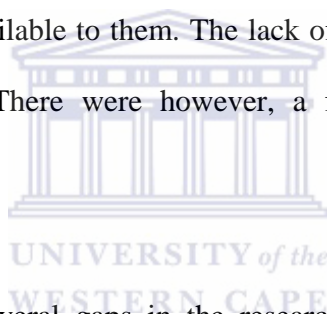
There were also studies done in South Africa in which the participants expressed positive responses regarding information provided by rehabilitation service providers. At one of the CHCs in Cape Town, De la Cornillere (2007) found that the participants had learnt a lot from the educational talks given by the service providers though the nature of information given in the talks was not specified. As mentioned before, the fact that the author was an occupational therapist at this CHC could have introduced bias in the participants' responses, with fear of alienating their service provider. Similarly in South Africa, Njoki (2004) also found that the participants in her study with spinal cord injury were positive about information given by health professionals and this was mainly information about health risk behaviours and complications that could arise.

## **2.4 Summary**

The literature review highlighted that in the United States and in Europe, some of the clients struggle with structural barriers when accessing health care rehabilitation services. Transport was the main problem facing persons with disabilities in accessing rehabilitation services in South Africa and also among rural residents in the United States of America. In some studies done in America and the United Kingdom, relationship of persons with disabilities with rehabilitation

services providers was described as hierarchical, with the former reinforcing their power on the powerless disabled persons. On the other hand, there have been positive findings regarding interaction with service providers in some studies done in the same countries and in some of the previous studies done in South Africa. There are variations in findings regarding persons with disabilities' involvement in rehabilitation, with some participants in Europe echoing that they are not concerned about getting involved.

Experiences regarding provision of information by the service providers are mainly negative with most participants complaining about lack of information that they need regarding their disability and support services available to them. The lack of information is common in Europe and in South African settings. There were however, a few positive experiences reported regarding information provision.



The literature review revealed several gaps in the research done on clients' experiences of rehabilitation. Firstly most of the studies were done in the United States of America and Europe, with only a few done in other continents, more so in Africa. Secondly there are many studies looking at persons with disabilities' experiences of health care in general, not specifically rehabilitation, though the health care services to some extent involve rehabilitation. Most of the studies reviewed looked at persons with disabilities' experiences regarding services offered by medical practitioners and a few included OTs and physiotherapists. Thirdly, most of the studies also looked at experiences of stroke clients and this applies to two of the few studies done in South Africa. The experiences of persons with other diagnoses like spinal cord injury, head injury, amputations have not received enough attention.

The studies mainly used qualitative research methods which have been found to be more appropriate for exploring participants' experiences (Hammell, Carpenter & Dyck, 2000) as opposed to quantitative methods. However, use of mixed methods research could have provided a more comprehensive picture of the topic of enquiry in these studies (Avis, 1995) than that given by one method alone. The fact that most of the studies used qualitative methods raises the question of generalisability of these studies and therefore requires one to be cautious when comparing the results.

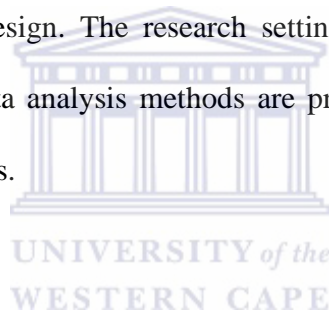
The instruments that include some of the aspects of rehabilitation which the participants were asked about in the present study like the Picker Survey Instruments (Picker Institute, 2008) and the Measure of Processes of Care (King et al, 2004; Bjerre et al, 2004) looked at other groups of participants like somatic in-patients and parents of children with disabilities therefore could not be used in the present study. These instruments however provided some of the information that was incorporated in designing the questionnaire used in the present study.

## CHAPTER THREE

### METHODOLOGY

#### 3.0 Introduction

This chapter presents a background of the methodology used in the present study. A mixed methods design was utilised, in the form of a sequential exploratory strategy. This chapter describes the sequential exploratory strategy used followed by a detailed description of the qualitative phase of this study design. The research setting, inclusion and exclusion criteria qualitative data collection and data analysis methods are presented. The chapter ends with an outline of the ethical considerations.



#### 3.1 Research setting

The study was conducted in the Cape Town Metro Health District of the Western Cape Province in South Africa. This district is an urban area that has eight geographically defined health sub-districts namely: Tygerberg, Klipfontein, Khayelitsha, Mitchells Plain, Eastern, Northern, Southern, and Western sub-districts. Within these sub-districts, there are 42 Community Health Centres (CHCs) and 31 of them offer rehabilitation services. The CHCs that offer rehabilitation services are distributed as shown in table 3.1 below.



**Table 3.1 Distribution of CHCs within the eight sub-districts**

| <b>Sub-district</b> | <b>CHCs</b>   | <b>Total</b> |
|---------------------|---|--------------|
| Tygerberg           | Bishop Lavis, Delft*, Elsie's River*, Kasselsvlei, Parow, Ravensmead, Ruyterwacht | 7            |
| Klipfontein         | Dr Abdurahman, Hanover Park, Heideveld*, Guguletu*                                | 4            |
| Khayelitsha         | Khayelitsha Site B*, Michael Mapongwana, Khayelitsha Site C*                      | 3            |
| Mitchells Plain     | Mitchells Plain*, Crossroads  | 2            |
| Northern            | Kraaifontein*   | 1            |
| Southern            | Grassy Park, Hout Bay, Lady Michaelis, Lotus River, Retreat*                      | 5            |
| Western             | Robbie Nurock, Vanguard, Woodstock, Green Point, Kensington, Maitland             | 6            |
| Eastern             | Macassar*, Rusthof, Strand  | 3            |
| <b>Total</b>        | 31  | 31           |

\*CHCs that were involved in the present study

The CHCs are primary health care facilities which provide comprehensive services including promotive, preventative, curative and rehabilitative services. The services offered at CHCs include antenatal care, reproductive health, chronic disease care, tuberculosis management, HIV

and AIDS facilities, mental health, oral health, rehabilitation and disability services, occupational health, casualty and maternity services (DOH, WP, 2007).

According to the PHC package (DOH, 2001) the specific rehabilitative services rendered at the CHCs in South Africa include:

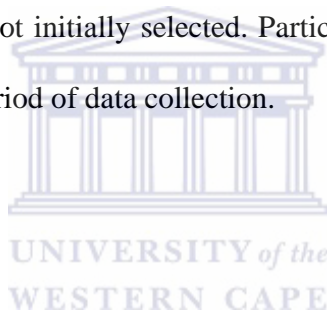
Basic assessment of people with disabilities for example, stroke, spinal cord injury, cerebral palsy, developmental delay, blindness, communication problems, arthritis, amputations, backache, followed by an appropriate treatment programme, in consultation with the disabled person and his family. Consumable assistive devices, for example, continence devices, rubber ferrules and other aids to daily living are prescribed, provided and people trained in their use. Management of continence problems of patients with spinal cord injury, mental retardation, spina bifida, traumatic conditions and the elderly includes the supply of continence devices and devising continence programmes. Patients are also assessed for disability and care dependency grant applications. (p. 57).

The rehabilitation services at the community health centres are mainly in form of physiotherapy and occupational therapy offered individually or in groups. Due to shortage of rehabilitation personnel, some of the centres have a physiotherapist at least once a week and an OT at least once a month. Speech therapy students from two of the local universities offer services at two of the centres (Vanguard and Bishop Lavis), during their clinical rotations.

The centres only offer rehabilitation services to those clients who come by referral and these referrals are usually from specialised rehabilitation centres, tertiary hospitals, secondary

hospitals, private doctors, industries, home based carers and private physiotherapists and occupational therapists. All the rehabilitation services at the CHCs are offered free of charge (C. M. de Wet, Chief Therapist, CMHD, personal communication, 8 September 2008).

To select CHCs to be involved in the present study, the non-probability purposive sampling was used (Domholdt, 2000). The centres selected were those offering physiotherapy services for at least three days per week and OT for at least once a week. Participants could not be found at two of the selected centres every time the researcher contacted the therapists (Hanover Park and Woodstock) and the researcher decided on adding three more centres (Macassar, Delft, Khayelitsha, Site C) which were not initially selected. Participants could not be found from the Western District throughout the period of data collection.



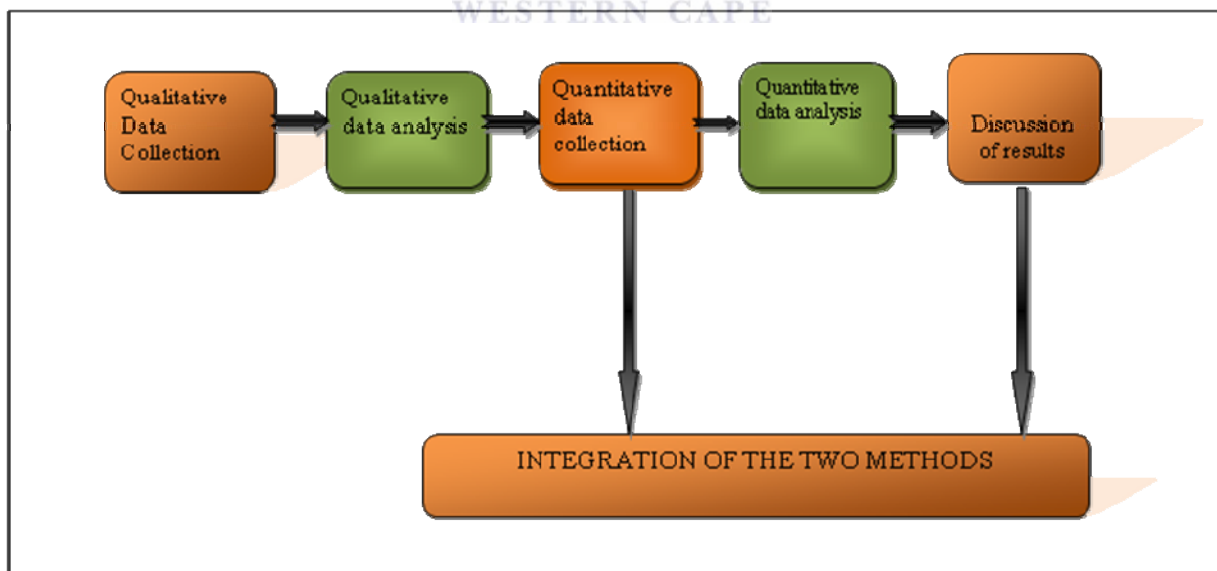
### **3. 2 Study design**

The mixed methods design was used in the present study. As indicated by Cresswell, Fetters and Ivankova (2004), this form of research is more than simply collecting qualitative and quantitative data. It indicates that data will be integrated, related or mixed at some stage of the research process to yield a more complete analysis. In this design, the two methods are meant to complement each other.

According to Cresswell (2009), there are three general strategies used in mixed methods research and they have several variations within them. The three strategies are the sequential, concurrent and transformative mixed methods strategies. In the present study, the sequential exploratory

strategy was used. In this design, qualitative data collection and analysis precedes quantitative data collection and analysis that builds on the results of the first qualitative phase and the first phase is generally given more weight (Cresswell, 2009).

The primary focus of the sequential exploratory strategy is to explore a phenomenon that has not been researched before and it uses quantitative data to assist the interpretation of qualitative findings. The phenomenon in the current study refers to the experiences of persons with physical disabilities regarding rehabilitation services and only minimal literature is available regarding this subject in Cape Town Metro Health District and in South Africa at large. The strategy is also useful to expand on the qualitative findings using the subsequent quantitative findings (Pope & Mays, 1995; Creswell, 2003). The sequence followed in integrating the two methods in the present study was as illustrated in Figure 3.1 below.



**Fig 3.1 Sequence followed in integrating the two methods**

The two methods were integrated during quantitative instrument development (whereby results from the qualitative phase informed the designing of the questionnaire) and in the discussion of results.

The qualitative part of the methodology is going to be discussed next and the quantitative part will be described in Chapter Five.

### **3.3 Qualitative research methodology**

Qualitative research has been described by Pope and Mays (1995) as the development of concepts which helps the researcher to understand social phenomena in natural rather than experimental settings giving due emphasis to meanings, experiences and views of the participants. In the present study the understanding of phenomena (participants' experiences of rehabilitation services) is enhanced by the quantitative or numeric description of trends followed by the quantitative results presented in Chapter Six.

#### **3.3.1 Qualitative research sample**

The non-probability purposive sampling method was used to select individuals to participate in the in-depth interviews. This method allows the researcher to make a deliberate choice of a sample that is representative of the study population's characteristics (Bowling, 2002). Ten individuals were purposefully selected to take part in the in-depth interviews following consultations with the therapists and looking at the client records to see the common disabling conditions and the trends regarding age and gender of their clients with physical disabilities. The

first available client who met the inclusion criteria was interviewed and the researcher stopped after reaching data saturation which occurred after the tenth interview. Age, gender and diagnosis were the characteristics considered for purposive sampling. Availability of contact details also influenced the selection of participants since some of those who were eligible to participate did not have telephone numbers and addresses which were needed in order to follow them up.

### **3.3.2 Inclusion criteria**

Since this was an exploratory study, inclusion criteria were very broad and the following were included:

- Persons with physical disabilities who had received rehabilitation services at the CHCs.
- Persons with physical disabilities who had received at least three rehabilitation sessions at the CHC.
- Age range was between 18 and 70 years. This age range was chosen to include adults who would have been able to provide personal experiences. Children might have required their parents to answer for them and adults above the age of 70 years might have forgotten their experiences due to dementia and other conditions which affect one's memory in old age.

### **3.3.3 Exclusion criteria**

The following were excluded to participate in the study:

- Persons with physical disabilities and severe cognitive and communicative disabilities.

- Persons with any other disabilities beside physical disability.

### 3.3.4 Qualitative data collection

Qualitative data collection was conducted in form of face-to-face in-depth interviews to explore the experiences of the participants regarding the rehabilitation services they received at the CHCs. The interviews were purposeful conversations in which the participants were allowed to freely express themselves on what they thought regarding different aspects of their rehabilitation process (Greef, 2002). An interview guide (Appendix E), was developed from an extensive review of the literature (Bowers et al. 1996; DOH, 2000; Swain & French, 2001; Cott et al. 2006; Garrat et al. 2006; Morris et al. 2007) and consultation with experts in the field of disability and rehabilitation. The interview guide asked questions about the services received, interaction of service providers with the persons with physical disabilities, participation of clients in the rehabilitation process, involvement of family members, accessibility of the services and type of information given to the persons with physical disabilities.

The interviews started with a general question to set the motion of the conversations which allowed the participants to openly express themselves without being directed by the researcher and the question read *“Tell me what your life has been like ever since the time you got disabled, how has disability impacted on your life?”* This question was relevant to all the participants since all of them had acquired disabilities when they were already adults so they could remember most of their experiences from the time they were disabled.

The conversations allowed the participants to speak in their own words and they were made as comfortable as possible. The interviews were concluded with a general question; “*What else can you tell me about your rehabilitation at the Community Health Centre?*” This was to encourage the participants to talk about anything that they might not have said in the interview that could provide the researcher with more information.

### **3.3.5 Procedure for the qualitative phase of the study**

Ten participants were purposively selected to participate in the in-depth interviews. The researcher arranged with the therapists for appointments to go to the CHCs to look at client records. The clients who were eligible to participate were selected from the records and contacted telephonically by the researcher, to explain the purpose of the study and ask the clients if they were willing to participate. Appointments were made at a time and date convenient to the participants to meet with the researcher at the CHC or at the participant’s workplace.

Although it is recommended that qualitative researchers collect their data while the participants are in their ‘natural setting’ (Babbie & Mouton, 2001), in the present study the researcher avoided going into the homes of the participants for safety reasons. The researcher however gave all the participants who came to the CHCs for interviews money for transport. The interviews were also done in private rooms where the participants had no fear of being overheard by the service providers.

Six of the interviews were conducted in English by the researcher and the remaining four were conducted in Xhosa by a trained Xhosa speaking research assistant. The interviews lasted an



average of forty-five minutes. The interviews were conducted in quiet rooms that were private, comfortable, and non-threatening to the participants.

### **3.3.6. Trustworthiness**

Trustworthiness was described by Lincoln and Guba (1985) as establishing the “truth value” of the study, that is, its neutrality, applicability and consistency. To ensure trustworthiness in the present study, the criteria of credibility, transferability, dependability and confirmability were followed as described below.

**Credibility:** This construct is analogous to internal validity and demonstrates that the inquiry was conducted in such a manner as to ensure that the subject of inquiry was accurately identified and described (de Vos, 2002). In the present study, the interview guide was developed after the researcher conducted a thorough literature search to find out what most clients have reported as their experiences in health care and rehabilitation. Peer debriefing was done by colleagues specialised in the field of disability and rehabilitation to give their opinion on what kind of questions could be asked in the interviews. The same individuals also reviewed the interview transcripts and the researcher’s interpretations .

The participants were interviewed in languages of their own choice and the interviews were tape-recorded and transcribed verbatim. According to de Vos (2002), tape recording allows a much fuller record of the interviews than just taking notes and it allows the researcher to concentrate on the proceedings of the interview.

The interviews were conducted in quiet rooms that were private, comfortable, and non-threatening to the participants and the researcher made sure there were no interruptions.

The use of triangulation, as postulated by Babbie and Mouton (2001), is generally considered to be one of the best ways to enhance validity and reliability in qualitative studies. In the present study, the involvement of different participants from different CHCs and the subsequent use of quantitative methods achieved data triangulation and methodological triangulation respectively (Bowling, 2002).

**Dependability:** According to Babbie and Mouton (2001), this is analogous to reliability, that is, the evidence that if the inquiry was to be repeated with similar respondents in the same context, its findings would be similar. Since there can be no validity without reliability, demonstration of credibility is sufficient to establish the existence of dependability (Lincoln & Guba, 1985).

**Transferability:** This is the extent to which the findings can be applied in other contexts or with other respondents (Babbie & Mouton, 2001). In the present study, the participants were purposively selected to ensure that the characteristics of the larger population were represented. To ensure sufficient detail and precision, thick description of the results were given, using verbatim quotations to preserve meaning of the participants' responses.

**Confirmability:** This refers to the objectivity of the study, or the degree to which the findings are the product of the focus of the inquiry and not the researcher's biases (Babbie & Mouton, 2001). In the present study, the researcher was a neutral someone in the sense that she had

minimal experience of working with persons with disability at primary care level. Peer reviewing of the interview guide and interview transcript also directed the researcher to keep focused on the subject of inquiry.

### **3.3.7 Qualitative data analysis**

Analysis of data began with verbatim transcriptions of all the interviews. The transcripts were then compared to the voice recordings to verify accuracy. A professional translator then translated the Xhosa transcripts to English and another translator read the translated scripts, comparing them with the original Xhosa transcripts to verify accuracy.

After all the transcriptions and translations were completed, the researcher carefully read all the transcripts several times to get a general sense of the information and to reflect on the overall meaning of the participants' words (Cresswell, 2003).

Data were coded into predetermined themes, which were; general experiences, accessibility, interaction with service providers, client involvement and participation, family and caregiver involvement and information provision. The only emerging theme was 'organisation of rehabilitation sessions.'

Information under each theme was then coded into different categories for example; waiting time for appointments, transport, entering into the CHC and reception were all categorised under the

theme 'accessibility'. Corresponding verbatim quotations were written under different categories to avoid losing the original meaning of the participants' words.

### **3.4 Ethical considerations**

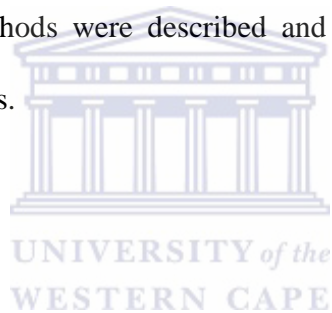
Permission to carry out the study was granted by the Senate Research and Study Grant Committee of the University of the Western Cape (Appendix D). The director of District Health Services and Programmes of the Western Cape District Health Services (Appendix C) also granted permission for the study to be conducted.

Participant information was kept confidential and the interview transcripts, questionnaires and tape recorder were kept away in locked cardboards. Throughout the study, participants were given the names C1 to C10 instead of their actual names to preserve anonymity. The purpose of the study was explained to the participants in form of detailed participant information sheets (Appendix M). The information sheets explained that participation was completely voluntary and that participants could withdraw from the study at any time and this would not influence their rehabilitation in any way. Written informed consent was obtained from all the individuals who participated or their caregivers, in case of those who could not write. Before each interview, permission to record the interviews was sought from the participants. The researcher ensured support counselling for any of the participants who could have been negatively affected by the research. The researcher also included her contact details and those of the research coordinator in the information sheet so that anyone with questions or queries could be able to contact them.

Results of the study will be made available to the rehabilitation staff at the CHCs, where participants can access them and to the Western Cape District Health Services and Programmes Office in form of written reports.

### **3.5 Summary**

This chapter presented an outline of the methodology used in the present study. The research setting and inclusion and exclusion criteria are described. A description of the mixed methods design used was given, together with the procedures followed in collecting the qualitative data. The qualitative data analysis methods were described and lastly, the chapter ended with an outline of the ethical considerations.



## **CHAPTER FOUR**

### **QUALITATIVE RESULTS**

#### **4.0 Introduction**

This chapter presents the findings of the qualitative phase of the study which used in-depth interviews as the method of data collection as described in Chapter Three. A brief presentation of the participants' demographic information, which comprises of their age and gender, is given together with their disability related information. Presentation of results relating to participants' experiences, beginning with their general experiences of disability, followed by their experiences of rehabilitation at CHCs is given. Direct quotations of the participants' statements are given to preserve the participants' original words that relate to specific themes.

#### **4.1 Participants' demographic characteristics and disability related information**

Table 4.1 below summarises the participants' demographic characteristics and disability related information.

**Table 4.1 Participants' demographic and disability related information**

| <b>PARTICIPANT CODE*</b> | <b>GENDER</b> | <b>AGE (years)</b> | <b>DIAGNOSIS</b>                | <b>TIME SINCE ACQUIRING DISABILITY (years)</b> |
|--------------------------|---------------|--------------------|---------------------------------|--|
| C1                       | Female        | 50                 | Stroke                          | 0.25   |
| C2                       | Male          | 33                 | Head injury                     | 4  |
| C3                       | Male          | 48                 | Spinal cord injury (paraplegia) | 18   |
| C4                       | Female        | 65                 | Stroke                          | 0.25   |
| C5                       | Female        | 63                 | Stroke                          | 0.5  |
| C6                       | Female        | 47                 | Below knee amputation           | 1  |
| C7                       | Male          | 54                 | Head injury                     | 2  |
| C8                       | Male          | 53                 | Spinal cord injury (paraplegia) | 3  |
| C9                       | Male          | 49                 | Head injury                     | 2  |
| C10                      | Male          | 50                 | Spinal cord injury (paraplegia) | 11   |

\*Participants were given the codes C1 to C10 instead of their actual names to preserve anonymity.

The sample for the qualitative phase of this study consisted of 10 persons (6 male and 4 female) with physical disabilities who had received rehabilitation services at CHCs. Their age ranged from 33 to 65 years with a mean age of 51 years (standard deviation= 8.9). Three of the participants had suffered spinal cord injuries, three had suffered head injuries, another three had suffered stroke and one had right below knee amputation. The period after acquiring disability ranged between 3 months and 18 years.

#### **4.2 Experiences of rehabilitation services received at CHCs**

The study aimed to explore the participants' experiences regarding the rehabilitation services they received at CHCs in Cape Town Metro Health district. Pre-determined themes, which were in line with the objectives of the study, were used to analyse the data from the in-depth interviews. The pre-determined themes were as mentioned above in 3.7.1. There was one main emerging theme, 'Organisation of rehabilitation sessions,' which is also going to be presented in this chapter.

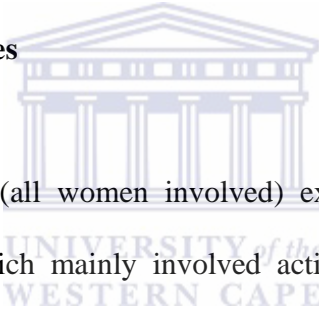
Although not part of the aims and objectives of the present study, the researcher asked for the participants' general experiences of disability as a general opening question to start the motion of the interviews. The results from this theme are going to be presented in 4.3 below.



### **4.3 Participants' general experiences of disability**

Under this theme, the participants mentioned several issues of concern that affected them since they acquired disabilities. The fact that one could no longer perform the roles they used to perform before acquiring disability was the central subject that participants talked about regardless of their age, gender or disabling condition. The main sub-themes that arose under this theme were: inability to perform activities of daily living (ADLs) and household chores, loss of employment, sexual dysfunction, society's attitudes, depression and emotional pain.

