



Physiotherapy rehabilitation in the context of HIV and disability in Kwazulu-Natal

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Table of Contents

Abstract.....	1
Acknowledgments	2
Chapter 1: Introduction.....	3
1.1 Introduction	3
1.2 Background.....	3
1.3 Problem statement.....	5
1.4 Research question	6
1.5 Study aim.....	6
1.6 Study objectives	6
1.7 Significance	7
Chapter 2: Literature review	8
2.1 Introduction	8
2.2 HIV pathology	8
2.3 HIV and exercise.....	11
2.4 The International Classification of Functioning, Disability and Health	14
2.5 Disability and HIV.....	16
2.6 World Health Organisation Disability Assessment Schedule	18
2.7 The rights of people living with disabilities	19
2.8 Summary	21
Chapter 3: Methodology	22
3.1 Study design	22

3.2 Research setting	22
3.3 Study population	23
3.4 Inclusion criteria	23
3.5 Exclusion criteria	24
3.6 Sampling strategy	24
3.7 Data collection	24
3.8 Data analysis	26
3.9 Ethical considerations	27
3.10 Conclusion	28
Chapter 4: Results	29
4.1 Introduction	29
4.2 WHODAS 2.0 data	29
4.3 Interview data	33
4.3.1 Knowledge of health condition	34
4.3.2 Medication	34
4.3.3 Impairments	36
4.3.4 Activities	37
4.3.5 Participation	38
4.3.6 Contextual factors	40
4.3.7 Rehabilitation experience	41
4.3.8 Barriers to rehabilitation	43
4.4 Conclusion	44

Chapter 5: Discussion	45
5.1 Introduction	45
5.2 Participants' demographics and diagnoses	45
5.3 Knowledge of health condition	48
5.4 Medication	49
5.5 Impairments, activity limitations and participation restrictions	49
5.6 Rehabilitation experience	54
5.7 Barriers to rehabilitation	55
5.8 Summary	60
Chapter 6: Conclusion	61
6.1 Conclusion	61
6.2 Limitations	62
6.3 Recommendations	63
References	65
Appendix 1: WHODAS 2.0 - 36-item, interviewer-administered	75
Appendix 2: Interview question schedule	84
Appendix 3: Interview question schedule (isiZulu)	86
Appendix 4: Study information sheet for participants	88
Appendix 5: Study information sheet for participants (isiZulu)	90
Appendix 6: Study consent form in both English and isiZulu	92
Appendix 7: Study consent form for research assistants	93
Appendix 8: Letter of permission from St Mary's Hospital	94
Appendix 9: UKZN H.S.S. ethics approval letter	95

Abstract

Aim: The purpose of this study was to describe the experiences of people living with the human immunodeficiency virus who underwent a physiotherapy rehabilitation programme, with the aim of informing and improving future physiotherapy rehabilitation interventions. **Methodology:** *Design:* A qualitative research design was adopted, using the International Classification of Function, Disability and Health as a guiding framework. *Population:* All adult HIV positive patients who were referred for physiotherapy rehabilitation at a public-funded South African hospital during the course of a five week clinical block. *Sample:* Fourteen participants were eligible for the study. Eight of these participants, who were able to attend the post-rehabilitation interview, were considered for final analysis in the study. *Study setting:* A public-funded hospital within the eThekweni district of KwaZulu-Natal, South Africa. *Research procedure:* All eligible participants were requested to complete a questionnaire, the World Health Organisation Disability Assessment Schedule, prior to commencing a physiotherapy rehabilitation programme. After the period of rehabilitation, participants were interviewed using 14 open-ended questions designed to explore their experiences of this programme. **Results:** The questionnaire data described the participants' demographics and illustrated the varying cognitive and physical challenges faced by these eight individuals. Content analysis of the eight interviews revealed the following themes: the participants' knowledge of their health conditions and their prescribed medication, the impact of their illness on their impairments, activities and participation in their daily lives, the context in which these factors exist, the participants' experience of physiotherapy rehabilitation and the barriers they faced in accessing continued rehabilitation. **Conclusion:** While participants reported mostly positive experiences related to physiotherapy rehabilitation, they face a number of barriers that limit their access to continued rehabilitation. It is hoped that the results of this study will assist in informing the development of future physiotherapy interventions, which are better designed to suit the needs of PLHIV in a South African public health context.