#### **4.3.1 Inability to perform activities**



The majority of the participants (all women involved) expressed deep concern about their inability to perform activities which mainly involved activities of daily living (ADLs) and household chores. Participants expressed the problems they encountered when performing activities like ironing, dressing up, gardening and cooking. The following quotations relate to the participants' experiences regarding performance of ADLs and household chores:

*"... everything has changed, I can't cook. I like to do 2 or 3 things you know, I always work, I would do my own work at home like ironing, I am left handed and the stroke is on the left side my whole life has changed. I can't iron I can't tie my scarf or do my buttons you know I can't sweep, everything is just changed emotionally also because when you want to put washing on the line I can't or I want to sweep I can't do it." (C1, stroke).*

*“I am not used to sitting like this I used to be up and about and now I look and I see my garden is going down but I can’t do anything because... ” (C4, stroke).*

*“I want to make biscuits and cakes for us but I can’t.”(C5, stroke).*

*“Oh very bad, I can’t do anything for myself, I try and make my self strong and I say I must do this and that around the home but I tell you its so hard, I try to work for myself but my hand is still dead and...” (C2, head injury).*

Failure to perform different tasks as mentioned above affected some of the participants emotionally. The fact that the participants failed to perform the activities they used to do before acquiring disability left some of them feeling hurt and some expressed that they felt depressed. These emotional feelings were expressed in the following quotations:

*“... but when I get home I have to do this and I have to do that and I can’t do it, then I feel so depressed, maybe if I wasn’t that active before and I was a person that like to sit and relax then I would be happy ...” (C1, stroke).*

*“I was hurt badly because everything I used to do is on stand still because I can’t do anything for myself” (C7, head injury).*

*“I was badly hurt because I couldn’t walk.” (C10, paraplegia).*

In addition to the emotional pain caused by inability to perform household chores, the participants expressed financial strain since they now had to hire people to do their housework and to drive them to the hospital. This was encapsulated in the following quotations:

*“I have always done my own things and now I can’t, every time I ask someone to come and help today and the other day I have to pay, you understand what I am saying, paying is being a problem now” (C1, stroke).*

*I have to ask someone to take me to the hospital then we must pay. We pay R50, or whatever they charge, paying is the problem...” (C4, stroke).*



#### **4.3.2 Loss of employment**

Loss of employment was mainly a problem among male participants. Most of them were struggling to adjust to the “new persons” they had become, who could not do the jobs they used to do before they were disabled. The inability to return to work also affected them emotionally it also meant being unable to care for their families. Some of them could not move on to do any other job different from what they used to do before acquiring disability. The following statements relate to the participants’ experiences regarding loss of employment:

*“Yeah you see for me to be in this wheelchair it’s not easy for me because before I used to work and there was nothing wrong with me but after the accident it was very hard for me to accept this because I used to be a working person” (C10, paraplegia).*

*“I was hurt really when I found out that I’m having a disability because I was working for my family and all of a sudden I was unemployed” (C8, paraplegia).*

*“They don’t want to employ me now because I’m having a disability, and I am hurt” (C9, head injury).*

*“No I am just sitting at home doing nothing now you see for me it’s very strange because all my life I did work. I cannot do any other thing because my heart, my soul and my mind is at the sea, you see” (C3, paraplegia).*



#### **4.3.3 Societal attitudes**

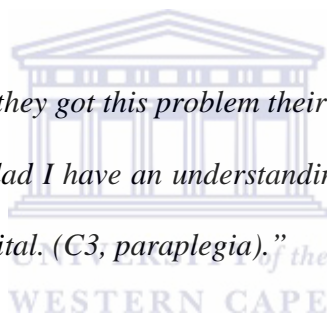
The attitudes of people in the society towards the participants’ disability were another issue raised by the participants. The majority of the participants felt that their society showed negative attitudes towards them. There was a feeling that some people treated the participants differently as compared to what they used to do before the latter were disabled. Some participants felt that the society was feeling sorry for them, pitied them and would try to go out of their way to help the participants. The following statements were said regarding societal attitudes:

*“People treat me differently man, when I see someone and someone stops next to me then they offer me a lift, although I am walking far I say I am just going to the next house. I don’t want to bother them. They go out of their way to help me. I don’t want that” (C2).*

*“Like with my child’s mum she is like turning a page she is like the back page of the book. She is like blaming everything before me. She doesn’t want me to see the child coz before I was in an accident she was like good, we were supposed to get married also.” (C7, head injury).*

However, one participant shared positive feelings about the way his wife had been so nice to him despite his disability. He expressed his sentiment in the following quotation:

*“... because some people when they got this problem their wives go that way and they go that way because of that but I am glad I have an understanding with my wife; she is very helpful she is going with me to the hospital. (C3, paraplegia).”*



#### **4.4. Accessibility of the rehabilitation services at CHCs**

The issues echoed by the participants as far as accessibility of the rehabilitation services was concerned were: transport, appointment times, reception from service providers and accessibility of the toilets.

#### 4.4.1. Transport

Transport was found to be the main issue of concern in the present study as far as accessing the rehabilitation services was concerned. The participants echoed the financial problems that they had to incur to pay for private transport, discrimination from the taxi operators and problems with walking because of their disability. The following quotations relate to the participants' financial concerns related to transport problems:

*“...My son brings me. If he can't I have to ask someone to take me to the hospital then we must pay. We pay R50, or whatever they charge, paying is the problem...” (C4, stroke).*

*“Yeah sometimes for me to get here, it's sometimes a problem because I haven't got money all the time, you see to buy petrol to come here, then I must go somewhere to get a loan for some money to come here, that is the problem” (C3, head injury).*

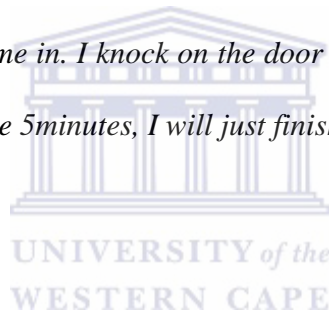
Amongst those who said they walked to the CHC, one man with head injury complained that he was having trouble with walking.

*“...I am so busy experiencing like now I am experiencing problems walking. I get tired man, but I still walk...” (C2, head injury).*

#### 4.4.2 Appointments

The participants were happy with the way the service providers received them and attended to them on time. The participants also expressed how the service providers would make it convenient for them by booking them for rehabilitation sessions on the day that they would be booked to see the doctor. The following statements relate to appointment times:

*“No there was no problem. I just walk and come there at the physiotherapy department. I knock the door and they say come in. I knock on the door to tell X (physiotherapist) that I am here and she says, “Just sit there 5minutes, I will just finish with the other patient,” and I wait for her.” (C9, head injury).*



*“You just come straight here, then you knock on the door because you have an appointment so they just let you in. They are nice.” (C4, stroke)*

*“When I have an appointment for 9 o’clock or 10 o’clock they see me on time, nothing really I can’t really say a thing you know I can’t complain they treat me well when I come here” (C1, stroke).*

*“Ah! No when I come here I just waited for about the longest an hour then they help you.”(C6, below knee amputation).*

One lady who appreciated the way her appointments were scheduled, whereby the therapists would book her on the day that she was supposed to see the doctor said:

*...so now they said I must go to see the doctor and come back to see the physio and the OT, all in one day, which is fine so I don't have to come back for each one of them.(C1, stroke).*

#### **4.4.3 Physical accessibility**

Physical accessibility of the CHCs was reported to be generally good by the participants. They expressed that there were no barriers to their movement around the CHCs. Some of them related;

*“Yeah at the gate there is no problem. Even moving around the clinic with my wheelchair, it is alright. It's ok I just pass through the doors and everywhere” (C3, paraplegia).*

*“It's ok. I have no problem with moving around the clinic (CHC) you see. The ground is ok and I can move around nicely, also the doors are wide for our wheelchairs.” (C5, stroke).*

However, only one participant, an old woman with stroke who was using a wheelchair raised a strong complaint about the accessibility of the toilets. She said;

*... “I definitely think they should do something with the toilets. Sometimes I went to the toilets, the disabled people struggle a lot. I think they can put like rails in the toilets for the disabled people so we can at least balance on that while we are moving. Sometimes we have to wait,*

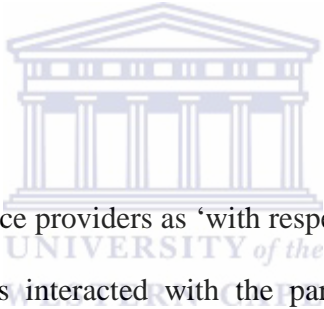


*there are two toilets and we have to wait. We need something to lean on. The space is also small in that toilet, it's not nice..." (C4, stroke).*

#### **4.5 Interaction with service providers**

All the responses given by the participants regarding their interaction with service providers were positive. The participants mentioned that the service providers respected them, communicated well with them and supported them emotionally.

##### **4.5.1 Respect for the client**



The participants described the service providers as 'with respect', 'caring and 'nice', all of which indicate that the service providers interacted with the participants in a way that the latter appreciated. The following statements relate to respect for client:

*"They treat me well and they show respect. The physio people are caring and they understand what kind of person you are regarding disability..." (C6, below knee amputation).*

*"It is the second time seeing the OT but I always come to see the physio but they both treat me well..." (C1, stroke).*

*"Ah I must say the people at the physio and at the clinic have been nice towards me. They treat me with respect ..." (C2, head injury).*

#### 4.5.2 Communication

Participants were happy with the way the service providers communicated with them. In addition to the respect shown to the participants, the service providers also communicated with a language that the clients could understand. The following statements were said regarding communication:

*“They explain because if I don’t understand I tell them, I say I don’t know what you mean and they explain and encourage me. They are very soft and they are very caring I can’t complain honestly I can’t complain” (C5, stroke).*

*“She does her job and she tells me what I must do and what must I not do and I must sit like this and I understand what she says. I haven’t got no problem with her” (C4, stroke).*

#### 4.5.3 Emotional support

The participants in the present study reported that the service providers took care of their emotional needs. Some of them said the following:

*“Yes they talk to me, what can I say? I mean they encourage me when I feel down...” (C5, stroke).*

*“When I just had the stroke I came here and she said to me when you feel like crying cry, don’t keep it in because it will make you more frustrated...”(C1, stroke).*

## **4.6 Client participation and involvement**

Participants in this study gave mixed responses regarding their participation and involvement in rehabilitation. The main issues echoed by the participants under this theme were opportunity to express rehabilitation goals, opportunity to give feedback to the service providers and explanation of activities done during rehabilitation sessions.

### **4.6.1 Opportunity to express goals**



Some of the participants stated that the service providers asked them for their goals in rehabilitation, some were even asked to write down what they expected to achieve as expressed in the following statements:

*“No. It was her who asked me last week what was the thing that I would like to do most and she told me to write it down...” (C2, head injury)*

*“Yes the physio asked me since the first time I was here every time that I came I must tell her what I want to do and like now I told her I want to sweep and she gave me this thing to use with the broom...” (C1, stroke)*

However, some participants expressed that the service providers would not ask for their priorities but would just tell them what to do or would just continue with exercises which the client was not informed about. The following statements were said by the participants who thought they were not given an opportunity to express their goals:

*“They just tell me what to do. They don’t ask me what I want” (C8, paraplegia)*

*“It’s a bit ok, but it’s also a bit not. They just do their own thing and I don’t want to come and do the same things over and over again” (C2, head injury)*

#### **4.6.2 Opportunity to give feedback to the service providers**



The participants expressed that their service providers asked for feedback from them, especially feedback regarding progression with rehabilitation as indicated in the following quotations:

*“Yes they ask me questions just like how are you doing and they write it all down. Like how I feel, do I notice any change and how the exercises at home are going?” (C6, below knee amputation).*

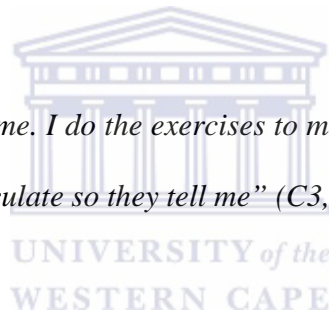
*“She first asks, where is the problem, do you feel sore here or here? Something like that and when she finishes with treatment she is asking me how I feel.” (C5, stroke,).*

*“Yeah they ask me “How are you feeling, how are you doing, how is the bladder” and I tell them I just come here for you to check on me” (C3, paraplegia).*

#### **4.6.3 Explaining activities done during rehabilitation sessions**

The participants gave mixed responses when asked whether the service providers explained the activities they did with the participants for example explaining why they did certain exercises. C3 was very enthusiastic while he talked about the exercises he had done and said he understood what the service providers did with him. He said the following statement:

*“I understand it, yeah they tell me. I do the exercises to make the blood flow since I am doing nothing and the blood can’t circulate so they tell me” (C3, paraplegia)*



On the contrary, C2 who complained that the service providers did not explain anything to him but just did “their own thing” related:

*“They just do their own thing and I just tell them sorry but I don’t know what you are doing now. You used to do this and that, last week or the month before and I don’t know this what you are busy doing now” (C2, head injury)*

#### 4.6.4 Family support and involvement

Only four of the participants had gone for rehabilitation to the CHCs with a family member. The participants expressed that the service providers explained and demonstrated to their family members how the latter were supposed to help the participants at home. The following quotations illustrate this:

*“Yes they explain to them(family), because even at home I must exercise especially when I am going to sleep I must put some cushion under this leg and continue doing what we did while I was here...” (C6, below knee amputation).*

*“Yes they do, they even show them how they can help at home to do types of exercises. She would show you if you come with someone, they say “Come and see so that you can help at home, while she waits for the next appointment this is how it must be done and this is how you do it...” (C4, stroke).*

*“Say if they are helping me with a problem then they are talking, “You see if sometimes we do this it’s for this reason, we want you to see what we are doing.” Sometimes I haven’t got money all the time you see, so they show her (wife) how to go about it at home, sometimes I don’t have to come here and she does it herself” (C3, paraplegia).*

## 4.7 Provision of information

The two main types of information that the participants were asked about in the interviews were information regarding their disabilities (causes, complications, management) and information regarding support services available for persons with disability both in their communities and in South Africa at large.

### 4.7.1 Information regarding disability

When asked whether the service providers informed them about the condition causing their type of disability, the participants gave mixed responses. Those who thought the service providers had informed them could not give much detail of what the service providers had told them. Some of them said,

*“...Yeah, they told me I won’t to be able to walk again because of this spinal cord injury, that’s all they told me, the injury was very low at L1 level...” (C3, paraplegia).*

*“...Yes they told me, they explained. I know. I know what a stroke entails, it affects my brain...” (C5, stroke).*

Others expressed that the service providers had not given them information regarding their disability. Some of them said,

*“They didn’t tell me anything that I understand but they just did the exercise on me” (C9, head injury).*

*“I don’t know what a stroke entails like how it should take to get better. I was not told that. That I don’t know” (C1, stroke).*

#### **4.7.2 Information regarding support services**

Under this theme, the participants were asked about their experiences regarding information relating to support services available for them (support groups, disability grant, vocational training) and where they could access these support services. The following statements relate to information regarding support services:

*...“ No I was not told anything about my rights or support groups or anything. I don’t know...” (C7, head injury)*

*...“No, I don’t know about those things. I don’t know where to get the information but I am too shy to ask them (service providers) ...” (C1, stroke)*

#### **4.8 Structure/organisation of rehabilitation sessions**

When asked to give general comments regarding their rehabilitation, most clients commented about the way the rehabilitation sessions were structured. The need for group therapy was a



major issue that the participants talked about, together with need for variety in exercises and need for extended time for rehabilitation sessions.

#### **4.8.1 Need for group sessions**

The following statements relate to the need for group therapy:

*“I saw in another big hospital a group exercise for people who have amputations who were playing with big balls. I was afraid thinking that I was late for the group exercise the time I started here at physio but here they just put you on the bed, I like to see where I stand with other disabled people...” (C6, below knee amputation).*

*“There must be a support group and an exercise group for us. We want to see others with disability...” (C8, paraplegia).*

#### **4.8.2 Variation in types of exercises**

One participant complained that the therapy sessions were becoming monotonous and he wanted the service providers to vary the activities that they did with him. He said,

*“It’s a bit ok, but it’s also a bit not. I don’t want to come and do the same things over and over again...” (C2, head injury).*

*“Yeah, you see I want them to do different exercises, not just the same thing all the time...”*

*(C3, paraplegia).*

#### **4.9 Summary**

Participants in this study expressed their struggle with loss of ability to perform activities they used to be involved in pre-injury. Generally, the experiences regarding their interaction with service providers and family support and involvement were positive. The participants expressed problems encountered with getting transport to travel to the CHCs, especially the high costs of hiring other people’s cars. Information received from the service providers was inadequate, particularly information regarding disability and support services available for persons with disabilities. Experiences regarding participants’ involvement in the rehabilitation were varied. However most of the participants were not concerned about whether the service providers gave them an opportunity to express their preferences or not.

## CHAPTER FIVE

### QUANTITATIVE METHODOLOGY

#### 5.0 Introduction

This chapter presents the quantitative phase of the research methodology. The research sample, data collection methods, instrumentation and data analysis methods are described. The research setting, inclusion and exclusion criteria and ethical considerations were the same as those described in Chapter Three.



#### 5.1 Quantitative research sample

The convenience sampling method was used to select the sample for quantitative data collection. This is a form of non-probability sampling which involves the use of readily available subjects (Domholdt, 2000). In the present study, it was difficult to come up with a study population from which to calculate the study sample. This was so because the rehabilitation departments record all the clients with physical disabilities in either the OT or the physiotherapy register, together with all the other conditions they see. There were no separate statistics for clients with physical disabilities. Therefore the researcher based the sample size on the statistical analysis that was going to be used as Strydom & Venter (2002) suggested that to conduct basic statistical analysis, a sample size of 30 to 100 participants is sufficient. A sample of 95 persons with physical

disabilities participated in the present study and this excluded those who had participated in the qualitative phase of the study.

## **5.2 Quantitative data collection**

An interview questionnaire designed by the researcher based on the literature review and on the results of the qualitative phase of the research was used to collect quantitative data (Appendix G). The results obtained from the qualitative phase of the study which were presented in Chapter Four were used together with an extensive literature review to inform the development of the questionnaire for quantitative data collection. Since most of the literature on clients' experiences of health care and rehabilitation was from studies done in the United States (Iezzoni et al. 2002; Bowers et al. 2003) and in European countries (Payton et al. 1998; Morris et al. 2007) use of in-depth interviews to initiate data collection also helped to highlight some aspects of rehabilitation experiences that are relevant to the South African situation. This information made the quantitative survey more informative and appropriate for the current study setting. The in-depth interviews also helped the researcher to identify the right terminology to use in the questionnaire (Pope & Mays, 1995).

According to Bless and Higson-Smith, (1995: 111) the interview questionnaire has the following advantages:

The interview questionnaire has the following advantages:

- “It can be administered to respondents who cannot read or write,

- It helps to overcome misunderstandings or misinterpretations of words or questions, as a result the answers given are clearer and all the items are considered,
- The respondents do not omit difficult questions
- The interviewer can reassure the participants and encourage them to persevere.”

The questionnaire mainly comprised of closed-ended questions and a few open-ended questions, which were included as follow-up questions for clarification of prior closed-ended questions. Closed-ended questions were used for their ease of analysis and for the fact that they provided a greater uniformity of responses (Babbie & Mouton, 2001).



## **5.2.1 Instrumentation**

### **5.2.1.1 Development of the questionnaire**

To expand on the findings of the qualitative phase, the items in the questionnaire included the same aspects of rehabilitation service provision as in the interviews. The wording of the questionnaire items was guided by the results from the in-depth interviews. There were also other items derived directly from the interviews as outlined below.

In the interviews participants expressed their need for group therapy sessions so an item was included which asked about type of therapy. Transport was highlighted as one of the participants’ main problems as far as accessing the CHCs was concerned so the questionnaire asked for the type of transport used to travel to the CHCs. Accessibility of toilets was also

another issue of concern that arose from the interviews and an item was included about this issue. Length of the rehabilitation sessions was also included in the questionnaire because some of the interview participants expressed their need to spend more time with the service providers.

It was also noted that the clients lacked information about their disabilities and the support services available to them within their communities so the section on information provision asked about these two types of information. The interview participants were also not aware of their right to ask questions during their rehabilitation sessions and some said they were shy to ask so items were included in the questionnaire to ask them if they would ask questions. The questionnaire was comprised of the following eight sections:

**Section A** included items that required demographic information of the participants. Age, gender, educational qualifications and employment status of the participants were determined. Literature suggests that these characteristics influence the health and rehabilitation clients' reported experiences and level of satisfaction (Danielsen et al. 2007).

**Section B** included items regarding the participant's disability. The participants were asked to indicate the cause of their disability and their diagnosis, for example spinal cord injury as the diagnosis and road traffic accident as the cause. Whether the participant used assistive devices or not was also determined in this section.

**Section C** included items to determine the rehabilitation services received by the participant, the period of time over which they had been receiving the services and whether they mostly

received, individual therapy, group therapy or both. This section mainly covered the first objective of the study, which was to determine the rehabilitation services received at the CHCs.

**Section D** sought information regarding accessibility of the services. The items included transport, reception given by the service providers, appointment times, length of rehabilitation sessions, location of the rehabilitation departments and the physical environment around the CHCs.

**Section E** comprised of 5 items regarding the relationship of the service providers with the participants. The title of the section was “Your interaction with the service providers”. The items were in form of statements to which the participants had to respond to using a continuous scale with 1=strongly agree, 2=agree, 3=disagree and 4=strongly disagree. The items included respect for client, emotional support and treatment of client as a complete person, not just emphasising on the disability.

**Section F** looked for information regarding the participants’ involvement and participation in the rehabilitation process. This section was structured in the same way as Section E above with 5 items to which the participants had to respond to using the scale given in section F. The items sought for information about clients’ expectations, involvement in goal setting, clarity of explanations and opportunity to ask questions. The last two items in this section were open-ended and they determined whether the participants asked questions and their satisfaction with the answers they got from the service providers.

**Section G** sought information regarding involvement of family and caregivers in the participant's rehabilitation process and only those clients who went for rehabilitation with family or caregivers had to respond to this section. This section comprised of 5 items to which participants had to respond using the following scale; 1=always, 2=sometimes and 3=never. The information included whether the service providers had helped family/caregivers to understand participant's disability, whether they were involved during rehabilitation sessions and whether they got any kind of information they might have wanted to know from the service providers.

**Section H** comprised of items regarding information provided by the service providers to the clients. This included information regarding cause of disability, possible complications and home programme. The participants had to respond using a scale similar to the one in sections E and F. The last item in this section was open-ended and it asked the participants whether they had been told about the facilities for people with physical disabilities in their communities and in the country at large. These were, support groups, organisations for persons with disabilities, disability grants and vocational training facilities.

The questionnaire was presented in the same way with the same instructions to each respondent to minimise the role and influence of the interviewer and to enable a more objective comparison of the results (Bless & Higson-Smith, 1995). The instructions were clearly explained in a language that the participants understood.



## **5.2.1.2 Validity of the Questionnaire**

### **5.2.1.2.1 Literature**

The researcher conducted a thorough literature review to get an idea of what clients talk about when describing their experiences of rehabilitation services. There was high consistency in the literature of the aspects that clients talked about when describing experiences. The information from literature and the findings of the qualitative phase of the study were used to ensure that the questionnaire had high content validity.

### **5.2.1.2.2 Peer review**

The questionnaire was subjected to a peer review after completion of the first draft, to further verify content validity. Three individuals with expertise in the field of disability and rehabilitation did the peer review. All of them were lecturing in this field with two of them having worked as physiotherapists at Community Health Centres for at least five years. The issues outlined below came up during the peer review.

It was brought to the researcher's attention that some of the clients would know the Community Health Centres as "Day Hospitals" so the two terms had to be used together in the questionnaire. Day Hospital was written in parenthesis after Community Health Centre.

It was also suggested that the researcher added a separate section to seek for information relating to cause and type of disability and assistive devices used by the participants. This was added as

section B of the questionnaire. The researcher had initially included only four options on assistive devices and the following were added after the peer review; raised shoe, AFO, callipers, none and other. The item in section F that originally read, “The therapists asked me what I wanted to achieve”, was changed to “The therapists asked me what I expected to benefit from rehabilitation” and two examples, ‘to walk’ and ‘to use my arm’ were given.

One of the reviewers suggested the addition of a section on outcome of rehabilitation but after discussing with the researcher consensus was reached that outcome would fit more in an evaluation study than this one that just seeks to explore the clients’ experiences.



#### **5.2.1.2.3 Pilot study**

Subsequent to the peer review, a pilot study was conducted with 16 persons with physical disabilities who were receiving services at Bishop Lavis CHCs. The pilot study was done to pre-test the questionnaire to see if the wording was comprehensible to the persons with physical disabilities receiving services at CHCs. It was also an opportunity for the research assistants to get some training in the field before the actual data collection began. During the pilot study, clients responded in the presence of the researcher and the research assistants so that all the items that were not clear to the participants could be noted.

The item that asked about assistive devices did not include prosthesis among the given options and one client in the pilot study sample had prosthesis. This led to the addition of prosthesis as one of the assistive device options.

Initially the item that asked for rehabilitation services received was written as a single item from which the participants had to indicate all the services they received. In the pilot study, the participants would only indicate one service. The services were therefore put separately with 'yes' or 'no' as responses so that those who received more than one type of service will indicate all of them.

When responding to the item on the length of time that they had to wait for their appointments, the participants would start talking about what happened on that particular day. This highlighted the importance of telling the participants that the study did not require their experiences of that particular day only but the usual trend of what used to happen all the other times they went to receive rehabilitation services the CHCs.

In section D, clients had problems understanding what 'the problems' were so the final version of the questionnaire had to include examples, which were; 'moving the wheelchair around', 'climbing stairs', and 'going through narrow doors'.

In section H, item 30 originally asked the clients to mention the support services for persons with physical disabilities that the service providers had mentioned to the former. The majority of the participants did not understand the meaning of the phrase 'support services' so the final item had to specify all the services so that the participants would indicate the ones they were informed about (refer to item 36 of questionnaire).

### **5.2.1.3 Test-retest reliability**

A test-retest reliability study was done with another group of 8 clients from the same centre, Bishop Lavis. The clients were requested to complete the questionnaire, which was administered again after 2 weeks. The two sets of results from these 8 participants were used for the test-retest result analysis. The researcher compared the results without using any statistical test as the sample size was too small to get significant results (Professor Madsen, Department of Statistics, University of the Western Cape, personal communication, 30 October, 2008). Consistency of the responses was very high, with only three items for which participants gave different responses in the first and second administration of the questionnaire. The three items were removed from the questionnaire and these were:

- The therapists informed me about different methods of treatment
- The therapists gave me the opportunity to express my concerns
- The therapists gave me information about the nature of my disability

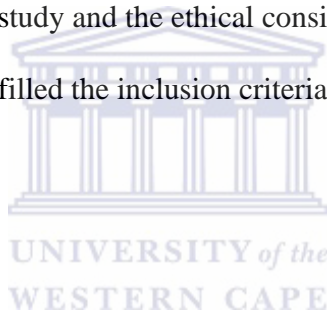
### **5.2.1.4 Translations**

The questionnaire was originally developed in English but since this was not the first language for most of the participants, it was translated to Xhosa and Afrikaans. Four translators, two whose first language was Xhosa and the other two whose first language was Afrikaans did the translations. One translator translated from English to Afrikaans or Xhosa and another one back translated to English. The translators for each language then sat down to discuss the few discrepancies that were there until consensus was reached on the final wording of the questionnaires.

### **5.2.2 Procedure for quantitative data collection**

When the questionnaire was ready, the researcher called the physiotherapists and occupational therapists at the CHCs to arrange the days and times that the researcher and the assistants would go to the centres. Days on which specific centres were having group therapy were also noted.

All the data collection was done at the CHCs. The questionnaires were administered by the researcher and the assistants after the clients come out of their therapy sessions. This was done after explaining the purpose of the study and the ethical considerations of the study and obtaining written consent from those who fulfilled the inclusion criteria.



### **5.3 Quantitative data analysis**

The SPSS version 16.0 package was used to analyse the quantitative data. Descriptive statistics in form of means, standard deviations and frequencies were calculated using this statistical package and the results were presented in form of graphs and tables.

### **5.4 Summary**

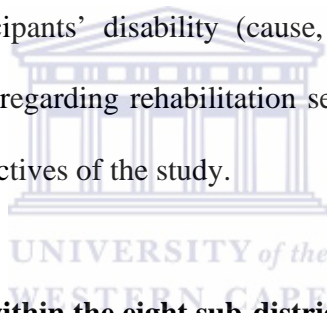
The chapter described the quantitative phase of the mixed methods design used in the present study. The research sample, instrument design and validation and data collection and analysis methods were described. The results obtained from this phase of the study will be discussed in the next chapter.

## CHAPTER SIX

### QUANTITATIVE RESULTS

#### 6.0 Introduction

This chapter presents the findings of the quantitative phase of the study. Firstly, the distribution of participants within the different sub-districts where they were receiving services is illustrated. This is followed by a presentation of the participants' demographic details. Presentation of information relating to the participants' disability (cause, type, assistive device used) then follows. Participants' experiences regarding rehabilitation service are presented under different sub-headings that relate to the objectives of the study.



#### 6.1 Distribution of participants within the eight sub-districts

The distribution of participants according to the sub-districts where they were receiving services was as shown in Table 6.1 below.

**Table 6.1 Distribution of participants within the eight sub-districts (N=95)**

| <b>Sub-district</b> | <b>Participants N (%)</b> |
|---------------------|---------------------------|
| Tygerberg           | 15 (15.8)                 |
| Klipfontein         | 2 (2.1)                   |
| Western             | 0 (0)                     |
| Southern            | 12 (12.6)                 |
| Khayelitsha         | 9 (9.5)                   |
| Mitchells Plain     | 22 (23.1)                 |
| Nothern             | 15 (15.8)                 |
| Eastern             | 20 (21.1)                 |



The total number of participants from all the sub-districts was 95. There was uneven distribution of participants within the sub-districts. The participants came from seven sub-districts. Mitchell's Plain sub-district had the highest number of clients participating in the study, followed by the Eastern sub-district. Only two individuals from Klipfontein sub-district participated in the study and no participants were recruited from the Western District throughout the period of data collection.

## 6.2 Demographic characteristics of the participants

Table 6.2 illustrates the frequencies and percentages of participants according to their demographic characteristics.

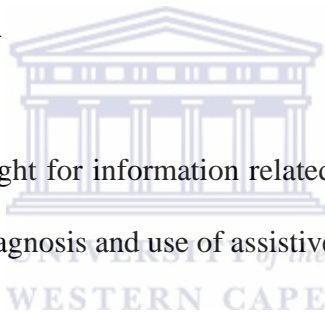
**Table 6.2 Participants' demographic characteristics (N=95)**

| <b>Variable</b>                   | <b>Category</b>     | <b>Frequency (%)</b> |
|-----------------------------------|---------------------|----------------------|
| <b>Age (years)</b>                | 18-30               | 4 (4.2)              |
|                                   | 31-40               | 8 (8.4)              |
|                                   | 41-50               | 28 (29.5)            |
|                                   | 51-60               | 27 (28.4)            |
|                                   | 61-70               | 28 (29.5)            |
| <b>Gender</b>                     | Male                | 48 (51)              |
|                                   | Female              | 47 (49)              |
| <b>Employment status</b>          | Employed            | 1 (1.1)              |
|                                   | Unemployed          | 94 (98.9)            |
| <b>Educational Qualifications</b> | No formal education | 4 (4.2)              |
|                                   | Primary             | 26 (27.4)            |
|                                   | Secondary           | 61 (64.2)            |
|                                   | Tertiary            | 4 (4.2)              |



The participants' age ranged from 18 to 70 years with a mean age of 53 years and standard deviation 11.9. The 18 to 30 years age group had the lowest number of participants and the frequency increased with increasing age up to the 41 to 50 years age group. The number of participants in each of the last three age categories (41-50, 51-60, 61-70) is almost the same. The gender distribution was almost equal. There were 48 males and 47 females. Only one male participant was employed and no female was employed. The majority of the participants (64%) had gone up to secondary school and 27% had only gone up to primary school.

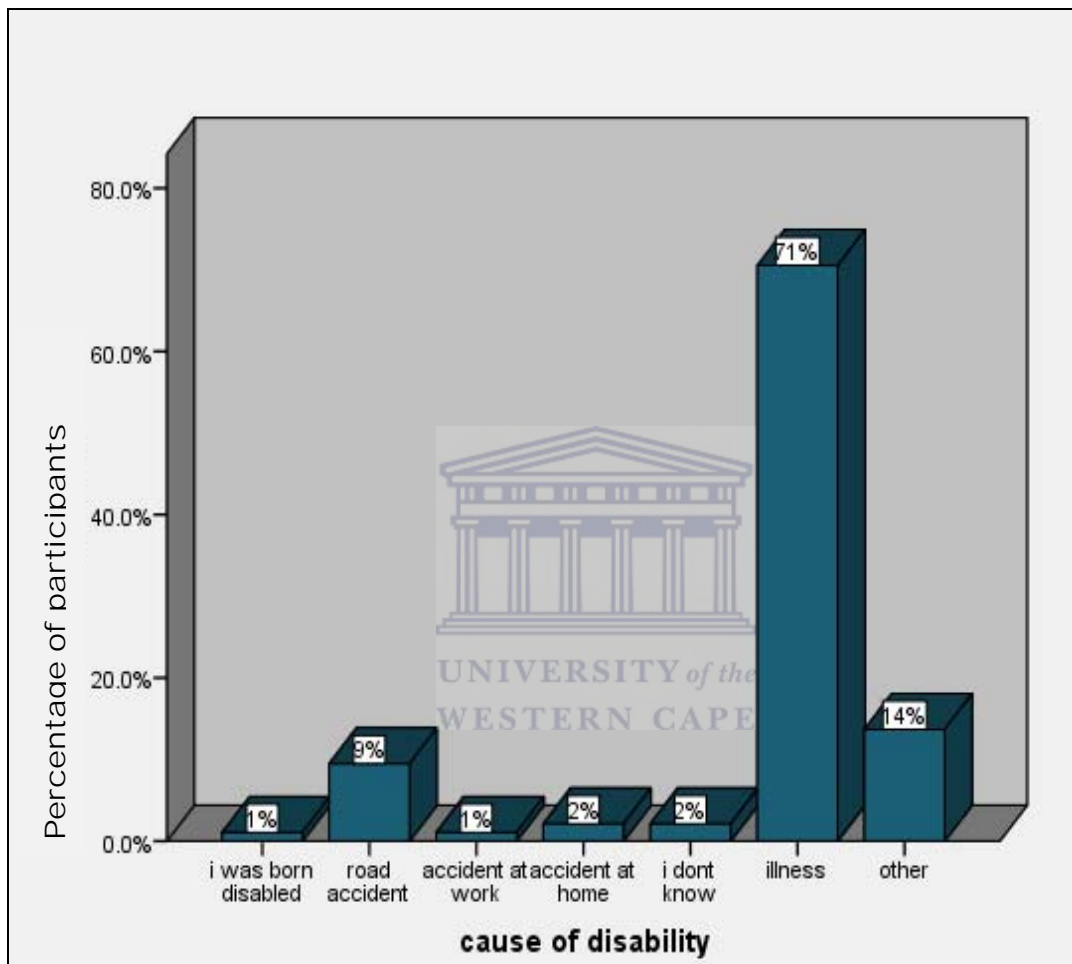
### **6.3 Disability related information**



Section B of the questionnaire sought for information related to the participants' disability. The information comprised of cause, diagnosis and use of assistive devices.

#### **6.3.1 Cause of disability**

Figure 6.1 shows the distribution of different causes of disabilities reported by the participants.



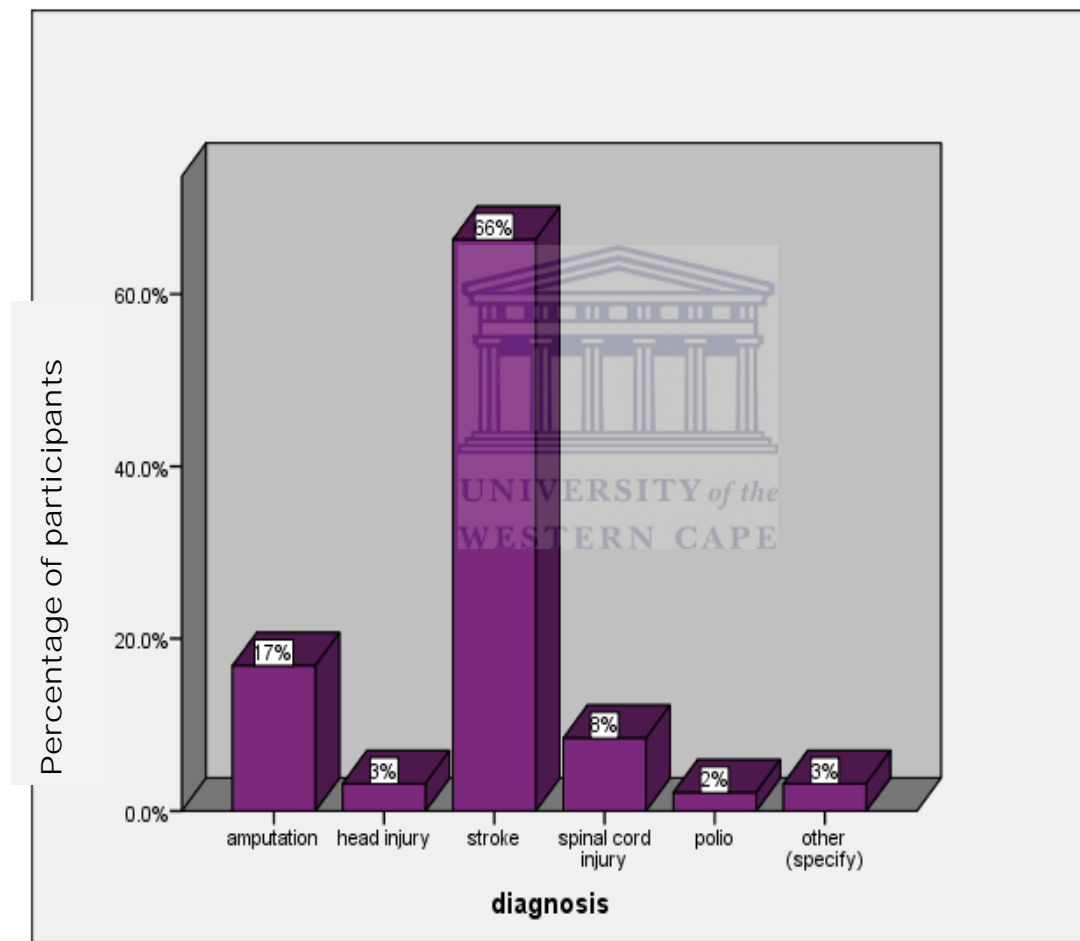
**Figure 6.1 Percentages of participants according to causes of disabilities (N=95)**

The majority of the participants (71%) reported that their disability resulted from illness. The kinds of illnesses specified in the open ended question included cardiovascular diseases, diabetes, polio, meningitis, and systemic lupus erythmatosus. ‘Other’ followed with a proportion

of 14% with stress and violence as the specified causes within this category. Road accidents were the cause of disability for 9% of the participants.

### 6.3.2 Diagnosis

Figure 6.2 illustrates the percentages of participants based on their diagnoses.

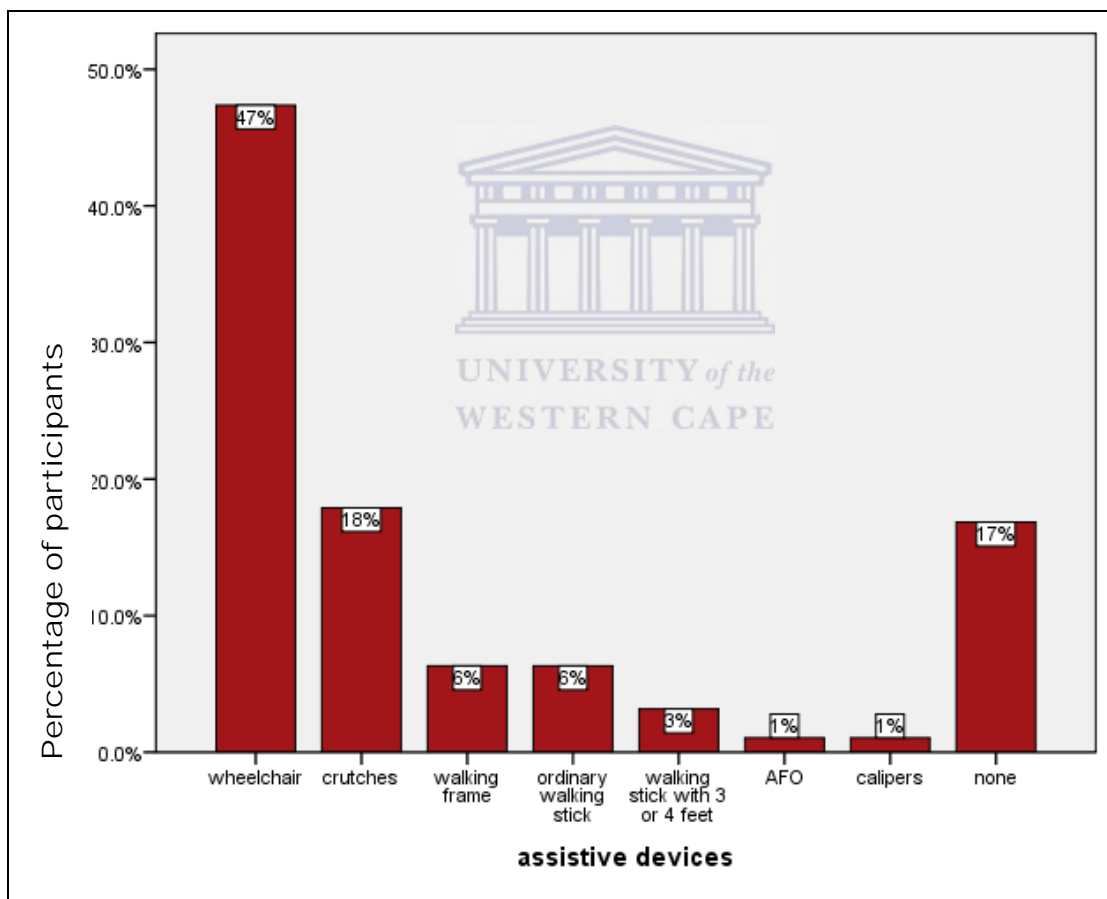


**Figure 6.2 Percentages of participants according to diagnosis (N= 95)**

The majority of the participants in this study (66%) had suffered stroke. This was followed by those with amputations and spinal cord injuries. The specified responses under 'Other' were Parkinson's disease and systemic lupus erythmatosus (SLE).

### 6.3.3 Use of assistive devices

Figure 6.3 illustrates percentages of participants based on the assistive devices they were using



**Figure 6.3 Percentages of participants according to the assistive devices they were using**

**(N= 95)**

Eighty three percent of the participants were using assistive devices. The wheelchair was the most common assistive device used by the participants and it was used by 47% of them. This was followed by those using crutches who made up 18% of the sample. Seventeen percent were not using an assistive device.

## **6.4 Findings related to rehabilitation services received at the CHCs**

### **6.4.1 Rehabilitation services received by the participants**

The items that sought for information regarding rehabilitation services received were put separately for each type of service in the instrument because some of the participants had received more than one service. The rehabilitation services were physiotherapy, occupational therapy (OT) and speech therapy.

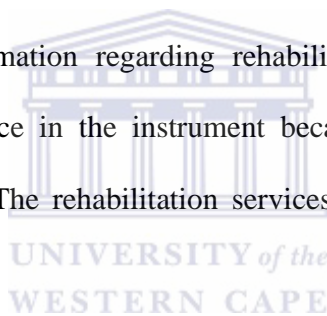
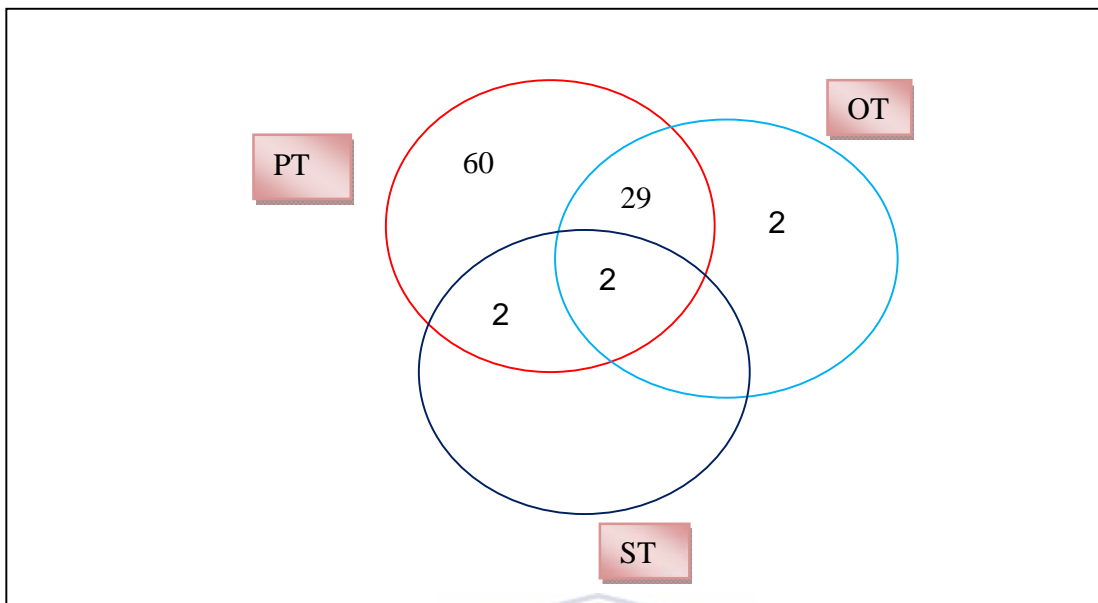


Figure 6.4 illustrates the frequencies of participants who received each of the three types of services, indicating those who received more than one type of service. PT stands for physiotherapy, OT for occupational therapy and ST for speech therapy.

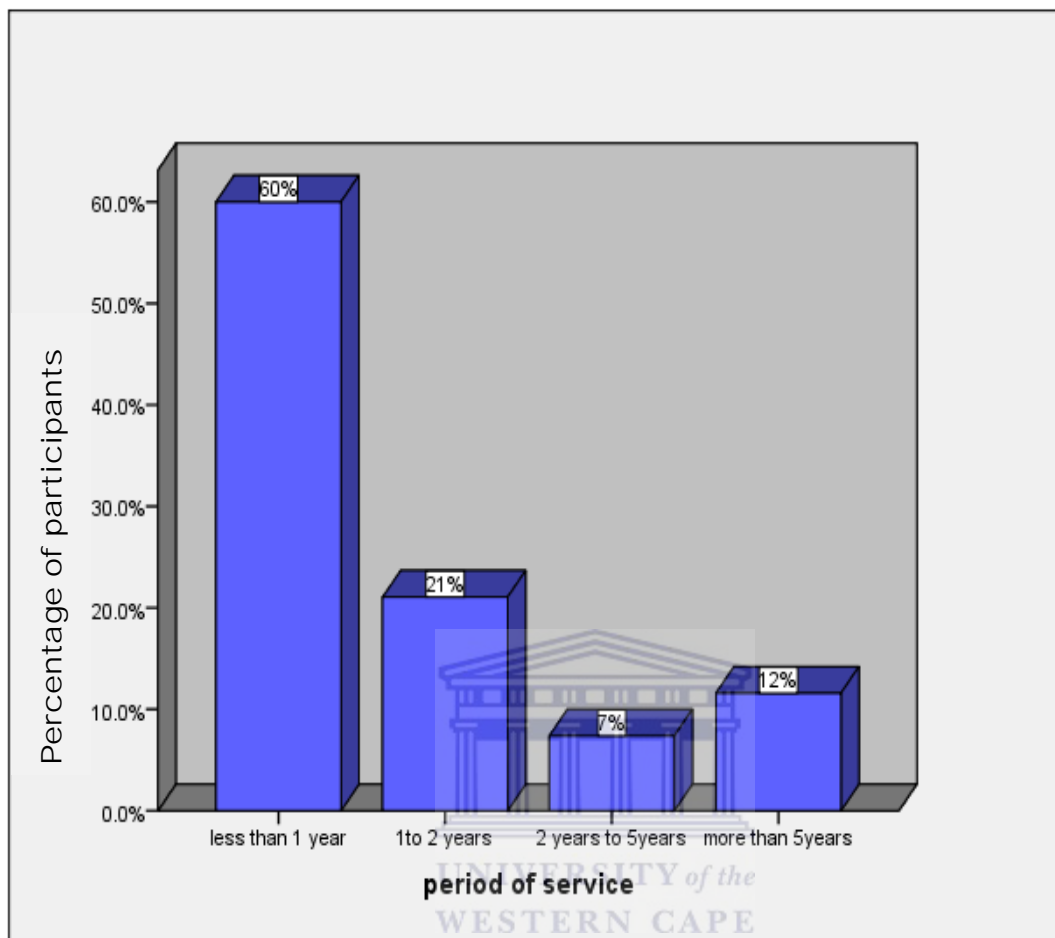


**Figure 6.4 Distribution of participants according to type of services they received (N=95)**

Only 2 of the participants had received all the three types of services. Physiotherapy was the service received by the majority of the participants, followed by OT and only 4 participants had received speech therapy.

#### **6.4.2 Duration of receiving rehabilitation services**

Figure 6.5 illustrates the different periods of time that the participants had received rehabilitation services at the CHCs.

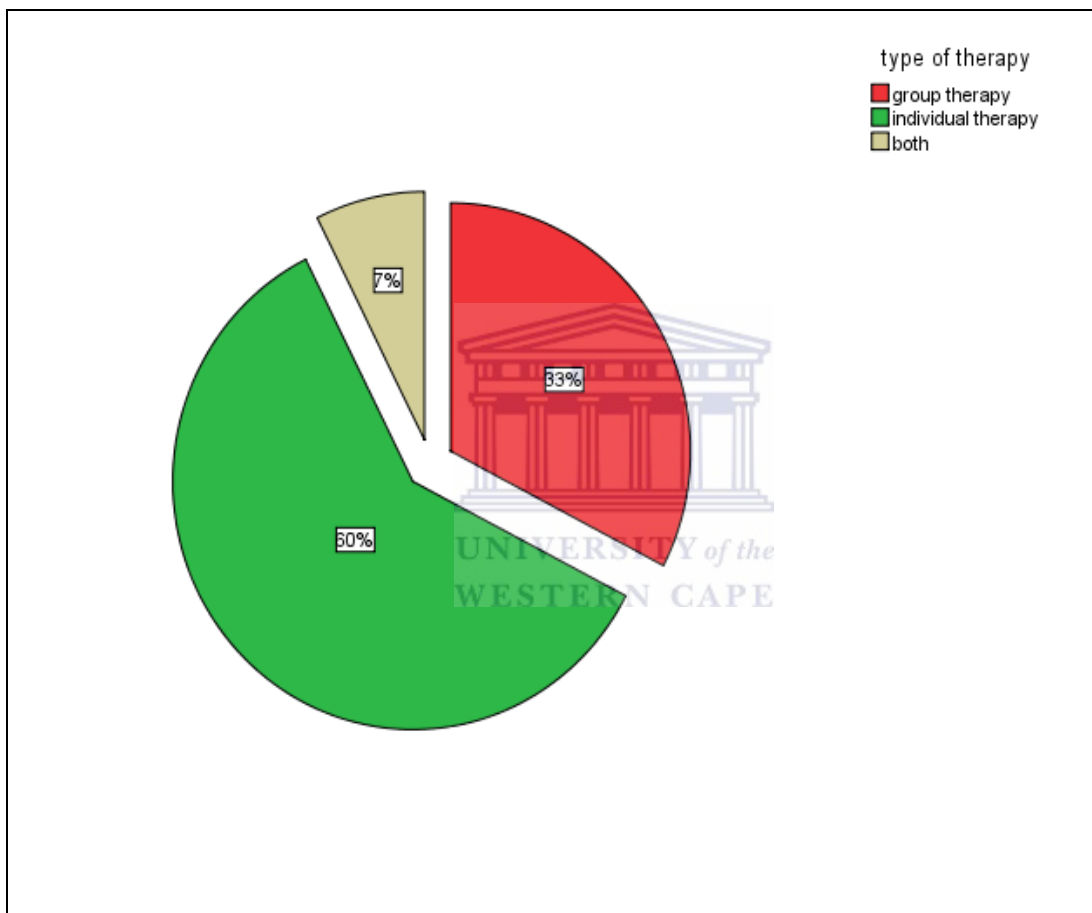


**Figure 6.5 Percentages of participants showing period of time which they had received rehabilitation services at CHCs (N=95)**

The general trend was that the percentages of participants decreased with increasing length of time. Sixty percent of the participants had received services at the CHCs for less than one year, and amongst these the majority had received services for three months or less.

### 6.4.3 Type of therapy

Figure 6.6 illustrates the percentages of participants based on the type of therapy they were receiving.



**Figure 6.6 Percentages of participants showing the types of therapy they had received**

**(N=95)**



The majority of the participants had received individual therapy (60%), followed by 33% who had received group therapy. Only a few had experiences of both group and individual therapy.

## **6.5 Accessibility of the rehabilitation services at CHCs**

In the present study, accessibility was determined by transport used to travel to the CHCs, reception given by the service providers, time spent waiting for appointment and time spent with the service providers during each session and physical accessibility of the CHC environments including toilets.

### **6.5.1 Transport used by participants to travel to the CHCs**

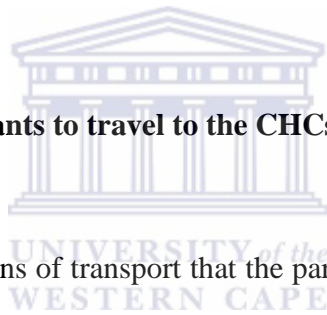
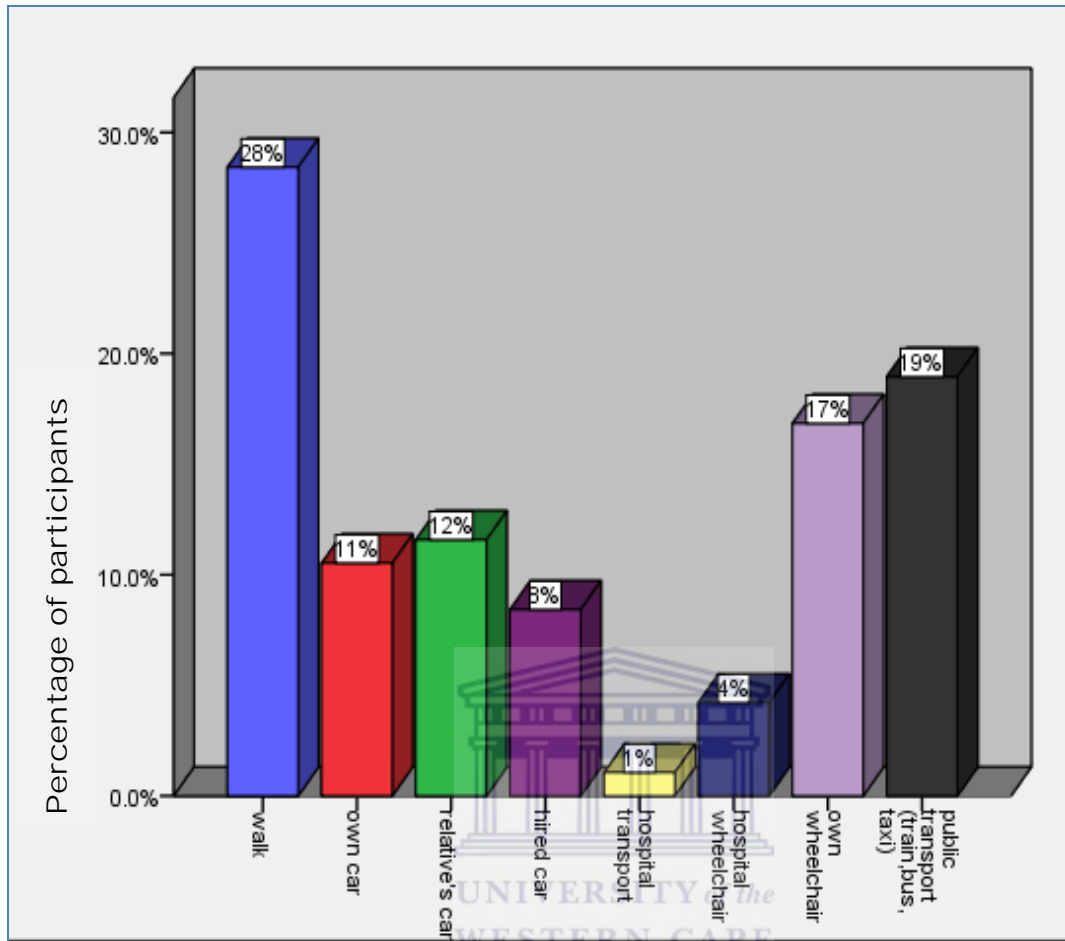


Figure 6.7 shows the different means of transport that the participants were using to travel to the CHCs



Means of transport

**Figure 6.7 Means of transport used to travel to CHCs (N= 95)**

The participants were using a wide variety of means of transport. The highest proportion was made up of those who walked to the CHCs (28%), followed by those who were using public transport in form of buses, trains and commuter minibuses (19%). A total of 21% were using either personal wheelchair or hospital wheelchair to travel from their homes to the CHCs. Others were using private cars which were hired (8%), owned by relatives (12%) or personal cars (11%).

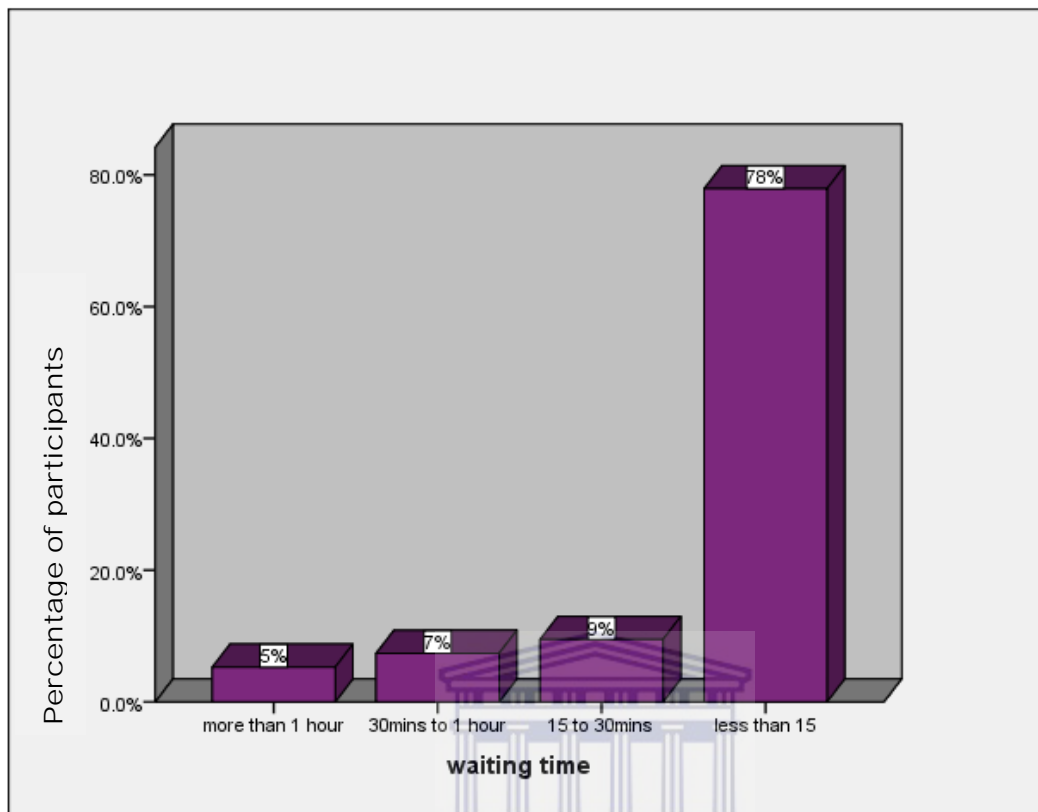
### **6.5.2 Reception from service providers**

All the participants reported that the service providers made them feel welcome on arrival at the rehabilitation departments.

### **6.5.3 Time spent waiting to see the service providers the appointment day.**

Figure 6.8 illustrates the percentages of participants against the times that they had to wait to receive services when they went to the CHCs.



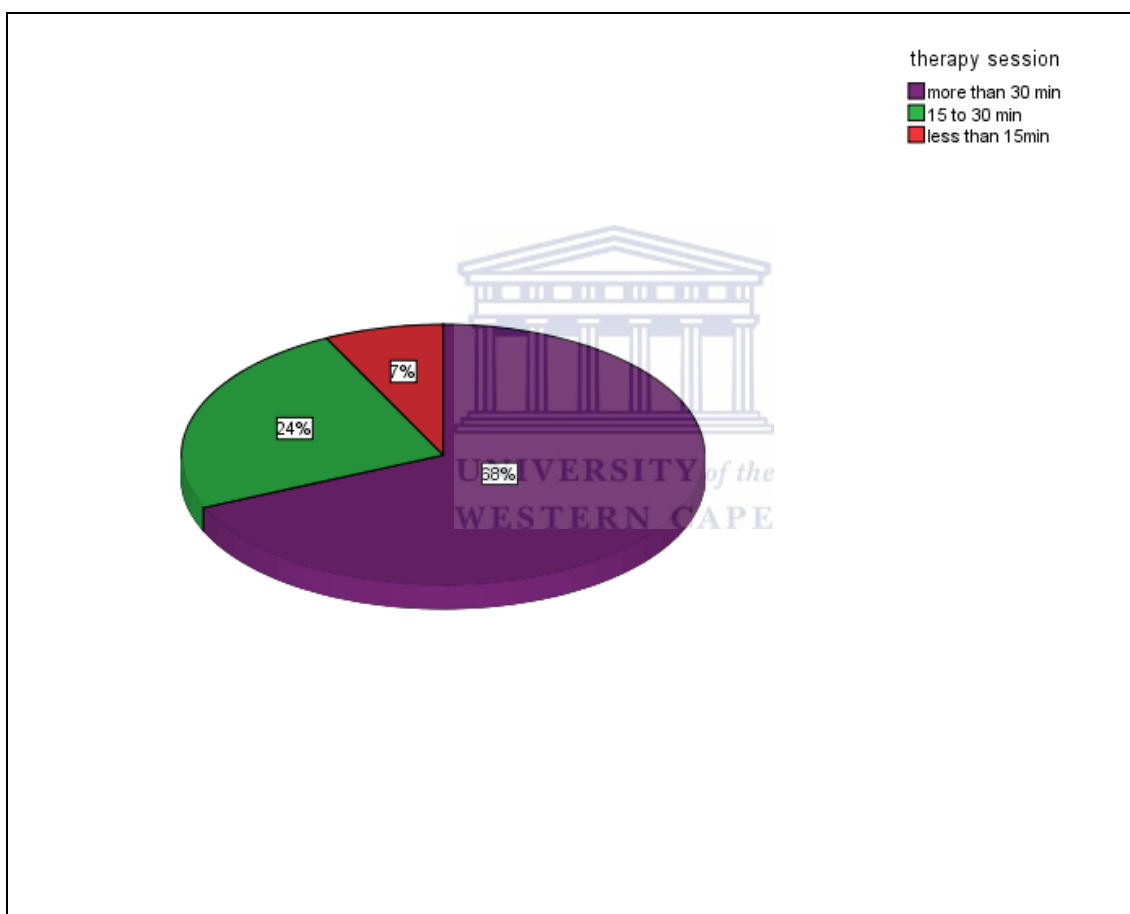


**Figure 6.8 Percentages of participants showing length of time they had to wait to receive rehabilitation services (N= 95)**

Generally, the participants' responses show that the service providers were quick to attend to them when they went to the CHCs for their appointments. The majority of the participants (78%) reported that they waited to get rehabilitation services at the CHCs for "less than 15 minutes."

#### 6.5.4 Length of rehabilitation sessions

Figure 6.9 illustrates the percentages of participants based on the length of their rehabilitation sessions.



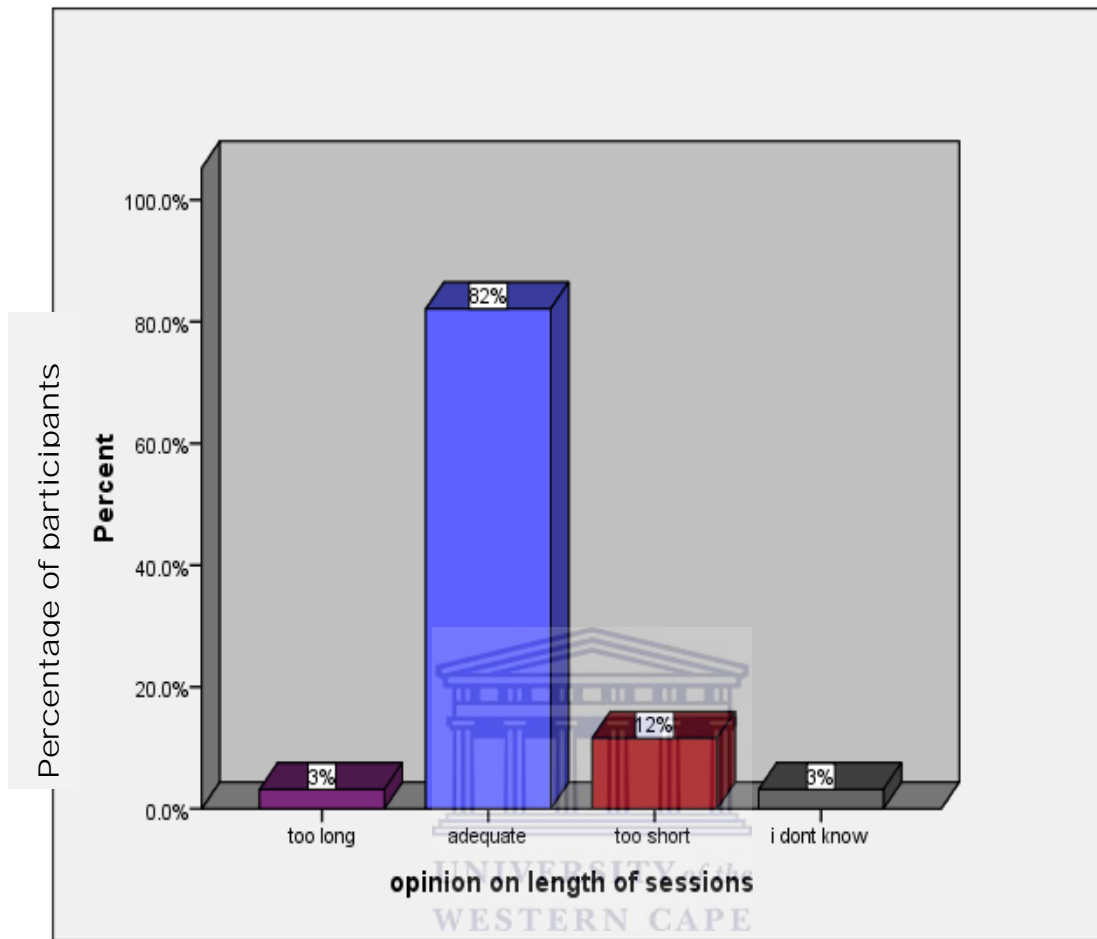
**Figure 6.9 Percentages of participants according to the reported length of rehabilitation sessions (N= 95)**

The majority of the participants (68%) reported that their rehabilitation sessions were more than 30 minutes, 24% reported that their sessions were 15-30 minutes and only 7% reported sessions less than 15 minutes.

### **6.5.5 Participant's opinion on length of rehabilitation sessions**

Figure 6.10 shows distribution of participants based on their opinion regarding length of rehabilitation sessions.





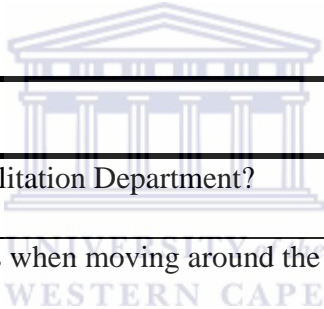
**Figure 6.10 Percentages of participants' showing their opinion on the length of rehabilitation sessions (N= 95)**

The majority of the participants (82%) thought that the time for rehabilitation services was adequate for them. 12% thought the time was too short and 3% thought it was too long. Only 3% were not sure whether the time was short, long or adequate and they gave the response “I don’t know.”

### 6.5.6 Physical accessibility of the CHCs

Item 16 of the questionnaire asked for difficulties experienced by the participants when moving around the CHCs for instance uneven ground, steps and narrow doors which made it difficult to manoeuvre wheelchairs and inaccessible equipment like unadjustable beds. Ease of location of the rehabilitation departments was also used to determine physical accessibility.

**Table 6.3 Participants' responses regarding location of the department and moving around the CHC environment (N= 95)**



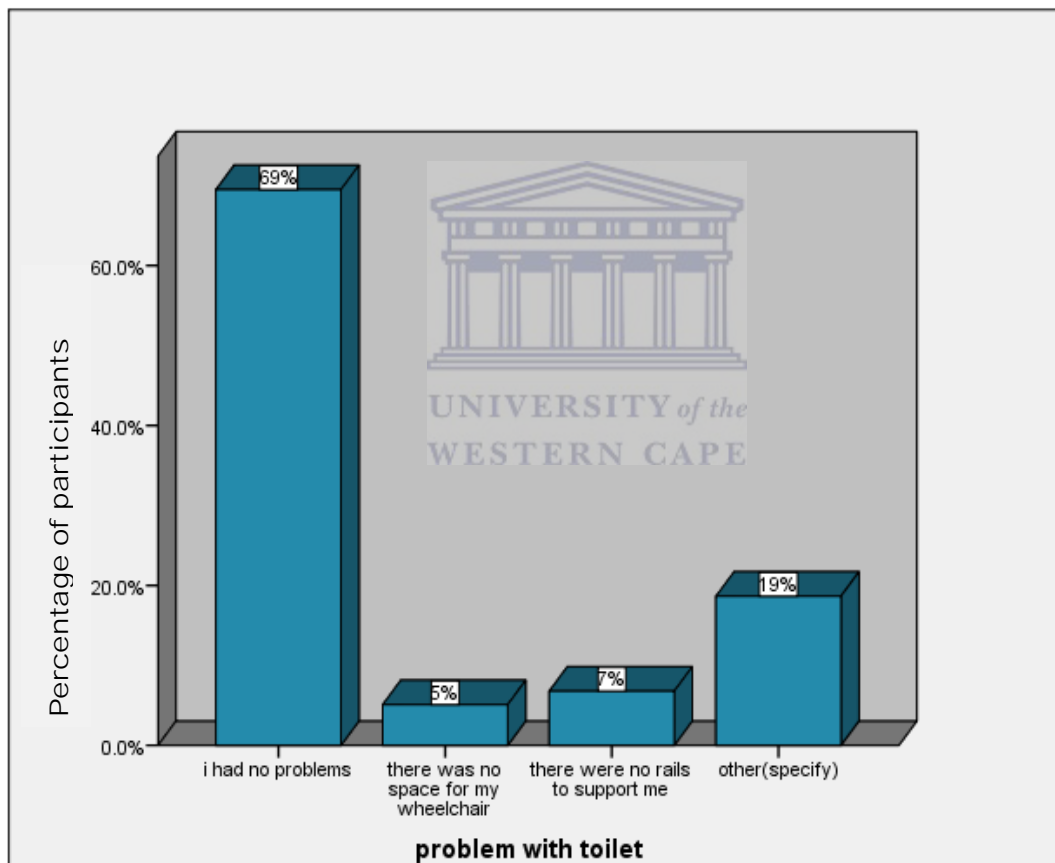
| Variable statement   | Yes (%) | No (%) |
|--|---------|--------|
| Was it is easy to find the Rehabilitation Department?      | 82      | 18     |
| Did you encounter any problems when moving around the CHC? | 19      | 81     |

Eighty two percent of the participants reported that it was easy for them to locate the rehabilitation department the first time they went to the CHCs for rehabilitation. Only 19% of the participants reported that they had encountered problems when moving around the CHCs. All of the 19% reported in the subsequent open ended question that the CHCs were overcrowded with lots of people in the corridors which made it difficult for them to move around in their wheelchairs.



### 6.5.6.1 Problems encountered when using toilets

Figure 6.11 illustrates the distribution of responses given regarding accessibility of the toilets at the CHCs.



**Figure 6.11 Percentages of participants according to their experiences regarding accessibility of the toilets (N=95)**

Only those participants who had used toilets at the CHCs responded to this item (n=59). The majority of these participants (69%) reported that they had not encountered problems when using the toilets. 5% reported that the space was not enough for them to manoeuvre their wheelchairs and 7% reported that there were no rails to support them. Nineteen percent of the participants gave the response “other” and the main issue echoed here was the fact that the toilets were dirty and sometimes the floors would be wet.

## **6.6 Experiences regarding service providers’ interaction with participants**

In this section, participants were asked to rate their agreement to particular statements relating to their interaction with service providers. A 4 point Likert scale was used with responses “strongly agree=1, agree=2, disagree=3 and strongly disagree=4.” The results are presented in form of percentages of participants who gave each type of response, the medians score for each variable and first and third quartiles of the response scores. Table 6.4 presents the distribution of responses given by the participants regarding their interaction with service providers

**Table 6.4 Service providers' interaction with the participants (N = 95)**

| Variable statement   | Strongly agree (%) | Agree (%) | Disagree % | Strongly disagree (%) | Median | Q1-Q3 |
|--|--------------------|-----------|------------|-----------------------|--------|-------|
| The therapist treated me with respect  | 55.8               | 44.2      | 0          | 0                     | 1      | 1-2   |
| The therapists gave me the opportunity to express my fears                     | 38.9               | 54.7      | 6.3        | 0                     | 2      | 1-2   |
| The therapists encouraged me when I felt depressed                             | 40                 | 56.8      | 3.2        | 0                     | 2      | 1-2   |
| The therapists showed interest in me as a person and not just in my disability | 51.6               | 48.4      | 0          | 0                     | 1      | 1-2   |

The majority of the participants gave positive responses regarding their interaction with service providers. All of them reported that the therapists respected them and treated them as human beings not just as persons with disability. The medians were all within the positive side. More than 75% of the participants gave responses of 2 and below.

### **6.7 Experiences regarding participants' involvement and participation in rehabilitation**

In this section, the same scale was used as in 6.4 above and the responses are presented in form of percentages medians and the first and third quartiles.

Table 6.5 presents the distribution of responses given by the participants regarding their involvement and participation in rehabilitation

**Table 6.5 Involvement and participation in rehabilitation (N=95)**

| Variable statement   | Strongly agree (%) | Agree (%) | Disagree (%) | Strongly disagree (%) | Median | Q1-Q3 |
|--|--------------------|-----------|--------------|-----------------------|--------|-------|
| The therapist asked for my expectations from rehabilitation      | 34.7               | 48.4      | 16.8         | 0                     | 2      | 1-2   |
| The therapists involved me in goal setting                       | 31.6               | 54.7      | 13.7         | 0                     | 2      | 1-2   |
| The therapists gave me the opportunity to comment on my progress | 37.9               | 50.5      | 11.6         | 0                     | 2      | 1-2   |
| The therapist explained procedures in an understandable way      | 34.7               | 56.8      | 8.4          | 0                     | 2      | 1-2   |
| The therapist gave me the opportunity to ask questions           | 35.8               | 48.4      | 15.8         | 0                     | 2      | 1-2   |

The participants generally gave positive responses regarding their involvement in the rehabilitation process with all the variables getting a median response of 2. “*Asking for participant’s expectations*” got the highest number of negative responses. The variable that got the most positive responses was “*The therapists explained procedures*” with only 8.4% of the participants giving negative responses.

## 6.8 Experiences regarding family support and involvement in the rehabilitation of the participants

In this section, a 3 point Likert scale was used to assess family support and involvement in the rehabilitation process. The three responses were; Always= 1, sometimes= 2 and never= 3. Table 6.6 illustrates the results relating to family support and involvement in the rehabilitation process.

**Table 6.6 Support and involvement of family (N=58)**

| Variable statement   | Always (%) | Sometimes (%) | Never (%) | Median | Q1-Q3 |
|--|------------|---------------|-----------|--------|-------|
| The therapists helped my family to understand my disability      | 71.4       | 17.2          | 8.6       | 1      | 1-2   |
| The therapist talked to my family during rehabilitation sessions | 69.0       | 22.4          | 8.6       | 1      | 1-2   |
| My family was given a home program to assist me at home          | 60.3       | 20.7          | 19.0      | 1      | 1-2   |
| My family members were given time to ask questions               | 53.4       | 24.1          | 22.4      | 1      | 1-2   |
| My family got satisfactory answers to their questions            | 56.9       | 22.4          | 20.7      | 1      | 1-2   |

Only 58 of the participants had gone to CHCs for rehabilitation with a family member. They generally gave positive responses regarding the involvement of their family in the rehabilitation process with all the variable statements getting a median score of 1. The variable with the most positive responses was “*Did the therapist help your family to understand your disability? “Did they get answers to what they wanted to know?”*” had the highest percentage of negative responses of 20.7%.

### **6.9 Experiences regarding provision of information**

As in sections 6.6 and 6.7, a 4 point Likert scale was used with the responses “strongly agree=1, agree=2, disagree=3 and strongly disagree=4” to seek for experiences regarding provision of information related to participant’s disability. To determine experiences regarding provision of information related to support services the participants were required to give the responses “Yes” or “No” to each statement. The results are presented in form of percentages, medians and the first and third quartiles.

Table 6.7 illustrates the responses given by the participants regarding the information they were given about their disabilities.

**Table 6.7 Information given to the participants regarding their type of disability (N=95)**

| <b>Variable statement</b>   | <b>Strongly agree (%)</b> | <b>Agree (%)</b> | <b>Disagree (%)</b> | <b>Strongly disagree (%)</b> | <b>Median</b> | <b>Q1-Q3</b> |
|---|---------------------------|------------------|---------------------|------------------------------|---------------|--------------|
| I was given information about the cause of my disability                      | 35.8                      | 47.4             | 15.8                | 1.1                          | 2             | 1-2          |
| I was given information about possible complications related to my disability | 32.6                      | 50.2             | 14.7                | 2.1                          | 2             | 1-2          |
| I was given information about how my family and I can manage at home          | 34.7                      | 47.4             | 14.7                | 3.2                          | 2             | 1-2          |

The participants generally gave positive responses although there were a few who gave strong negative responses. The median score for all the variables was 2 and 75% of the participants gave a score of 2 or less as indicated by the third quartile .

Table 6.8 illustrates the responses given by the participants regarding provision of information about support services available for them.

**Table 6.8 Information received regarding support services (N=95)**

| <b>Support service</b>   | <b>Yes</b>  | <b>No %</b> |
|--|-------------|-------------|
| Were you given information about disability grant?                             | 58.4        | 41.6        |
| Were you given information about organisations for persons with disabilities?  | 38.9        | 61.1        |
| Were you given information about support groups for persons with disabilities? | 53.7        | 46.3        |
| Were you given information about vocational training facilities?               | 32.6        | 67.4        |
| <b>Average</b>   | <b>48.4</b> | <b>51.6</b> |

Most of the participants indicated that they had not received information regarding organisations for persons with disabilities and vocational training facilities.

### **6.10 Summary**

The chapter presented the results from the quantitative phase of the study. Physiotherapy was the service received by the majority of the participants in this study. Most of the participants expressed positive experiences with different aspects of the rehabilitation services. Service providers' interaction with the participants got the highest frequencies of positive responses.



Information provision had the lowest frequencies of positive responses, especially information regarding support services.

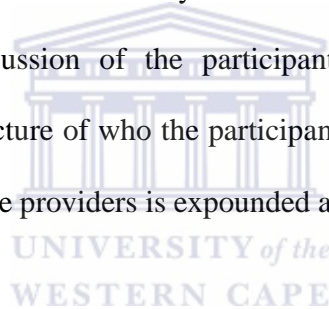


## **CHAPTER SEVEN**

### **DISCUSSION**

#### **7.0 Introduction**

In this chapter the major findings are summarised and discussed in comparison with findings of previous studies. Within the discussion, the researcher integrates the findings from the in-depth interviews and the quantitative phase of the study. Prior to the discussion of results that answer the study question, a brief discussion of the participants' demographic characteristics is presented to give a background picture of who the participants were. The relevance of the study findings to the rehabilitation service providers is expounded at the end of the discussion.



#### **7.1 Demographic characteristics of the participants (quantitative sample)**

The sample for the present study was very heterogeneous with a wide age range and different diagnoses. There was no significant difference in the gender distribution and the majority of the participants were unemployed. Stroke was the most common diagnosis, followed by amputations with spinal cord injuries coming third among the causes.

It is difficult to compare the demographic characteristics of participants in the present study with previous findings because previous studies mainly focused on a particular diagnosis for example stroke, spinal cord injuries, multiple sclerosis, arthritis and others. However, since stroke was the

most dominant diagnosis (66%), the age distribution might have been biased towards that of persons who suffered stroke in the Cape Town Metro Health District. Among stroke clients accessing rehabilitation services at CHCs within this district, Biggs (2005) found a mean age of 61.4 years and at one of the CHCs within the same health district, Rhoda and Hendry (2003) found a mean age of 59 years. The lower mean age in the present study could have been due to the other conditions like polio, spinal cord injuries and amputations which are generally more prevalent in younger participants in the present study than stroke.

Despite the findings from Census 2001 in South Africa that there are more males with physical disability in the Western Cape Province as compared to females, (Statistics South Africa, 2005), there was a slight difference in the gender distribution among participants of the present study. This could have been due to the convenient method of sampling used in the present study which did not give an equal chance of all the persons with disabilities accessing rehabilitation services at the CHCs to be selected and just involved those who happened to be available.

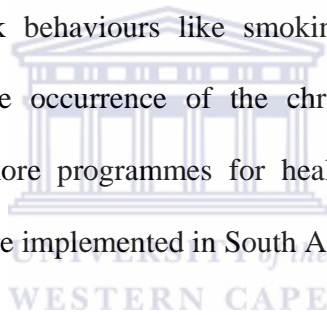
In the present study, the majority of the participants had some form of formal education, either up to primary school or secondary school but very few had a tertiary qualification. These results are in contrast with the findings reported by Loeb, Eide, Jelsma, Toni and Maart (2008) in a small town in Western Cape and in one of the informal settlements within the same province who reported low educational level amongst persons with disability (5-18 years). They reported that 22% had never attended school and the mean level of education (highest grade or number of years completed) was 2.9 years. The difference could be attributed to the fact that the present study was done with participants who resided in Cape Town Metropole District which is mainly

urban and peri-urban with more resources and opportunities for persons with disabilities to go to school. Moreover, most of the participants in the present study were adults who had acquired disabilities, and were all above the age of 18 years, there might have acquired their education before they were disabled.

There was a very high rate of unemployment among the participants of the present study. These results follow the trend in previous studies regarding employment among persons with disabilities. Ward (2003) reported an unemployment rate of 90% among persons with physical disability in her study conducted in Ireland. In the same setting as the present study (CTMHD), Biggs (2005) found that among stroke clients with age ranging from 31 to 98 years, the rate of unemployment was 98%. Similarly, Rhoda and Hendry (2003) reported that in their study at Bishop Lavis CHC in Cape Town, out of the 31% persons with stroke who were employed at the time when their stroke occurred, only 7% were eligible to return to work.

The fact that only 4% of the participants had a tertiary qualification might be one contributing factor to the high rate of unemployment found among the participants in the present study. Further, the loss of employment after acquiring disability that was echoed by several participants in the qualitative phase, either because they could no longer perform certain tasks or they were being denied the chance by employers because of their disability could also be another reason for the high rate of unemployment among the survey participants. The high rate of unemployment is a potential cause of financial hardships among persons with disabilities. The financial hardships result in anxiety and depression among persons with disability (Craig, Hancock & Dickson, 1994), hence reducing their quality of life.

The majority of the survey participants reported illness as the cause of their disability. Similarly, chronic conditions have been reported by other authors as the main causes of conditions that result in physical disability (Picavet & Hoeymans, 2002; Valderrama-Gama, Damian, Ruigomez, Marti-Moreno, 2002; Biggs, 2004). Scheneider et al, (1999) in the CASE report highlighted that causes of impairment and disability in South Africa reflect global trends whereby non-infectious and infectious diseases (26%), rank highest. The high rate of occurrence of illness related disabilities might be an indication that prevention and appropriate management of these chronic illnesses is inadequate in South Africa. The results could also be an indication that many people are being involved in health-risk behaviours like smoking, excessive drinking and eating unhealthily, which exacerbate the occurrence of the chronic diseases. The occurrence of disabilities may be reduced if more programmes for health promotion and prevention and management of chronic illnesses are implemented in South Africa.



In the present study, stroke, to a large extent, contributed the highest percentage amongst the diagnoses. Previous studies that involved clients with physical disabilities reported stroke to be the most common diagnosis among the participants (Fried, Bandeen-Roche, Kasper, Guralnik, 1999, Ward; 2003). It is also interesting to note that the literature review in chapter two of the present study highlighted that most of the studies done on experiences of rehabilitation service provision were done with stroke clients which may be an indication that stroke is the most common condition attended to in rehabilitation settings. The reasons for occurrence of chronic illnesses above might also be contributing the high prevalence of stroke among the participants.

## 7.2 Rehabilitation services received at the CHCs

The rehabilitation services received by the participants were sought so as to inform the researcher about the services that the participants were referring to in the present study. Physiotherapy was the most common received service followed by occupational therapy and lastly speech therapy. This was not an unusual finding as Biggs, (2005) also reported the same findings within the Cape Town Metro Health District. Generally there are more physiotherapists rendering rehabilitation services at PHC level in the district as compared to the other two disciplines. Therefore, most of the persons with physical disability receive physiotherapy at the CHCs and only a few receive the other two services.

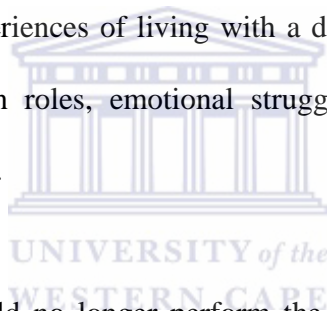
Investigating whether those who did not receive OT and speech therapy needed these services was beyond the scope of this study. However, given the shortage of rehabilitation professionals mentioned before, one cannot go without mentioning the need to attract more of these professional to work at PHC level which would improve the situation at the CHCs. The need for more OTs was reported by Misbach (2004) in the study to investigate implementation of the rehabilitation service package in the Cape Town Metro Health District. The OTs who participated in the study conducted by Misbach (2004) echoed the need for more OT posts at the CHCs in this district as they were struggling to cope with their workload. The high rate of unemployment among the participants could also be reduced if there were enough OTs to resettle them back into their workplaces and to facilitate vocational training programmes. The shortage of rehabilitation personnel may also result in long waiting lists which may result in clients

getting services at a much reduced frequency and therefore affect the clients' rate of improvement.

The inclusion criteria of this study excluded clients with communicative and speech defects. Together with the shortage of speech therapists, this might have contributed to the reasons why only a very small proportion of the sample had received speech therapy.

### **7.3 General experiences of disability**

When reporting their general experiences of living with a disability the participants mentioned loss of ability to perform certain roles, emotional struggle, financial problems and sexual dysfunction as their main concerns.



The fact that the participants could no longer perform the roles they used to perform before acquiring disability was the main issue that the interview participants talked about in this study, regardless of their age, gender or diagnosis. These results are consistent with previous findings. Carpenter (1994) and Levins et al. (2004) reported results from in-depth interviews and focus group interviews with persons with acquired disabilities in which the participants expressed that they missed the activities they used to do before acquiring disability.

The loss of ability to perform certain tasks can have a devastating emotional impact on the life of the person with disability as indicated by the reflections of the participants in the present study. They expressed feelings of hurt and depression because they could not play certain roles that

they used to be involved in before acquiring disability. The emotional impact of disability was reported by Craig, Hancock and Dickson (1994) who conducted a longitudinal study to investigate anxiety and depression over the first two years of spinal cord injury. The authors found that about 30% of persons with spinal cord injury had raised levels of anxiety, depression and feelings of helplessness. Occurrence of depression and other emotional problems have the potential of increasing morbidity among persons with physical disabilities and increase their need to use healthcare services. This may worsen the financial problems reported by the participants as discussed in the following paragraph.

The participants in this study also echoed the economic impact of disability on their lives and this is a common subject within the literature whereby occurrence of disability usually thrusts the individual into serious poverty (Venter et al. 2003; Mont, 2007; Loeb, Eide, Jelsma, Toni & Maart, 2008). The participants reported a need for money to hire transport to the CHCs and to hire people to perform certain tasks in their homes. These findings support the INDS, which states that although in some countries, a percentage of people receive social security benefits, these benefits are usually used to pay neighbours and relatives to perform tasks (Office of the Deputy President, 1997). The need to pay other people to assist them leaves the persons with disabilities without enough money for their other day to day needs, hence they are locked in the poverty cycle.

Loss employment after acquiring disability, which is another major factor contributing to the economic impact of disability was echoed as one of the participants' concerns. This was mainly expressed as a problem amongst male participants, which could be due to the fact that men are



usually the breadwinners in their families and loss of this role may have an agonizing impact on their lives. These findings are similar to what was reported by Biggs (2005) and Hare et al. (2006). In the Cape Town Metro Health District, Biggs (2005) found a return to work rate of 2.9% among 417 stroke clients who participated in her study. Hare et al. (2006) in the United Kingdom reported that among the stroke clients participating in their study, negative attitudes of existing employers or prospects for securing new employment were perceived as a problem, particularly for the younger clients.

Ward (2003) argued that persons with disabilities experience financial hardships since many of them are unemployed, incur additional costs due to their disability and do not receive adequate disability allowances. Determining those who were getting disability allowances was beyond the scope of the present study but the high rate of unemployment could be an indicator of poverty among the persons with physical disabilities receiving rehabilitation services at the CHCs in Cape Town Metro Health District.

Sexual dysfunction due to spinal cord injury was mentioned as one of the participants' concerns in the present study. This may have an adverse effect on the participants' quality of life as was reported by Anderson, Borisoff, Johnson, Stiens and Elliot (2007) in their study on the impact of spinal cord injury on sexual function. The authors reported that for 82.9% of the participants, improving sexual function was important to improving their quality of life. The loss of sexual function reported by participants in the present study might also affect their relationships with spouses and leave them feeling inadequate. This can have a serious effect mentally as was found

by Sipski (1997) that dysfunction after spinal cord injury may cause psychological trauma especially among men.

It is apparent from the results of the current study that occurrence of a disability may have a devastating impact on the person with disability. To improve the quality of life of those with physical disability, there is need during rehabilitation service provision not only to concentrate on improving functional independence but also to look into the issues echoed in this study and provide or refer for relevant care.

#### **7.4 Participants' experiences of the rehabilitation services**

In the present study, the participants were asked about their experiences regarding specific dimensions of rehabilitation which were used as sub-themes in analysis of results. The discussion is going to be based on these sub-themes which were as follows:

- accessibility of the rehabilitation services,
- interaction of service providers with participants,
- participants involvement and participation in rehabilitation,
- support and involvement of family and
- provision of information.

### **7.4.1 Accessibility of the rehabilitation services**

In the present study the aspects that were investigated in order to determine accessibility of the rehabilitation services offered at CHCs were transport, location of the rehabilitation departments, time spent waiting for appointments and physical facilities (buildings and equipment).

#### **7.4.1.1 Transport**

The Integrated National Disability Strategy in South Africa states that,

There is need for rapid progress in developing public transport that is flexible and accessible. Without this, people with disabilities will continue to remain largely invisible and unable to contribute to or benefit from the services and commercial activities available to most of their fellow citizens (Office of Deputy President, 1997, INDS, p. 32).

The qualitative results of the present study revealed that the need stated by the INDS still persist in South Africa. The participants mentioned transport as the main problem as far as accessing the rehabilitation services at CHCs was concerned. The participants expressed their concern about the trouble they had to go through for them to get transport to travel to the CHCs. It was difficult for some to get a taxi and others had to hire transport from neighbours for which they had to pay a fee, which strained them financially. Others expressed that they were experiencing problems with walking but they had no other alternative means of transport but to walk.

Transport has been reported to be a hindrance for persons with disabilities receiving rehabilitation services, in previous studies, both in South Africa and internationally. Rimmer, Rubin and Braddock (2000) reported that women in their study cited transportation as one of the major barriers preventing them from participating in physical activity, a major component of rehabilitation for those with physical disabilities. Scheneider et al. (1999) stated that in South Africa, transport is generally not geared for persons with disability and participants in their survey expressed frustration about being unable to lead a normal life, get to school or work due to accessibility problems. Previous research in Cape Town reported similar findings (Whitelaw et al. 1994; De la Cornellere (2007) whereby transport problems were the main negative influence to attendance of rehabilitation sessions by stroke clients.

The findings of the present study give evidence that despite the need mentioned above in the INDS and the findings of previous studies, the problem of transport is still persisting and affecting rehabilitation service provision at CHCs in the Cape Town Metro Health District. This problem not only affects rehabilitation service provision but it also affects inclusion of persons with disability into the mainstream society because it is difficult for them to travel from their homes to work, shops, recreational places and other facilities within the community. In addition to improving accessibility of the CHCs, improvement to transport services would also contribute to poverty alleviation amongst persons with disability by allowing them to travel to workplaces and schools.

There is evidence from the results of the present study that some taxi operators were discriminatory against persons with physical disabilities. This was echoed in the statement, “*The*

*taxis are not the same, there are those who stop for me and some others don't...*” Possibly, some of the taxis might not have been transporting persons with physical disabilities because they were not designed for such passengers as mentioned by Scheneider (1999) that in South Africa transport systems are generally not geared for persons with disability. The stigma associated with being disabled could also be evident here whereby the taxi operators just did not want their taxis to transport persons with disabilities.

The use of private cars (either personal, hired or owned by relatives) was also common among the survey participants. Although not asked in the quantitative survey, participants in the in-depth interviews expressed the expenses that they had to incur to hire friends, neighbours or relatives' cars or to buy fuel for their own cars. The financial strain cannot be ruled out among the survey sample; given the fact that only one participant was employed. This again is one of the factors that lock up the persons with disabilities within the poverty cycle even if they get disability grants because they constantly have to fork out money for transport whenever they have to travel.

The quantitative survey revealed that 28% of the participants were walking to the CHCs to receive rehabilitation services, despite the fact that some of the participants struggled with walking as echoed in the in-depth interviews. Walking could have been good for them as a form of exercise and for improvement of their mobility. However, on days when some could have experienced pain, dizziness and other forms of illness, walking might not have been possible, hence attendance of rehabilitation sessions could be negatively influenced. For those who used wheelchairs, this form of transport might not have been a problem to them, assuming they lived

close to the CHCs. However, this form of transport has its own drawbacks, as mentioned by De la Cornillere (2007) that in her study; some participants stated that they had to pay for neighbours to propel their wheelchairs to the CHCs. As a result, the financial challenges echoed in the in-depth interviews might also be a problem for this group of participants. On the other hand, travelling in a wheelchair might not be feasible during winter when the weather is bad and this might negatively affect attendance to rehabilitation sessions. The problem of bad weather might also affect those who walked to the CHCs as mentioned above.

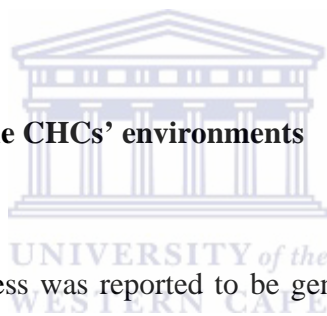
#### **7.4.1.2 Keeping appointment times**

The majority of the participants gave positive responses regarding the time that they had to wait to be attended to by the service providers. The trend of results under this sub-theme was the same in both the qualitative and quantitative phases of the study. The researcher did not find any published literature specifically looking at the persons with disabilities' waiting time to see the service providers on the appointment day. However studies done with patients accessing medical services to determine the effects of longer appointment waits have revealed that longer waiting time may result in patients leaving without seeing the service providers or reduce the chances of the patients coming back to the same provider (Fernandes, Daya, Berry & Palmer, 1993; Christopher & Forrest, 1998).

Despite the fact that the rehabilitation departments at the CHCs are under-staffed, the results of the present study reveal that the service providers at the CHCs are doing well in keeping the participants' appointment times. This might have a positive impact on attendance of

rehabilitation sessions because the clients would not worry about waiting for too long to see the service providers. It also came out from the interviews that the rehabilitation service providers would to make appointments on the days that the participants were supposed to see other service providers at the CHCs as one participant narrated: “...so now they said I must go to see the doctor and come back to see the physio and the OT, all in one day, which is fine so I don't have to come back for each one of them.” This is also an indication that the rehabilitation service providers at were organised in terms of scheduling and keeping appointments. This would increase convenience for the clients since they would not need to travel to the CHC several times, given the transport problems aforementioned.

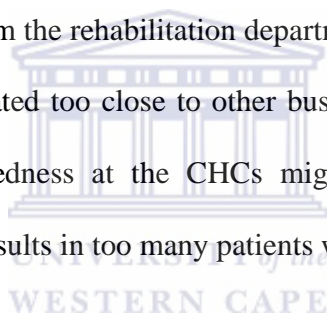
#### **7.4.1.3 Physical accessibility of the CHCs' environments**



In the present study, physical access was reported to be generally good by the majority of the participants who made it clear that they could move around the CHCs smoothly with their wheelchairs. Contrary to these findings, previous studies reported complaints by persons with physical disabilities about inaccessible environments that hindered them from successfully receiving rehabilitation services. For example, in the United States of America, Bowers et al. (2003) reported that it was common for clients with physical disabilities to receive substandard care because primary health care doctors' offices and clinics often lacked accessible examination tables and scales and because narrow doorways and cluttered exam rooms prevented entry of wheelchairs. The contrasting findings in the present study could be due to the fact that the rehabilitation departments at the CHCs were constructed specifically for persons with disabilities and therefore issues of accessibility were considered. The previous studies mentioned

investigated accessibility of primary care services offered by doctors in their practices which were built for people with all sorts of medical needs, the majority of whom without wheelchairs or with no problems that could hinder them from using stairs and other equipment in the practices.

However, in response to the open-ended question that asked those who had problems with accessibility of the CHCs to specify the problems, some of the participants reported that they struggled to move around because of other patients who would be overcrowded in the CHC corridors. They mentioned that patients queuing for other services at the CHCs would block their way as they try to move to and from the rehabilitation departments. This might be so because the rehabilitation departments are located too close to other busy departments like pharmacies and doctors' rooms. The over-crowdedness at the CHCs might also be due shortage of other professionals like doctors which results in too many patients waiting all the time.

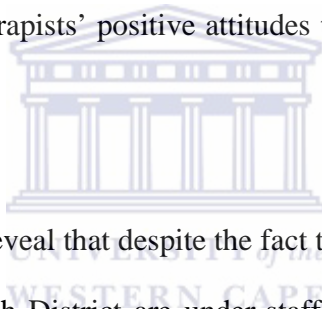


#### **7.4.2 Service providers' interaction with the participants**

In the present study, the majority of the participants gave positive responses regarding their interaction with service providers both in the qualitative and quantitative phases, with some variable items in the quantitative survey scoring 100% positive responses. In the in-depth interviews, the participants kept on referring to the attitudes of service providers even when the interviewer asked about other aspects of rehabilitation. They seemed to care more about the service providers' attitudes than other aspects of rehabilitation they were asked about in the interviews.



Positive responses regarding service providers' interaction with persons with disability are not unusual in previous studies. Morris et al. (2007) stated that in their study, stroke patients and carers praised the physiotherapists' positive attitudes and reported high levels of commitment of the latter. Similarly, Keith (1998) reported that in the Medical Outcomes Study, personal aspects of outpatient physician encounters with persons with physical disabilities were rated highest of all elements of care, with 92% of ratings either excellent or very good. At one of the CHCs within the district where the present study was conducted, De la Cornillere (2007) stated that the participants with stroke highly commented the therapists' friendliness, politeness and love. Some even mentioned that it was the therapists' positive attitudes that kept them coming to the stroke group.



The findings of the present study reveal that despite the fact that the rehabilitation departments at CHCs in Cape Town Metro Health District are under-staffed; the service providers are doing their best to treat the clients with a positive attitude. The service providers' positive attitudes in the present study might help to encourage the participants to continue coming for rehabilitation sessions since negative attitudes might result in clients seeking services elsewhere as was the case with some participants in Swain and French (2001)'s study.

There were other studies in which the participants with disabilities reported negative experiences regarding their interaction with their service providers. According to Crisp (2000), in Australia, disabled people perceived attitudes from rehabilitation personnel as ineffectual and they reported concern about lack of quality in their relationships with health and rehabilitation personnel.

Swain and French (2001) stated that client-service provider relationships were varied but were experienced by some disabled people as dehumanising and abusive. These two studies however involved a broader spectrum of services providers which included doctors, nurses and rehabilitation therapist. In the present study, participants were mainly referring to their interaction with physiotherapists and/or occupational therapists, most of whom had experience of working with persons with physical disabilities. The prolonged exposure to working with persons with disabilities might also have contributed to the service providers' positive attitudes since they had more experience and would understand disability issues better.

The service providers' positive attitudes should be highly commended and the service providers should be encouraged to keep up such standards, especially given that in other settings persons with disabilities have complained about their service providers' negative attitudes and their impact on the persons with disabilities. Swain and French (2001) stated that some persons with disabilities ended up dismissing rehabilitation services because of the service providers' negative attitudes.

There is however, a possibility that participants in the present study gave positive responses just to avoid saying bad things about their service providers. This notion is supported by Keith (1998) who argued that rehabilitation clients may feel uncomfortable conveying critical comments about care for fear of alienating service providers.

However, despite that responses regarding interaction with service providers were generally positive, noteworthy is the fact that the two items that got the highest mean scores (more

negative responses) were closely linked to emotional support. These were: “*opportunity to express fears*” and “*encouragement when one felt depressed*”. This might be an indication that some of the service providers were not spending enough time dealing with the clients’ emotional concerns. Therefore, the service providers need to be encouraged to use a holistic approach when providing rehabilitation services so that they can also fulfil the clients’ need for emotional support. This would improve quality of life among the clients and reduce occurrence of anxiety and depression.

#### **7.4.3 Participation and involvement of participants in rehabilitation**



The National Rehabilitation Policy in South Africa emphasises the need for direct involvement of persons with disabilities and their families in decision-making because they have first-hand experience of the impact of disability on their lives (DOH, 2000). This promotes the implementation of the social model of rehabilitation, which emphasizes the client’s active participation in rehabilitation rather than just being passive recipients of the services.

The participants in the present study generally gave positive responses regarding their participation and involvement in the rehabilitation process both in the in-depth interviews and in the survey. On the contrary, previous studies reported varied results regarding client involvement in rehabilitation but there were more negative experiences reported as compared to positive ones (Payton & Nelson, 1996; Swain & French, 2001; Talvitie & Reunanen, 2002). The previous

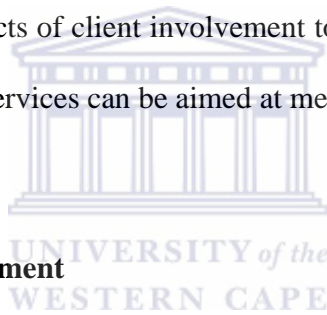
studies were done in Europe and the United States of America, where the clients' expectations of involvement in rehabilitation might be higher than in developing countries.

The results of the present study indicate that the service providers involved the participants in the rehabilitation process which helps the service providers to target the clients' specific needs. This might also improve rehabilitation outcomes as was found in the study by Payton and Nelson (1996) that clients who were involved were more satisfied with physiotherapy services and had better therapeutic outcomes. Involvement of the clients might also improve the clients' understanding of what happens in their rehabilitation and hence improve their compliance with rehabilitation programmes which again may improve outcome of the rehabilitation process.

However, despite the positive responses given by some of the participants concerning their involvement in the present study, it is not clear from these results whether the clients wanted to get involved or not. Four out of ten of the in-depth interview participants made it clear that they would accept what the service providers offered because they believed that their service providers knew everything. These findings are similar to those reported by Wressle (2002), whereby some clients were not confident enough to ask questions and some of the elderly clients were not used to making demands on care, relying instead on the knowledge of the professionals. Payton et al. (1998) also reported that participants in their study thought that the physiotherapists 'knew what was important for them' and many of them were not concerned about involvement in goal setting and treatment decisions. This 'surrendering' of treatment planning can have a negative impact on the outcome of rehabilitation since in some cases the therapists might

concentrate on areas that are not important to clients. It also limits the clients' exercising their right to get the kind of treatment that they want as human beings.

Although some of the participants in the in-depth interviews expressed that they were not concerned about their involvement and would not ask questions, "*Asking for participant's expectations*" and "*Opportunity to ask questions*" got higher percentages of negative responses as compared to the other variables in the quantitative survey. This might be an indication that some of the service providers were also not seeking the clients' expectations and did not give clients an opportunity to ask questions. There is therefore, need for rehabilitation service providers to improve in these aspects of client involvement to have a better understanding of the clients' specific needs so that the services can be aimed at meeting these needs.



#### **7.4.4 Family support and involvement**

In the present study, the participants generally gave positive responses regarding family support in rehabilitation, especially as far as how to care for the participant at home was concerned. However, it remains difficult to tell from these results whether the family members share the same sentiments with the participants since the former were not involved in the study.

There is a dearth of published findings regarding involvement of family in rehabilitation of persons with physical disability. However the few studies reviewed reported that feelings of stress and frustration have been reported among the family members. This was mainly due to lack of information regarding home programmes and transition from hospital to community care

(Gerteis et al., 1994; Hare et al., 2006). These studies however had the family members as the key informants regarding support given to them by service providers as opposed to the present study where the client had to give information regarding family support. Keith (1998) argued that responses from different types of respondents should not be seen as equivalent; therefore it remains difficult to compare results of the present study with findings of previous studies. Future research within the same setting with family members as the key informants is necessary to find out how they are experiencing the services and make the necessary improvements.

In the quantitative survey, “*Time to ask questions*” and “*Getting satisfactory answers,*” were the two variables with higher percentages of negative responses. These results could be a reflection that although the participants generally gave positive responses regarding family involvement, they felt that family members were not getting enough opportunities to ask questions and those that asked questions did not get satisfactory answers. This raises the need for the service providers to give family members more time to ask questions and to give them adequate answers. This might in turn lessen the burden of caring for the participants among the family members as they become more informed about their relative’s disability.

#### **7.4.5 Provision of information**

Provision of information to the persons with disabilities is a crucial component of rehabilitation, which is necessary for them to understand their disability better and to access the services that they need (Lui & Mackenzie, 1999; Morris et al., 2007). The present study sought the

participants' experiences regarding provision of information about their disabilities and information about support services available in their communities and within South Africa.

#### **7.4.5.1 Information regarding nature of disability**

The majority of the participants gave positive experiences regarding provision of information relating to one's type of disability both in the in-depth interviews and in the survey. De la Cornillere (2007) also reported positive findings regarding provision of information among persons with disability in South Africa, although the type of information was not disclosed. The author reported that participants with stroke in her study had learnt a lot from the educational talks given by the service providers and they were happy with the information they had received. However, contrasting findings were reported in a study done in China by Lui and Mackenzie (1999). The authors reported that the most frequently stated but largely unmet need was the need for information, particularly information about reasons for stroke and about the activities that promote recovery. The differences in these findings could be due to the fact that De la Cornillere (2007) explored experience of participants regarding a stroke group service which included educational talks as part of the group activities and Lui and Mackenzie (1999) interviewed clients who were receiving individual therapy.

Lack of information regarding nature of their disabilities might prevent the persons with disabilities from fully understanding their disabilities and any related complications. This might result in anxiety, confusion and/or depression among persons with disabilities as Morris et al. (2007) reported that lack of information was found to cause anxiety among participants with

stroke in their study. Furthermore, lack of information regarding their nature of disability might affect the clients' compliance to rehabilitation programmes because of certain myths associated to occurrence of disability which exist in some societies. An example of such myths was stated by Hammell (2006) that in some cultures, it is believed that impairments are the result of sin, witchcraft, the evil eye, the wrath of God/gods or the ancestors.

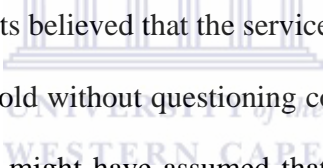
However, despite the positive trend followed by responses regarding provision of information about one's nature of disability, worth mentioning is the fact that, in the in-depth interviews, the participants did not show understanding of the information that they were given when the researcher probed them to elaborate on what the service providers had told them. One of the participants said, *"They did not tell me anything that I understand..."* and another one said he had been told that he will not be able to walk again because the spinal cord injury was at L1 and that was all he could say. This might have been due to some of the participants' low educational level as more than 30% had not gone beyond primary education. There is also a possibility that the participants were not given detailed information about their disabilities, which calls for further studies to investigate the participants' knowledge regarding their disability and implement relevant intervention.

#### **7.4.5.2 Information regarding support services**

The majority of the participants gave negative responses regarding provision of information about support services, especially information regarding vocational training facilities and organisations for persons with disabilities. Similar to these findings, lack of information



regarding support services among persons with disabilities in South Africa, was previously reported by Schneider et al. (1999) and Clacherty et al. (2004). In these two studies, persons with disabilities expressed their need for information regarding support groups, disability grants, vocational training and other support services available for them. The study done in the United Kingdom by Hare et al. (2006), found that the disabled participants were not aware of the existence of support groups such as the Stroke Association. The author reported that the general consensus was that more information was needed about what services were available and how they could be accessed. Lack of information regarding support services might be a hindrance to the persons with disabilities' integration into the community since they will not be having the knowledge regarding where to find facilities and organizations that can help them.



The fact that some of the participants believed that the service providers knew everything so they just had to follow what they were told without questioning could have contributed to the lack of information. The service providers might have assumed that the clients knew some things that the latter never asked about. The fact that some of the survey participants reported that they were not given enough time to ask questions might also be another reason for their lack of information. On the other hand, the fact that only 35% of the participants had received occupational therapy, which is the service mainly dealing with vocational training issues might be the reason why the majority of them did not know anything about vocational training services.

Although some participants mentioned that they were not concerned about getting information, one of the participants who had said she was shy to ask questions asked the researcher about the disability grant, something that they should have asked the service providers. This could be a

sign that despite the reported positive experiences regarding participants' interaction with service providers, some of the participants could not express their concerns to the service providers. This indicates the need to encourage client involvement in rehabilitation so as to enhance partnership between service providers and persons with disabilities, which might improve the latter's openness to discuss their concerns with service providers.

#### **7.4.6 Organisation of rehabilitation sessions**

Organisation of the rehabilitation services was one theme that emerged in the in-depth interviews, comprising the participants' issues of concern regarding how the rehabilitation sessions were organised. The participants mentioned they were receiving therapy as individuals and they wanted group therapy sessions. They felt that the rehabilitation sessions were too short and they also expressed lack of variety in types of activities done during rehabilitation sessions.

Group therapy sessions have been found to help clients both emotionally and psychologically (Hammel, 2006; Morris 2007; De la Cornillere, 2007). De la Cornillere (2007) mentioned several advantages of group therapy in rehabilitation, some of which being instillation of hope, universality, imparting information, altruism, catharsis and interpersonal learning. In the present study, participants expressed their desire to meet others with their type of disability, which could help them benefit in the areas mentioned above.

Despite the expressed desire to receive group therapy in the qualitative phase of the study, the majority of the participants in the survey (60%) were receiving individual therapy. The fact that

the clients expressed their need for group sessions and yet the majority were receiving individual therapy indicates the need for service providers, where applicable, to conduct group therapy sessions. This might help the clients to benefit from the advantages of group therapy mentioned above.

In the qualitative phase of the present study, the participants indicated that the length of rehabilitation sessions was an important aspect to them and they wanted the service providers to extend the time for rehabilitation sessions. One of them said, *“They must extend time for exercises and be more people to assist; an hour per session will be fine.”*

Bowers et al. (1996) reported similar findings whereby physically disabled persons expressed a desire to increase the time that they were allowed to spend with the health care providers. However, given the shortage of rehabilitation professionals within the public sector in South Africa (DOH, 2000), and hence the large number of clients that one therapist has to serve, it might be difficult for the service providers to increase the time they spend with the clients. On the other hand, establishment of groups might lessen the service providers’ workload, at the same time enabling them to lengthen the sessions.

The fact that the participants mentioned their desire for variation in types of activities done during rehabilitation sessions indicate the need for service providers to introduce variety, which could be done by alternating individual therapy with group therapy. Variation in the actual activities done during the sessions will also help to reduce monotony and keep the clients interested in the sessions, which could also enhance the clients’ participation.

## **7.5 Relevance of the study to rehabilitation service providers**

The results of the present study increase the service providers' (mainly physiotherapists and occupational therapists) and CHC administrators' awareness of their clients' perceptions of the services they offer. With this information, service providers can continue practices to which clients responded positively and improve on those aspects of rehabilitation service about which clients expressed negative experiences, thus promoting evidence based practice.

Rehabilitation programmes have often focused primarily on instructing persons with physical disabilities in the necessary techniques of mobility and activities of daily living sometimes neglecting the broader health needs (Carpenter, 1994). This study highlighted the emotional impact of living with disability among the participants, which indicates the need for service providers to broaden their focus to include counselling for those with emotional problems or to refer for relevant care.

In response to the transport problems reported by the participants, there is considerable need for the rehabilitation service providers to advocate and liaise with the relevant government sectors for improvement of transport services for persons with disabilities. Without improvement in transport systems, rehabilitation services and community reintegration for persons with physical disabilities might remain ineffectual.

This study promotes the adoption of client-centred and client driven methods of service delivery (Cott et al. 2005), which are characterised by the active involvement of clients in planning and managing their rehabilitation in partnership with service providers. This supports the movement to adopt the social model of rehabilitation, which advocates for the recognition of the rights of persons with disability (UNHCHR, 2006) by allowing them to participate in society like any other human being. The present study revealed the participants' indifference about getting involved in the rehabilitation process. Therefore there is need to encourage clients to become partners in the rehabilitation process, which was found in previous studies to increase satisfaction among the clients and to improve outcome of treatment.

This study revealed evidence of lack of information regarding support services available for persons with disabilities. This indicates the need for the service providers to devise information disseminating strategies that they can use during the rehabilitation process to ensure that the clients get relevant support from within their communities. One of the strategies suggested by the NRP might also help to solve the problem of lack of information. The strategy states that there should be an information centre, preferably located at district level where it will be easily accessible to provide information about all aspects of rehabilitation, including availability and location of rehabilitation services (DOH, 2000).

The study revealed the participants' desire to be involved in group therapy sessions. The rehabilitation service providers therefore need to enable their clients to benefit from the advantages of group therapy mentioned in 6.4.6 above. The group therapy sessions might also

introduce variety to the rehabilitation sessions since some of the participants mentioned their desire for variation in types of activities done during rehabilitation sessions.

In spite of the need for service providers to look into the issues mentioned above, one cannot go without mentioning the highly positive experiences reported by the participants regarding their interaction with service providers. The service providers should be commended and encouraged to maintain such standards, therefore promoting attendance to rehabilitation sessions and improve outcome of the services. In previous studies done in developing countries reported hierarchical relationships between persons with disabilities and service providers resulted in participants dismissing rehabilitation services (Swain and French, 2001).

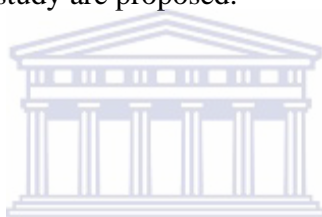


## **CHAPTER EIGHT**

### **SUMMARY, CONCLUSION, LIMITATIONS AND RECOMMENDATIONS**

#### **8.0 Introduction**

To wrap up this study, this final chapter gives a brief summary of the study and the major issues in the study are given in the conclusion. The limitations of the study are outlined and lastly the recommendations arising from the study are proposed.



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#### **8.1 Summary**

The primary purpose of this study was to explore the experiences of persons with physical disabilities regarding the rehabilitation services they received at CHCs in the Cape Town Metro Health District. The main objectives of the study were to determine the rehabilitation services received by the participants and to explore their experiences regarding specific dimensions of these rehabilitation services. The dimensions explored by the study included: accessibility of the services, interaction with service providers, participant participation and involvement, information provision and family support and involvement.

The need to conduct this study arose from the fact that there is a dearth of published information regarding provision of rehabilitation services in the Cape Town Metro Health District and in South Africa at large. Issues specifically related to the clients' perspective of the rehabilitation

services offered in this country have not been extensively researched. The aspects of rehabilitation service provision explored in the present study have been shown to influence effectiveness of the rehabilitation services in other settings outside South Africa. The knowledge gap regarding these issues might be a hindrance in planning and delivering rehabilitation services that address the persons with physical disabilities' specific needs and preferences. Furthermore, seeking clients' perspectives of the rehabilitation services they receive is a useful way to inform policies directed towards disability and rehabilitation issues. The study made use of a mixed methods design which gave the advantage of combining the strengths of both the qualitative and the quantitative designs.

There was remarkable consistency of experiences across the two samples. The results highlighted several issues that are relevant to improvement of the rehabilitation services at CHCs. Accessibility of the services; especially in terms of transport was an issue of concern among the participants. The participants lacked information regarding support services and those who were provided with information regarding their nature of disability lacked adequate understanding of this information. The results also revealed that the participants were not aware of their right to information and also their right to be involved in the rehabilitation process. The lack of involvement reported by some of the participants can also be attributed to this lack of knowledge since some participants believed that it is the service providers' duty to tell them what to do. Family support and involvement and interaction of the participants with the service providers were issues highly commended by the participants.



There is therefore, a need to improve accessibility of the community-based rehabilitation services through provision of transport that specifically caters for persons with disabilities and to give the clients more information regarding their disability and support services available for persons with physical disabilities in Cape Town metro Health District and in South Africa at large. The service providers also need to work in partnership with the persons with physical disabilities and give them more opportunities to participate in their rehabilitation and to encourage them to participate.

## **8.2 Conclusion**

Despite the limitations of the study mentioned below, important implications for rehabilitation service providers have been identified. As evidenced by this study, most of the persons with physical disabilities are not receiving adequate information that is important for them to understand their nature of disability and to inform them of the available support services. Some of the clients are ignorant of their right to participate in their rehabilitation and their right to get informed as far as their disability is concerned. Furthermore, the study also highlights the problem of lack of transport available for persons with physical disabilities to travel to the health care facilities.

One can therefore conclude that the rehabilitation service providers at CHCs in Cape Town Metro Health District need to attend to issues of transport, information provision and participation and involvement of clients in rehabilitation. Improving transport services will have an impact not only on attendance of rehabilitation services but on general mainstreaming of

persons with disabilities since the latter will be able to travel to schools, shops, recreational facilities, workplaces and any other place they might want to go to. This will result in poverty alleviation and better quality of life for persons with physical disabilities. Giving them information will empower them to participate in their rehabilitation and make rehabilitation services more client-centred. Information regarding support services might also improve their community reintegration through interaction with relevant support services within their communities.

Noteworthy is the way the qualitative and quantitative methods complemented each other in the present study. The quantitative phase of the study gave measurable trends regarding how the participants perceived certain dimensions of the rehabilitation services. On the other hand, the qualitative phase of the study brought out a complex picture of the subject of inquiry, unveiling some hidden concepts that can affect effectiveness of the rehabilitation services. A specific example can be given from results regarding participants' involvement in rehabilitation. With use of the quantitative survey only, one would assume that the clients knew that it is important for them to be involved in their rehabilitation. Fortunately, the qualitative results had already revealed that the participants thought that it was the duty of the therapist to make decisions and plan the course of their rehabilitation process for them. This indicates the need to educate the participants about their right to get involved and participate in rehabilitation and the benefits of doing so despite the positive experiences they reported regarding this dimension of rehabilitation care.

### 8.3 Limitations

- 1) The inclusion criteria of the present study made it difficult for the researcher to get participants for the quantitative survey. Most of the clients found at the CHCs were new clients or they were only coming for the second time which made them ineligible to participate. The researcher therefore ended up adding more CHCs and diverting from the initial sampling procedure. The same reason also resulted in the research having a small sample size.
- 2) Given the fact that the participants had received rehabilitation services at CHCs for three sessions or more, recall bias cannot be ruled. Some of the clients might have forgotten some of the issues they were asked about. The participants might have given only what they could remember and some valuable information might have been missed.
- 3) The interviews could not be conducted within the participants' natural settings for safety reasons as mentioned in section 3.6.1.1 above. The fact that the interviews were conducted at the CHCs where they had received the services poses a potential for respondent bias (Bless & Higson-Smith, 1995). Fear of being heard by the service providers might have made some of the participants to give positive responses.
- 4) Although the researcher had to use the convenient sampling method for its ease of implementation and affordability, this method is not the best for quantitative data

collection. The lack of randomness of this method leaves the researcher with no idea of how the results are representative of the study population and therefore limits generalisability of the results to the Cape Town Metro Health District.

- 5) Some important issues might have been missed because of the exclusion of clients with cognitive impairment and those with communicative disabilities. These clients might have different experiences due to their other disabilities and therefore the results cannot be generalised to this group of clients.
- 6) The research was conducted in three different languages which implicated translation and back translation. Despite the employment of professional translators and the back translation, there is still the chance that some of the original meaning of the data collection instruments could have been lost.
- 7) Direct and parallel comparison of the results of the present study with those of previous studies should be done with caution. This is so because the studies were conducted with participants of different ages, different diagnoses, different study designs, different environments and different sample sizes. Most of the studies were done only with stroke clients and this study involved participants with different diagnoses.

## 8.4 Recommendations

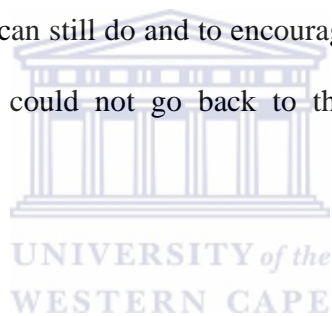
- 1) The results of the present study indicate the need for the responsible government sectors in South Africa to introduce transport systems that are accessible and affordable to persons with disabilities, without which provision of rehabilitation services and community reintegration will remain ineffectual. There is also the need to educate public transport operators about disability so as to remove their discriminatory behaviour towards persons with disabilities. Adjustments should be done to the taxis, buses, trains and other forms of public transport to make them accessible to persons with disabilities. This will improve in attendance of rehabilitation services, employment and education of persons with disabilities and hence alleviate poverty amongst them.
- 2) The rehabilitation service providers at the CHCs should set up ways to provide information to their clients, especially information to educate the clients about their disabilities and about support services available for persons with disabilities. This could be done in form of educational talks, especially during group sessions, distribution of pamphlets and putting up educational posters within the rehabilitation departments.
- 3) The persons with physical disabilities receiving rehabilitation services at CHCs need to be educated about the importance of their involvement and participation in their rehabilitation and the benefits of doing so. This will help them to get more information

through increased interaction with the service providers. Their involvement will also make the services more client-centred and therefore target the clients' specific goals and preferences.

- 4) There is need for future research that looks at other aspects of care including service provider technical skills, continuity of care, issuing of assistive devices and referral systems. This will make results of this study more complete and increase their usefulness in policy implementation and improvement of the rehabilitation services at the CHCs.
- 5) There is also need for further research to investigate whether the reported experiences have any correlation with service delivery outcomes for example improvement in functional status and community reintegration. This will help in establishing ways to improve both the clients' experiences during rehabilitation sessions and achieving the goals of rehabilitation.
- 6) It was difficult for the researcher in this study to find some of the client details for the purposive sampling because the registers at some of the CHCs did not record the clients' age, gender and contact details. There is need for service providers to document all the necessary client details especially for research purposes. Participants' records should also be put separately for different conditions for statistical purposes.
- 7) Since rehabilitation service provision in the public sector in South Africa follow the same principles, this study raises questions about how clients in other districts and provinces in

South Africa experience rehabilitation services and how these experiences impact on rehabilitation outcomes. This indicates the need for studies of this nature to be conducted in other parts of South Africa including rural areas for improved policy implementation since most of the policies are drafted at national level.

- 8) The fact that disability can result in emotional problems as found in this study raises the need for service providers to cater for their clients' emotional needs. This may be done through counselling during rehabilitation sessions or referral to relevant personnel like psychologists. It is also important to encourage the clients during rehabilitation to try and enjoy those tasks that they can still do and to encourage them to move on with their lives despite the fact that they could not go back to the activities they could do before acquiring disability.



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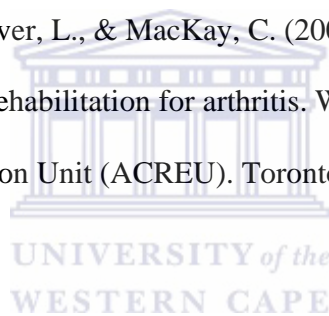
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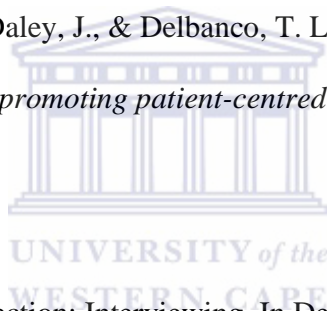
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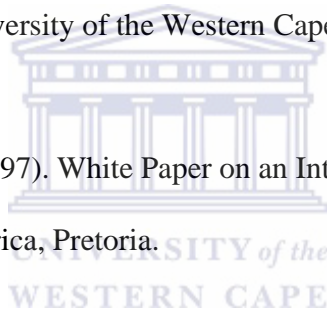
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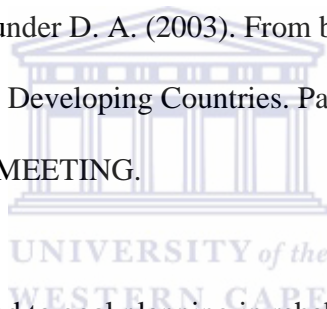
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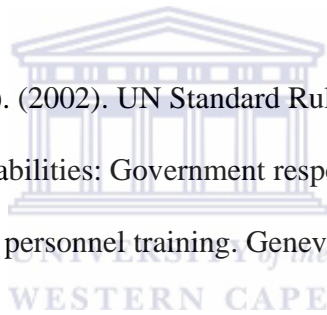
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## APPENDIX A

01 July 2008

The Director  
District Health Services and Programmes  
Cape Town Metro Health District

Dear Sir/Madam

### **RE: Request to conduct research project**

I hereby apply for permission to conduct a research project at the Community Health Centres in Cape Town Metro Health District. I am a Physiotherapy Masters Student at the University of the Western Cape. My research topic is **PERSONS WITH PHYSICAL DISABILITIES' EXPERIENCES OF REHABILITATION SERVICES AT COMMUNITY HEALTH CENTRES IN CAPE TOWN**. The target study setting includes all the Community Health Centres that offer rehabilitation services and the target population includes all the persons with physical disabilities who have received services at these centers.

The objectives of the study are:

- To determine the rehabilitation services received by the persons with physical disabilities at the centers.
- To determine the persons with physical disabilities' experiences regarding: education and provision of information, support given to the client and family, their involvement in decision making and goal setting, accessibility of the service, involvement of family and caregivers in the rehabilitation process and the attitudes of the service providers.

Approval to conduct the study was obtained from the University of the Western Cape's Study and Grant Committee and I also got ethical clearance from the Senate Committee.

I look forward to a favourable reply.

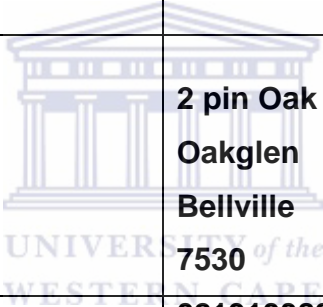
Yours sincerely

Callista K. Matsika

Mrs Anthea Rhoda  
Supervisor

## APPENDIX B

### ANNEXURE 2 PROPOSAL SUMMARY

| ANNEXURE 2 PROPOSAL SUMMARY   |   |
|---|---|
| Name of Institution/organisation conducting research                                    | University of the Western Cape  |
| Name of Investigators   | <b>Student: Callista K. Matsika</b><br><b>Supervisor: Mrs Anthea Rhoda</b>  |
| Postal Address  |  <b>2 pin Oak Street</b><br><b>Oakglen</b><br><b>Bellville</b><br><b>7530</b> |
| Telephone Number  | <b>0219193895</b>   |
| Fax number  | 9591217   |
| Mobile Number   | 0720679221  |
| Email Address   | 2827289@uwc.ac.za   |
| Institution which gave ethical approval   | University of the Western Cape  |
| Date of Ethical approval  | 11 June 2008  |
| Date research expected to commence  | Quantitative: December 2008   |
| Date research expected to end   | November 2009   |
| Date research reports should be expected  | January 2010  |
| Western Cape Districts where research will be done:<br>(Please mark with an X )         | Metro <input checked="" type="checkbox"/> X<br>Westcoast<br>Cape Winelands<br>Boland/Overberg<br>Central Karoo<br>Eden  |
| WC DOH Facilities where research will be done:<br>(Please list the name of the facility | <u>Tertiary Hospitals:</u>  |

ANNEXURE 2 PROPOSAL SUMMARY

under appropriate category)

**District Hospitals:**

**Community Health Centres: Heideveld,  
Michell's Plain, Kraaifontein,  
Woodstock, Gugulethu, Khayelitsha,  
Elsies River, Hanover Park**

**Clinics:**



UNIVERSITY *of the*  
WESTERN CAPE

| <b>ANNEXURE 2 PROPOSAL SUMMARY</b>   |  |
|--|--|
| <b>Other facilities in the WC DOH where research will be done (Please specify)</b>   | none   |
| <b>Research title</b>  | <b>The experiences of persons with physical disabilities regarding the rehabilitation services they received at Community Health Centres in Cape Town Metro Health District</b>  |
| <b>Research aim</b>  | <b>To explore the rehabilitation experiences of persons with physical disabilities and indicate areas for improvement</b>  |
| <b>Research objectives</b>   | <ol style="list-style-type: none"> <li><b>1) To determine the rehabilitation services received by the persons with physical disabilities at Community Health Centres</b></li> <li><b>2) To determine the persons with physical disabilities' experiences regarding their participation in the rehabilitation process, involvement of family members, accessibility of the services and education and information received</b></li> <li><b>3) To determine the persons with physical disabilities' overall satisfaction with the rehabilitation services</b></li> </ol> |
| <b>Brief description of methodology<br/>(Please specify estimated sample size and duration of contact with each participant e.g. interview length, clinical exams)</b> | <b>In-depth interviews- 35 to 40 minutes with each participant ( 12 participants)<br/>Questionnaire- about 30 minutes to complete (200 participants)</b>   |

| <b>ANNEXURE 2 PROPOSAL SUMMARY</b>   |   |  |
|--|---|--|
| <b>Type of Study Design: e.g. Case Control, RCT, Survey</b>                        | <b>Mixed methods (in-depth interviews + survey)</b> |  |
| <b>Budget for research</b>   | <b>R20000</b>                                       |  |
| <b>Source of funding for the research</b>  | <b>UWC research fund</b>                            |  |
| <b>The research will have implications for the requested facilities regarding:</b> | <b>Yes or NO</b>                                    | <b>If Yes what are these implications and how does your project plan to mitigate the impact</b>  |
| <b>1. Additional load on nursing</b>   | <b>NO</b>   |  |
| <b>2. Support services</b>   | <b>YES</b>  | <b>Will need therapists to arrange space and to give days and times that are appropriate for the researcher to visit their centres</b> |
| <b>3. Consumables</b>  | <b>NO</b>   |  |
| <b>4. Laboratory tests</b>   | <b>NO</b>   |  |
| <b>5. Equipment</b>  | <b>NO</b>   |  |
| <b>6. Space</b>  | <b>YES</b>  | <b>Will need space to meet the participants as they complete the questionnaire.</b>  |

| <b>ANNEXURE 2 PROPOSAL SUMMARY</b>  |  |  |
|---|--|--|
|   |  |  |
| <b>7. Communications</b>  | <b>NO</b>  |  |
| <b>8. Additional OPD visits</b>   | <b>NO</b>  |  |
| <b>9. Admission of patients</b>   | <b>NO</b>  |  |
| How will the sites be prepared to participate in your research?   | <b>Appointments will be made with therapists and facility managers for suitable times for distribution and completion of the questionnaire</b> |  |
| What is your results dissemination plan?  | <b>Will post results to the CHCs and District and Provincial offices. Will also send reports to peer reviewed journals for publishing</b>      |  |
| If your proposal is in another Official language have you included a one-page abstract of your project? | <b>The proposal is in English</b>  |  |

# APPENDIX C



Verwysing  
Reference  
Isalathiso 19/18/RP06/2008

Navre  
Enquiries  
Imbuzo Dr. I. Govender

Telefoon  
Telephone  
Ifowuni 021 483 0859

Departement van Gesondheid  
Department of Health  
iSebe iSeMpilo

Ms C. K. Matsika  
2 Pin Oak Street  
Oakglen  
Bellville  
7530

FAX: 021 9193895

Dear Ms Matsika


**The experiences of persons with physical disabilities regarding the rehabilitation services they receive at Community Health Centres in Cape Town Metro Health District**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following members of staff to assist you with access to the facilities:

- 1) Mrs L. Appolis at [lappolls@pgwc.gov.za](mailto:lappolls@pgwc.gov.za) tel: 021 3925181 (Mitchell's Plain CHC)
- 2) Mr M. Simpson at [masimason@pgwc.gov.za](mailto:masimason@pgwc.gov.za) Tel: 021 6300923 (Heideveld CHC)
- 3) Mrs Rainers at [arayners@pgwc.gov.za](mailto:arayners@pgwc.gov.za) Tel: 4809100 (Woodstock CHC)
- 4) Mrs Notshe at tel: 021 3613470 (Khayelitsha CHC)
- 5) Mrs Dziba at [ndziba@pgwc.gov.za](mailto:ndziba@pgwc.gov.za) Tel: 021 6923921 (Hanover Park CHC)
- 6) Mr A. Patentia at [apatentia@pgwc.gov.za](mailto:apatentia@pgwc.gov.za) Tel: 021 6310211 (Elsies River CHC)
- 7) Mrs Mabusela at [nmabusel@pgwc.gov.za](mailto:nmabusel@pgwc.gov.za) tel: 021 8371280 (Gugulethu CHC)
- 8) Mrs L. Steyn at [lsteyn@pgwc.gov.za](mailto:lsteyn@pgwc.gov.za) Tel: 021 9870080 (Kraaifontein CHC)

We look forward to hearing from you.

Yours sincerely

  
DR J. CUPIDO  
DEPUTY-DIRECTOR GENERAL  
DISTRICT HEALTH SERVICES AND PROGRAMMES  
DATE: 26/11/2009

UNIVERSITY of the  
WESTERN CAPE

Dorpstraat 4  
Postbus 2060  
KAAPSTAD  
8000

4 Dorp Street  
PO Box 2060  
CAPE TOWN  
8000



## APPENDIX E

### INTERVIEW GUIDE FOR CLIENTS

Tell me what your life has been like ever since the time you got disabled, how has disability impacted on your life

Please tell me any problems you might have encountered getting access to the rehabilitation services at the Community Health Centre?

Probes

- Transport
- Entrance into the centre
- Moving around the centre
- Reception from service providers



What would you say about your relationship with the service providers?

Probes

- Respect for the client
- Emotional support
- Communication

Did the service providers allow you to get involved in the proceedings of your rehabilitation?

Probes

- Asking what the client wants
- Explaining procedures to the client
- Client involvement in decision making

Did you go with a family member? Would you comment on the extent to which they were involved by the service providers in your rehabilitation?

Probe

- Did they discuss procedures with them?
- Demonstrations of what to do at home
- Where they given room to ask questions?

Did the service provider allow you enough time to ask questions?

Do you think they answered your questions adequately?

Do you think you were given enough information regarding your condition and its management?

Tell me more about this information

Do you think you were given enough information regarding support services for persons with disabilities?

Probes

- General information about the disability (cause, prognosis, management)
- Disability grant
- Vocational training
- Disabled people's organisations

What else can you tell me about your rehabilitation at the Community Health Centre?

Probes

- What do you think should be improved,
- Things that you appreciate that you think should do be maintained



## APPENDIX F

### IMIBUZO ELUNGISELELWE ABAGULI

Khawundichazele ukuba ubomi bakho bebunjani emveni kokuba ufumene ukhubazeko, ukhubazeko lukwenze wabangumntu onjani ebomini

Ndicela undichazele iingxaki othe wadibana nazo ngethuba ubuhambele uncedo olukhethekileyo lokhubazeko kwiziko lezempilo elisekihlaleni?

Isikhokelo

- Isithuthi
- Ukungena kwiziko lezempilo
- Ukuhamba-hamba phakathi kwiziko lezempilo
- Ukwamkeleka kubasebenzi

Ungathini ngonxibelelwano obunalo nabasebenzi?

Isikhokelo

- Ukuhloniba abaguli
- Ukuncedisana ngeengxaki zomphefumlo
- Unxibelelwano

Ingaba abasebenzi bakunikile ithuba lokuba uzibandakanye kwinkqubo lonyango olukhethekileyo lokhubazeko?

Isikhokelo

- Ukubuza iimfuno zesigulana
- Ukucacisa inkqubo kwisigulana

- Ukubandakanya umguli ngeziqgibo zonyango

Wawuhambe nelungu losapho? Ungasichazela ukuba babandakanywe kanjani ngumsebenzi kunyango lwakho olukhethekileyo lokhubazeko?

Isikhokelo

- Bazixoxile nabo inkqubo zonyango lwakho?
- Bababonisile izinto ekufuneka zenziwe ekhaya
- Bebelinikiwe ithuba lokubuza imibuzo?

Ingaba umsebenzi ukunikile ithuba lokuba imibuzo?

Ucinga okokuba bayiphendule ngokwanelisekayo imibuzo yakho?

Ucinga okokuba ulufumene lonke ulwazi malunga nesigulo sakho kwakunye nendlela ozakuthi uncedwe ngayo? Ndichazele ngolulwazi ulufumeneyo.

Ucinga okokuba ulufumene lonke ulwazi malunga neenkonzelo ezixhasa abantu abanokhubazeko?

Isikhokelo

- Ulwazi oluphangaleleyo malunga nokhubazeko(unobangela, inkqubela, unyango)
- Inkam-nkam
- Indawo ekuqeqeshwa khona abantu ukulungiselela ukusebenza
- Imibutho yabantu abakhubazekileyo

Ngeyiphi enye into onokundichazela yona ngonyango olukhethekileyo lokhubazeko kwiziko lezempilo elisekuhlaleni?

Isikhokelo

- Yintoni ocinga ukuba ingaphuculwa,
- Izinto ozithandileyo ocinga ukuba zingahlala ziqhubeka



## APPENDIX G

### QUESTIONNAIRE ON EXPERIENCES OF PERSONS WITH PHYSICAL DISABILITIES REGARDING REHABILITATION SERVICES AT COMMUNITY HEALTH CENTRES IN CAPE TOWN METRO HEALTH DISTRICT

#### Section A: SOCIODEMOGRAPHIC DATA.

1. Age..... years

2. Gender

1= Female

2= Male



3. Highest educational qualification.

1= No formal education/Pre-primary

2= Sub A

3= Sub B

4= Std 1

5= Std 2

6= Std 3

7= Std 4

8= Std 5

9= Std 6

- 10= Std 7
- 11= Std 8
- 12= Std 9
- 13= Std 10
- 14= Std 8 with Diploma/ Certificate
- 15=Std 9, with Diploma/ Certificate
- 16= Std 10 with Diploma/ Certificate (short course less than 2years)
- 17=Tertiary education: non-degree/diploma (minimum 2years)
- 18= Tertiary education: B degree
- 19= Tertiary education: M degree
- 20= Tertiary education: Doctorate
- 21= Other, please specify:.....



**4. Are you employed at the moment?**

- 1=YES
- 2= NO

**b) If you said YES above what type of work do you do?**

.....

**Section B: INFORMATION ABOUT YOUR DISABILITY**

**5. What caused your disability?**



1=I was born disabled

2=Road accident

3=Accident at work

4=Accident at home

5 = I don't know

6=Illness (please specify).....

7=Other (specify).....

**6. Which of the following conditions do you have?**

1=Amputation

2=Head Injury

3=Stroke

4=Cerebral palsy

5=Spinal cord injury

6=Polio

7=Multiple sclerosis

8=Other (specify).....



**7. Which of the following assistive devices do you use?**

1=Wheelchair

2=Crutches

3= Walking frame

4=Ordinary walking stick

5=Walking stick with 3 or 4 feet

6=AFO

7=Raised shoe

8=Calipers

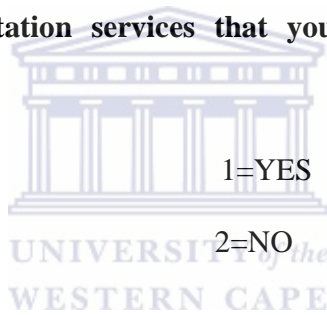
9=Prosthesis

10=None

11= Other (specify).....

**Section C: REHABILITATION SERVICES RECEIVED.**

**8. Please indicate the rehabilitation services that you received at the Day Hospital (Community Health Centre)**



a)=Occupational therapy

1=YES

2=NO

b)=Physiotherapy

1=YES

2=NO

c)=Speech therapy

1=YES

2=NO

**9. How long have you been coming to the Day Hospital (Community Health Centre) for rehabilitation?**

1=less than 1 year

2=1 to 2 years

3=>2 years to 5 years

4=More than 5 years

**10. Please indicate the type of therapy that you usually get**

1=Group therapy

2=Individual therapy

3=Both

**Section D: INFORMATION RELATING TO ACCESSIBILITY OF THE SERVICES**

**11. How do you usually travel to the Day hospital (Community Health Centre)?**

1=Walk

2=Own car

3=Relative's car

4=Hired Car

5=Hospital transport

6=Hospital wheelchair

7=Own wheelchair

8=Public transport (train, bus, taxi)



**12. Was it easy for you to find the Rehabilitation (Physiotherapy and Occupational Therapy) Department when you came for the first time?**

1=YES

2=NO

**13. Do the therapists make you feel welcome when you arrive at the Rehabilitation Department?**

1=YES

2=NO

**14. On average, how long do you wait for the therapist to attend to you?**

1=More than 1 hour

2=30mins to 1 hour

3=15 to 30minutes

4=Less than 15



**15. How much time do you usually spend with the therapist?**

1=More than 30 minutes

2=15 to 30 minutes

3=less than 15 minutes

**b) Please comment on the length of time that the therapist spends with you.**

1=Too long

2=Adequate

3=Too short

4=I don't know

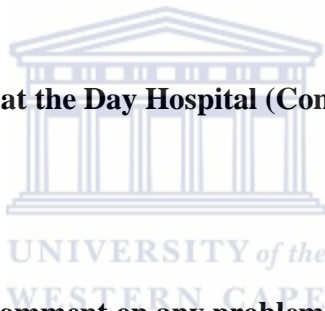
**16 Do you encounter problems when moving around the Day Hospital (Community Health Centre) e.g. moving wheelchair, climbing stairs, narrow doors?**

1=YES

2=NO

**b) If you said YES above please specify the kind of problems.....**

.....



**17 Have you ever used the toilets at the Day Hospital (Community Health Centre)?**

1=YES

2=NO

**b) If you said YES above please comment on any problems you had when using the toilets.**

1=I had no problems

2=There was no space for my wheelchair

3=There were no rails to support me

4=The sink(hand basin) was too high for me

5=Other(specify).....

**Section E: YOUR INTERACTION WITH THE SERVICE PROVIDERS**

Please indicate how you strongly agree, agree, disagree or strongly disagree with the following statements.

|   | <b>Strongly agree</b> | <b>Agree</b> | <b>Disagree</b> | <b>Strongly disagree</b> |
|---|-----------------------|--------------|-----------------|--------------------------|
| 18. The therapists treated me with respect                                    | 1                     | 2            | 3               | 4                        |
| 19. The therapists talked to me in a friendly manner                          | 1                     | 2            | 3               | 4                        |
| 20. The therapists gave me the opportunity to express my fears                | 1                     | 2            | 3               | 4                        |
| 21. The therapists encouraged me when I felt depressed                        | 1                     | 2            | 3               | 4                        |
| 22. The therapist showed interest in me as a person not just in my disability | 1                     | 2            | 3               | 4                        |

**Section F: YOUR INVOLVEMENT AND PARTICIPATION IN THE REHABILITATION PROCESS.** Please indicate how you strongly agree, agree, disagree or strongly disagree with the following statements.

|  | <b>Strongly agree</b> | <b>Agree</b> | <b>Disagree</b> | <b>Strongly disagree</b> |
|--|-----------------------|--------------|-----------------|--------------------------|
| 23. The therapists asked me what I expected to benefit from rehabilitation e.g. walking, using my arm. | 1                     | 2            | 3               | 4                        |
| 24. The therapists involved me in setting goals  | 1                     | 2            | 3               | 4                        |
| 25. The therapist gave me the opportunity to comment on my progress in rehabilitation                  | 1                     | 2            | 3               | 4                        |
| 26. The therapists explained what they were doing in an understandable way                             | 1                     | 2            | 3               | 4                        |
| 27. The therapists gave me the opportunity to ask questions  | 1                     | 2            | 3               | 4                        |

**Section G: INVOLVEMENT AND SUPPORT OF FAMILY. You can only respond to this section if you have gone with a family member to the Day Hospital (Community Health Centre) for your rehabilitation. If not please go to section G. Please indicate your response to this section using the given options.**

|   | Always | Sometimes | Never |
|---|--------|-----------|-------|
| 28. Did the therapists help your family to understand your disability?      | 1      | 2         | 3     |
| 29. Did the therapists talk to your family member during procedures?        | 1      | 2         | 3     |
| 30. Were your family members given a home program to help you with at home? | 1      | 2         | 3     |
| 31. Were your family members given time to ask questions?                   | 1      | 2         | 3     |
| 32. Did they get the answers to what they wanted to know?                   | 1      | 2         | 3     |



**SECTION H: INFORMATION GIVEN TO YOU BY THE SERVICE PROVIDERS.**

Please indicate how you strongly agree, agree, disagree or strongly disagree with the following statements. Use the codes provided to respond to item number 40.

|   | Strongly agree | Agree | Disagree | Strongly disagree |
|---|----------------|-------|----------|-------------------|
| 33. I have been given enough information about the cause of my disability     | 1              | 2     | 3        | 4                 |
| 34. I was given information regarding possible complications of my disability | 1              | 2     | 3        | 4                 |
| 35. I was given enough information on how my family and I can manage at home  | 1              | 2     | 3        | 4                 |

**36) I was given information about the following;**

a) Disability grant

1=YES

2=NO

b) Organizations for disabled persons in South Africa

1=YES

2=NO

c) Support groups for persons with disabilities in my community

1=YES

2=NO

d) Rights for the disabled persons in South Africa

1=YES

2=NO

e) Vocational training

1=YES

2=NO

THANK YOU FOR YOUR TIME



## APPENDIX I

### VRAESTEL OOR DIE ERVARING VAN FISIES GESTREMDE PERSONE TYDENS HUL REHABILITASIE BY GEMEENSKAPS GESONDHEIDS SENTRUM IN DIE KAAPSE METRO GESONDHEIDS DISTRIK.

#### Afdeling A: SOCIO-DEMOGRAFIESE DATA.

1. Ouderdom..... jare

2. Geslag?

1= Vroulik

2= Manlik



3. Hoogste opvoedings kwalifikasie.

1= Geen formele onderrig/Pre-primêr

2= Sub A

3= Sub B

4= Std 1

5= Std 2

6= Std 3

7= Std 4

8= Std 5

9= Std 6

10= Std 7

11= Std 8

12= Std 9

13= Std 10

14= Std 8 met Diploma/ Sertifikaat

15=Std 9 met Diploma/ Sertifikaat

16= Std 10 met Diploma/ Sertifikaat (kursus minder as 2 jaar)

17= Tertiële onderwys: Geen graad / diploma (minimum 2 jaar)

18= Tertiële opvoeding: B Graad

19= Tertiële opvoeding: M Graad

20= Tertiële opvoeding: Doktor's Graad

21= Ander, spesifiseer asseblief:.....



**4. Werk u tans?**

1= JA

2= NEE

**b) Indien ja, watter tipe werk doen u?**

.....

**Afdeling B: INFORMASIE IN VERBAND MET U GESTREMDHEID**

**5. Wat is die oorsaak van u gestremdheid?**

1=Ek is gestremd gebore

2=Padongeluk

3=Ongeluk by die werk

4=Ongeluk by die huis

5 = Ek weet nie

6= Siekte (spesifiseer asseblief).....

7=Ander (spesifiseer).....

**6. Watter van die volgende toestande het u?**

1=Amputasie

2=Kopbesering

3=Beroerte

4=Cerebral palsy

5=Spinal kord

6=Polio

7=Multiple sclerosis

8=Ander (spesifiseer).....



**7. Gebruik u enige van die volgende hulp middele?**

1=Rolstoel

2=Krukke

3= Loopraam

4=Gewone loopstok

5=Loopstok met 3 of 4 pote

6=AFO

7=Gehefde skoen

8=Kalipers

9=Prostese

10=Geen

11=ander(spesify)

### **Afdeling C: REHABILITASIE DIENSTE ONTVANG.**

**8. Dui asseblief aan watter tipe dienste u by die daghospitaal (gemeenskaps gesondheids sentrum) ontvang het.**

1=Arbeidsterapie

1=JA

2=NEE

2=Fisioterapie

1=JA

2=NEE

3=Spraakterapie

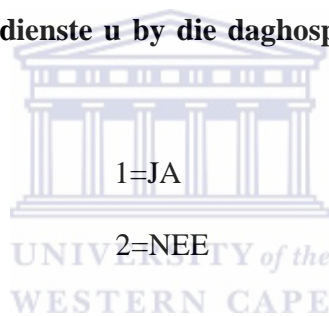
1=JA

2=NEE

**9. Hoe lank besoek u al die daghospitaal (Gemeenskapsgesondheidsentrum)?**

1= minder as 1 jaar

2=1 tot 2 jaar



3=2 tot 5 jaar

4=Meer as 5 jaar

**10. Watter tipe terapie ontvang u gewoonlik?**

1=Groep terapie

2=Individuele terapie

3=Albei

**Afdeling D: INFORMASIE IN VERBAND MET TOEGANKLIKHEID TOT HIERDIE  
DIENSTE**

**11. Hoe reis u gewoonlik na die daghospitaal (gemeenskapsgesondheidsentrum)?**

1=Loop

2=Eie motor

3=Familielid se motor

4=Gehuurde motor

5=Hospitaal vervoer

6=Hospitaal se rolstoel

7=Eie rolstoel

8=Publieke vervoer (trein, bus, taxi)



**12. Was dit maklik vir u om die terapie departement te vind met u eerste besoek?**

1=JA

2=NEE

**13. Laat die terapeut by die Fisioterapie Afdeling u welkom voel met u aankoms daar?**

1=JA

2=NEE

**14. Hoe lank het u ongeveer gewag om 'n terapeut te sien?**

1=Meer as 1 uur

2=30 minute tot 1 uur

3=15 tot 30 minute

4=Minder as 15 minute



**15. Hoeveel tyd spandeer u gewoonlik met die terapeut?**

1=Meer as 30 minute

2=15 tot 30 minute

3=Minder as 15 minute

**b) Gee kommentaar oor die tyd wat die terapeut met u spandeer.**

1=Te lank

2=Genoeg

3=Te kort

4=Ek weet nie



**16. Ondervind u enige probleme om binne in die daghospitaal (gemeenskaps gesondheids sentrum) rond te beweeg? Bv. Om rolstoel te beweeg, trappe te klim, nou deure?**

1=JA

2=NEE

**b) Indien u JA beantwoord het, spesifiseer asseblief watter tipe probleme**

.....  
.....

**17. Het u al ooit die toilette in die daghospitaal (gemeenskaps gesondheids sentrum) gebruik?**

1=JA

2=NEE



**b) Indien u JA beantwoord het, kommentaar asseblief op enige probleme wat u ondervind het gedurende die gebruik van die toilette.**

1=Ek het geen probleme ondervind nie.

2=Daar was geen ruimte vir my rolstoel nie.

3=Daar was geen relings om my te ondersteun nie.

4=Die sink (handewasbak) was te hoog vir my.

5=Ander (spesifiseer).....

**Section E: U INTERAKSIE MET DIE DIENSKAFFERS (TERAPEUT)**

**Dui asseblief aan of u volkome saam stem, slegs saam stem, nie saam stem nie of glad nie saam stem nie met die volgende verklarings.**

|  | <b>Stem volkome saam</b> | <b>Stem saam</b> | <b>Stem nie saam nie</b> | <b>Stem glad nie saam nie</b> |
|--|--------------------------|------------------|--------------------------|-------------------------------|
| 18. Die terapeute het my met respek behandel.  | 1                        | 2                | 3                        | 4                             |
| 19. Die terapeute het op 'n vriendelike wyse met my gepraat.                               | 1                        | 2                | 3                        | 4                             |
| 20. Die terapeute het my die geleentyd gegee om my vrese te deel.                          | 1                        | 2                | 3                        | 4                             |
| 21. Die terapeut het my aangemoedig waneer ek neerslagtig gevoel het.                      | 1                        | 2                | 3                        | 4                             |
| 22. Die terapeut het belangstelling in my getoon as persoon en nie net my gestremdheid nie | 1                        | 2                | 3                        | 4                             |

**Afdeling F: U BETROKKENHEID EN DEELNAME IN DIE REHABILITASIE PROSES.**

**Dui asseblief aan of u volkome saam stem, slegs saam stem, nie saam stem nie of glad nie saam stem nie met die volgende verklarings.**

|   | <b>Stem<br/>volkome<br/>saam</b> | <b>Stem<br/>saam</b> | <b>Stem<br/>saam nie</b> | <b>Stem<br/>nie<br/>glad<br/>nie saam nie</b> |
|---|----------------------------------|----------------------|--------------------------|---|
| 23. Die terapeute het my gevra wat verwag ek van terapie bv. Om te stap, om my arm te gebruik.      | 1                                | 2                    | 3                        | 4   |
| 24. Die terapeute het my laat deelneem in die doelwitte.  | 1                                | 2                    | 3                        | 4   |
| 25. Die terapeute het my geleentheid gegee om kommentaar te lewer oor my vordering in rehabilitasie | 1                                | 2                    | 3                        | 4   |
| 26. Die terapeute het op 'n vertaanbare manier verduidelik wat hulle doen.                          | 1                                | 2                    | 3                        | 4   |
| 27. Die terapeute het my die geleentheid gegee om vrae te vra.                                      | 1                                | 2                    | 3                        | 4   |

**Afdeling G: BETROKKENHEID VAN FAMILIE EN VERSORGERS. Beantwoord slegs hierdie gedeelte indien u wel vergesel was deur familielede, vriende of versorgers na die daghospitaal (Gemeenskapsgesondheidsentrum). Indien nie, gaan na Afdeling H.**

|   | <b>Altyd</b> | <b>Somtyds</b> | <b>Nooit</b> |
|---|--------------|----------------|--------------|
| 28. Het die terapeut jou familie/versorgers gehelp om u gestremdheid te verstaan? | 1            | 2              | 3            |
| 29. Het die terapeute met u familielid/versorger gepraat tydens die prosesse?     | 1            | 2              | 3            |
| 30. Was u familielede/versorgers 'n program gegee huis toe om u tuis mee te help? | 1            | 2              | 3            |
| 31. Het u familielede/versorgers tyd gekry om vrae te vra?                        | 1            | 2              | 3            |
| 32. Het hulle antwoorde gekry op wat hulle wou weet?                              | 1            | 2              | 3            |

**Afdeling H: INFORMASIE VERSKAF AAN U DEUR DIE DIENSVERSKAFFERS**

**Dui asseblief aan of u volkome saam stem, slegs saam stem, nie saam stem nie of glad nie saam stem nie met die volgende verklarings.**

|  | <b>Stem volkome saam</b> | <b>Stem saam</b> | <b>Stem nie saam nie</b> | <b>Stem glad nie saam nie</b> |
|--|--------------------------|------------------|--------------------------|-------------------------------|
| 33. Ek is genoeg verskaf in verband met die oorsaak van my gestremdheid                              | 1                        | 2                | 3                        | 4                             |
| 34. Ek het genoeg inligting gekry in verband met moontlike komplikasies met gestremdheid             | 1                        | 2                | 3                        | 4                             |
| 35. Ek het genoeg inligting ontvang oor hoe ek en my familie my gestremdheid by die huis kan hanteer | 1                        | 2                | 3                        | 4                             |

**36) Ek was informasie gegee oor die volgende:**

a) Ongeskikheids toelaag

1=JA

2=NEE

b) Organisasies vir gestremde mense

1=JA

in Suid Afrika

2=NEE

- c) Ondersteunings groepe vir mense wat gestremd is  
in my gemeenskap 1=JA  
2=NEE
- d) Regte van gestremde mense in Suid Afrika 1=JA  
2=NEE
- e) Beroeps opleiding 1=JA  
2=NEE

BAIE DANKIE VIR U TYD



**APPENDIX J**

**CONSENT FORM**

**Title of research project: THE EXPERIENCES OF PHYSICALLY DISABLED PEOPLE  
REGARDING THE REHABILITATION SERVICES THEY RECEIVED**

The study has been explained to me in a language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me in any way.

**Participant's name..... Participant's signature.....**

**Witness's name..... Witness's signature.....**

**Date.....**

Should you have any questions regarding this study or wish to report any problems you have experienced related to the study, please contact the study coordinator.

**Study Coordinator's Name: Mrs Anthea Rhoda**

**University of the Western Cape**

**Private Bag X17, Bellville 7535**

**Telephone (021) 959-2543**

**Fax (021) 959-1217**

## APPENDIX K

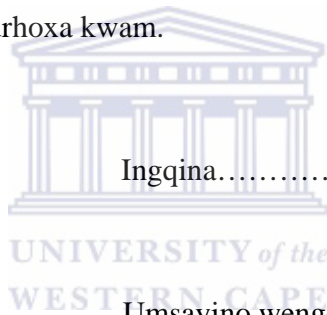
### IFOMU YESIVUMELWANO

Isihloko sophando lweprojekthi:

Esi sifundo siye sacaciswa kum ngolwimi endiluqondayo yaye ndiznikele ngokupheleleyo ndavumelana ukuba ndithathe inxaxheba kwesi sifundo. Imibuzo ebendinayo malunga nesi sifundo iye yaphendulwa. Ndiyayiqonda into yokokuba inkcukhaca zam azizokwaziswa yaye ndingarhoxa ukuthatha inxaxheba ndinganikezanaga sizathu nangaliphi na ixesha yaye ayizokuba nabuzaza kum into yokurhoxa kwam.

Igama lam.....

Ingqina.....



Umsayino wam..... Umsayino wengqina.....

Umhla.....

Ukuba unemibuzo onayo malunga nesi sifundo okanye unomnqweno wokwenza ingxelo malunga neengxaki othe wahlangana nazo malunga nesi sifundo, nceda qhagamishelana naba balandelayo:

Umphandi: Callista Matsika

University of the Western Cape



Physiotherapy Department

Private Bag x 17, Bellville, 7735

South Africa

Umnxeba wabucala: 0720679221

Fekisi: 021-9591217

Imbalelwano yekhompyutha: [2827289@uwc.ac.za](mailto:2827289@uwc.ac.za)

OKANYE

Umlawuli wesi sifundo: Mrs Anthea Rhoda

University of the Western Cape

Physiotherapy Department

Private Bag x 17, Bellville, 7735

South Africa

Umnxeba: 021-9592543

Fekisi: 021-9591217

Imbalelwano yekhompyutha: [arhoda@uwc.ac.za](mailto:arhoda@uwc.ac.za)



## APPENDIX L

### TOESTEMMINGSVORM

**Titel van navorsingsprojek: DIE ERVARING VAN FISIES GESTREMDE PERSONE TYDENS HUL REHABILITASIE BY GEMEENSKAPLIKE GESONDHEIDS SENTRUMS IN DIE KAAPSE METRO GESONDHEIDSDISTRIK, SUID AFRIKA.**

Hierdie studie is aan my verduidelik in 'n verstaanbare taal van my keuse. Hiermee onderneem ek vrywilliglik om aan hierdie studie deel te neem. Al my vrae rondom die studie is beantwoord.

Die volgende inligting is ook aan my verduidelik:

- My identiteit sal nie bekend gemaak word nie.
- Ek kan tydens my deelname aan die studie enige tyd onttrek sonder om redes te verskaf en sonder dat dit my negatief sal beïnvloed.

.....  
**Naam van Deelnemer**

.....  
**Handtekening van Deelnemer**

.....  
**Naam van Getuie**

.....  
**Handtekening van Getuie**

.....  
**Datum**

**Naam van Studie Koördineerder: Anthea Rhoda**

**Fisioterapie Departement**

**Univesiteit van Wes Kaapland**

**Privaatsak X17, Belville 7535**

**Tel: (021) 959 2543**

**Faks: (021) 959 1217**

**Epos: [arhoda@uwc.ac.za](mailto:arhoda@uwc.ac.za)**



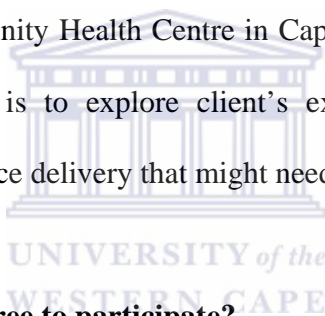
## **APPENDIX M**

### **INFORMATION SHEET**

**Title:** The experiences of persons with physical disabilities regarding the rehabilitation services they received at Community Health Centres in Cape Metro Health District in Western Cape Province.

#### **What is this study about?**

This is a research project being conducted by Callista Kanganwiro Matsika at the University of the Western Cape. You are being invited to participate in this project because you have received rehabilitation services at a Community Health Centre in Cape Town Metro Health District. The purpose of this research project is to explore client's experiences regarding rehabilitation services to identify aspects of service delivery that might need to be improved.



#### **What will I be asked to do if I agree to participate?**

You will be asked to complete a questionnaire. This questionnaire will be completed at the community health centre where you received rehabilitation services. It will take you about 30 minutes to complete this questionnaire.

#### **Would my participation in this study be kept confidential?**

We will do our best to keep your personal information confidential. To help protect your confidentiality, the survey is anonymous and will not contain information that may personally identify you, the completed questionnaires will be kept in locked filing cabinets until data

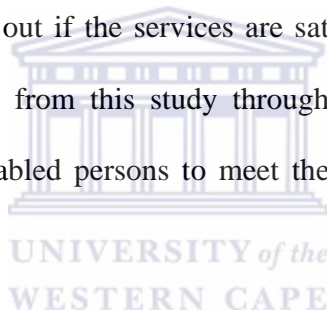
analysis is finished and only the researcher will have access to the questionnaires. If we write a report or article about this research project, your identity will not be revealed.

**What are the risks of this research?**

There are no known risks associated with participating in this research.

**What are the benefits of this research?**

This research is not designed to help you personally but the results may help the investigator learn more about how the physically disabled in the Western Cape Province perceive their rehabilitation services and to find out if the services are satisfactory to them. We hope that in future other people might benefit from this study through the improvement of policies and rehabilitation facilities for the disabled persons to meet their specific needs and hence, better quality of life for them.



**Do I have to be in this research or may I stop participating at any time?**

Your participation in this research is completely voluntary. You may choose not to take part at all. If you choose to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits for which you qualify.

**Is any assistance available if I am negatively affected by this research?**

If you are negatively affected by this research, you will be referred for relevant care.

### **What if I have questions?**

This research is being conducted by Callista Kanganwiro Matsika, Department of Physiotherapy, University of the Western Cape. If you have any questions about the research study itself please contact Callista K. Matsika at 2 Pin Oak Street, Oakglen, Bellville 7530, telephone number 0720679221. E-mail: 2827289@uwc.ac.za.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

Head of Department: Prof J. Phillips

Dean of the Faculty of Community and Health Sciences: Prof R. Mpofu

University of the Western Cape

Private bag X17

Bellville 7535



This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.

## APPENDIX N

### IPHEPHA ELUQULATHE ULWAZI

**Isihloko sophando lweprojekthi:** Izimvo zabantu abakhubazeke ngokwasemzimbeni malunga nonyango olungqamene nokhubazeko kumajelo ezempilo asekuhlaleni kwiphondo lezempilo laseNtshona Koloni iMetro, eMzantsi Afrika.

#### **Esisifundo singantoni?**

Olu phando lwenziwa nguCallista Kanganwiro Matsika okwiDyunivesithi yephondo leNtshona Koloni. Siyakumema ukuba uthabathe inxaxheba kolu phando njengokuba ufumana uncedo olungqamene nokhubazeko kwijelo lezempilo elisekuhlaleni kwiphondo lezempilo laseNtshona Koloni iMetro. Isizathu soluphando kukufuna ulwazi nezimvo zabaguli malunga nonyango olungqamene nokhubazeko ukuze kuchongwe izinto ezinokuthi zivele yaye ziphuculwe kwindlela elunikezelwa ngalo unyango.

#### **Yintoni ezakucelwa ukuba ndiyenze ukuba ndithe ndavuma ukuthabatha inxaxheba?**

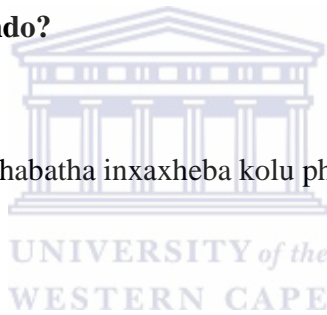
Uya kuthi ucelwe ukuba uphendule imibuzo ekwifomu. Le fomu iyakuthi iphendulelwe kwiziko lezempilo elisekuhlaleni apho ufumana khona unyango olukhethekileyo olungqamene nokhubazeko lwakho. Ukuphendula loo mibuzo iyakukuthatha malunga isiqingatha seyure.

### **Ingaba ukuthabatha kwam inxaxheba kwesi sifundo kuyakufihlakala?**

Sizakuzama ngandlela zonke ukuba inkcukhaca zakho zigcinwe ngokufihlakeleyo. Ukunceda ukukhusela ukufihlakala kwakho, oluphando alufuni gama lamntu yaye aluzukuba nolwazi olunokuthi likuchaze ukuba ungubani, ifomu ephendulweyo yonke imibuzo iyakuthi itixelwe kwikhabhathi ebucala kude kufikelele ithuba lokucalucalula iimpendulo yaye iyakubangumphandi kuphela ozakufikelela kwezi fomu. Xa sizakubhala ingxelo yesifundo okanye inxalenye yesifundo, iinkcukhaca zakho ziyakuthi zikhuseleke kwinqanaba eliphezulu.

### **Zithini izoyikiso/iingozi zesi sifundo?**

Akukho ngozi zayanyanise nokuthabatha inxaxheba kolu phando.



### **Ziintoni iinzuzo zoluphando?**

Oluphando alulungiselelwanga ukuba luncede wena buqu, kodwa iziphumo zophando ziyakuthi zancede umphandi azi ngokuphangaleleyo ngendlela abantu abanokhubazeko emzimbeni abalubona ngayo unyango olungqamene nokhubazeko lwabo kwakunye nokuqonda ukuba ingaba unyango luluncedo na kubo. Sinethemba kwilixa elizayo abanye abantu bayakuzuza ngesisifundo ngokuthi kuphuhlise imiqulu yezempilo neyenkonzo zonyango zokhubazeko elungiselelwe abantu abanokhubazeko ikhawulelane neemfuno zabo, ngokwenjalo iyakuphucula indlela abaphila ngayo.



**Ndinyanzelekile ukuba ndibekoluphando yaye ndingarhoxa nangaliphi na ixesha ukuthabatha inxaxheba?**

Inxaxheba yakho koluphando ibikukuthanda kwakho. Unalo ilungelo lokurhoxa ngokupheleleyo. Ukuba uqonde ukuba mawuthabathe inxaxheba koluphando unakho ukutshintsha urhoxe nangaliphi na ixesha. Ukuba uthe waqonda ukuba mawungathabathi inxaxheba kwesi sifundo okanye usuke urhoxe sowuyithabathile inxaxheba, awuzokufumana sohlwayo okanye ungafumani nzuzo ekufanelekileyo ukuba uyifumane.

**Lukhona uncedo olukhoyo ukuba ndithe ndaphazamiseka ngenxa yolu phando?**

Ukuba uthe waphazamiseka loluphando, ingcaphephe yezengqondo iyakuthi ichazelwe ngawe ukuba ikuncede okanye uthunyelwe kuncedo olungqamene ne meko yakho okuyo.

**Kuzakuthiwani xa ndinemibuzo?**

Olu phando lwenziwa nguCallista Kanganwiro Matsika, kwicandelo lokolula imizimba kwiDyunivesithi yeNtshona Koloni. Ukuba unemibuzo malunga noluphando nceda qhagamishelana no:

Callista Kanganwiro Matsika

University of the Western Cape

Physiotherapy Department

Private Bag x 17, Bellville, 7735

South Africa

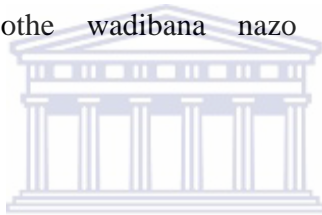
Umnxeba: 021-9592807

Umnxeba wabucala: 0743230051

Fekisi: 021-9591217

Imbalelwano yekhompyutha: ckmatsika@yahoo.co.uk

Ukuba unemibuzo engqamene nesi sifundo njengomthabathi-nxaxheba koluphando okanye unqwenela ukuchaza ingxaki othe wadibana nazo ezingqamena nesisifundo nceda qhagamishelana no:



Umpathi candelo: Professor Jullie Phillips

Umpathi wecandelo ledyunivesithi lezenzululwazi ekuhlaleni nezempilo: Professor Ratie

Mpofu

University of the Western Cape

Private Bag x 17

Bellville

7535

## APPENDIX O

### INLIGTINGSVORM

**Titel:** Die ervaring van fisies gestremde persone tydens hul rehabilitasie by Gemeenskapsgesondheidsentrums in die Kaapse Metro Gesondheidsdistrik, Suid Afrika.

#### **Waaroor gaan hierdie studie?**

Hierdie studie is onder leiding van Callista Kanganwiro Matsika van die Universiteit van Wes-Kaapland. Ons vra u samewerking om deel te neem aan hierdie studie aangesien u rehabilitasie ontvang het by een van die gemeenskapsgesondheidsentrums in die Kaapse Metro Gesondheidsdistrik. Die doel van hierdie navorsingsprojek is om aspekte te identifiseer wat kan bydra tot die verbetering van rehabilitasie dienste in gemeenskapsgesondheidsentrums in die Kaapse Metro Gesondheidsdistrik, soos ervaar deur persone tydens hul rehabilitasie.

#### **Wat is die vereistes indien ek besluit om aan die studie deel te neem?**

U sal gevra word om 'n vraestel te beantwoord. Hierdie vraestel sal voltooi word by die gemeenskapsgesondheidsentrum waar u rehabilitasie ontvang het. Dit sal u omtrent 30 minute neem om hierdie vraestel te beantwoord.

#### **Sal my deelname tydens die studie vertroulik wees?**

Alle persoonlik inligting wat u verskaf sal vertroulik wees. Om u vertroulikheid te waarborg sal u anoniem bly en sal die studie geen inligting bevat wat u kan identifiseer nie. Die voltooide vraestelle sal veilig bewaar word in 'n kabinet wat ten alle toegesluit sal bly tot en met die ontleding van die data. Slegs die navorser sal toegang tot hierdie inligting het.

Indien ons 'n verslag of 'n artikel oor hierdie navorsingsprojek skryf sal ons alle kanale moontlik volg om u identiteit te beskerm.

**Is daar enige risiko's verbonde aan hierdie studie?**

Daar is geen risiko's sover ons kennis strek aan hierdie studie verbonde nie.

**Is dit verpligtend om deel neem en kan ek my enige tyd onttrek?**

U deelname aan die studie is vrywilliglik. Dit is u vrye keuse om deel te neem of nie. Indien u tydens u deelname aan die studie besluit om te onttrek, mag u dit doen. U keuse om nie meer deel te neem aan die studie nie of om tydens u deelname te onttrek, sal u geensins benadeel of negatief beïnvloed nie.

**Is daar enige ondersteuning beskikbaar indien ek negatief beïnvloed word deur hierdie studie?**

Indien u wel negatief beïnvloed word sal ons 'n gekwalifiseerde psigoloog(sielkunde) aanstel om u by te staan of u vir relevante versorging verwys.

**Indien ek enige vrae het?**

Hierdie navorsingsprojek is onder leiding van Callista Kanganwiro Matsika, Fisioterapie Departement, Universiteit van Wes-Kaapland. Indien u enige vrae het in verband met hierdie navorsingsprojek kan u in verbinding tree met Callista K. Matsika by 2 Pin Oak, Oakglenstraat, Bellville, 7530, kontaknommer 0743230051. Epos: [ckmatsika@yahoo.co.uk](mailto:ckmatsika@yahoo.co.uk).

Indien u enige navrae aangaande hierdie studie het asook u regte as 'n deelnemer, of enige probleme ondervind het gedurende die studie kan u die volgende persone kontak;

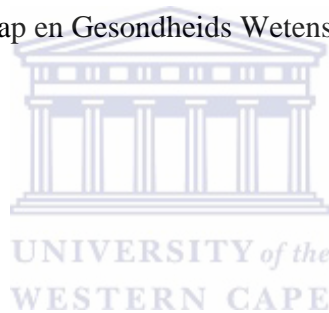
Departementshoof: Professor J. Phillips

Fakulteitsvoorsitter van Gemeenskap en Gesondheids Wetenskap: Professor R. Mpofu

Universiteit van Wes-Kaapland

Privaatsak X17

Bellville, 7535



Hierdie navorsingsprojek is goedgekeur deur die Universiteit van Weskaaplandse “Senaat Navorsingskommittee en Etiese Kommittee.