Keywords: *PLHIV, physiotherapy, rehabilitation, ICF, barriers*

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*“Yes [I would like to continue with exercise], so that my body
is going to be motivated always.” (Participant 2)*

Chapter 1: Introduction

1.1 Introduction

The purpose of this study was to explore and describe the experiences of people living with the human immunodeficiency virus (PLHIV) and disability after having undergone a physiotherapy rehabilitation programme at a public-funded hospital in KwaZulu-Natal province, South Africa. As PLHIV live longer due to modern pharmaceutical treatment regimes, it is important that they receive appropriate rehabilitation when required (Myezwa et al, 2012). While there is a body of literature highlighting the importance of exercise for the physical and emotional well-being of PLHIV (summarised concisely by O'Brien et al, 2009a; 2010), it is hoped that this study serves to highlight some of the specific successes and challenges of a physiotherapy rehabilitation programme in a South African public-funded hospital. This information will, in turn, be of value in informing the future design of improved rehabilitation programmes for PLHIV.

1.2 Background

On June 5, 1981, The Morbidity and Mortality Weekly Report published an account of pneumocystis carinii pneumonia in five previously healthy young men in Los Angeles, California, two of whom had died (Centre for Disease Control, 1981). This report is now acknowledged as the first published scientific account of what would become known as human immunodeficiency virus (HIV) and acquired immunodeficiency syndrome (AIDS). More than thirty years later, the most recent estimates by the Joint United Nations Programme on HIV/AIDS (UNAIDS 2010) reveal that there are 33.3 million people living with HIV (PLHIV) worldwide. This is compared with 26.2 million in 1999 - a 27% increase. Although the annual number of new HIV infections has been steadily declining since the late 1990s (Johnson et al, 2007), this decrease is offset by the reduction in AIDS-related deaths due to the significant scale up of antiretroviral therapy over the past few years (UNAIDS 2010). If this trend is maintained, it stands to reason that the total number of PLHIV will continue to increase world-wide.

Sub-Saharan Africa bears an inordinate share of the worldwide HIV burden, with an estimated 11.3 million PLHIV in 2009. AIDS-related deaths have fallen in this region from 1.4 million in 2001 to 1.3 million in 2009 and this trend looks set to continue with the more widespread availability and uptake of highly active antiretroviral therapy or HAART (UNAIDS 2010). This UNAIDS data (2010) shows that in Sub-Saharan Africa the access to HAART has increased from 2% to 27% in the period from 2002 to 2009/10. According to a recently published report by the Actuarial Society of South Africa (ASSA, 2011) an estimated 5.5 million people are currently living with HIV in South Africa, more than in any other single country in the world. Within South Africa itself, KwaZulu-Natal has the highest HIV prevalence of all the nine provinces, with 14.8% of the province's inhabitants living with HIV, as compared to the Western Cape, which has the lowest prevalence of 5%. This report estimates that the annual number of AIDS deaths in South Africa decreased from 257 000 in 2005 to 194 000 in 2010.

The statistics above indicate that there will be more and more people living with, rather than dying of, HIV in South Africa and more specifically in the province of KwaZulu-Natal. This is, of course, a positive development, but this increased longevity has been mirrored by an increase in the prevalence and impact of disability experienced by this population (Rusch et al, 2004). The effects of the increased burden of diseases can also be seen in the increased disability prevalence in the region with an estimated 24.2% of the South African population considered to live with disability (World Health Organisation, 2011). Physiotherapy as a profession can play a key role in assisting PLHIV to prevent and manage their disabilities and therefore enable their holistic participation in the occupational, social and recreational aspects of their lives (Nixon et al, 2011; Myezwa et al, 2012).

The profession of physiotherapy is concerned with the assessment and treatment of people challenged with a wide array of neurological, musculoskeletal and respiratory conditions. PLHIV are prone to opportunistic infections that damage one or all of the above physiological systems (Jenkins, 2009) and thus it is important that physiotherapists are involved in the rehabilitation of these patients (Myezwa et al, 2012). The University of KwaZulu-Natal (UKZN) is the only tertiary institution that trains

undergraduate physiotherapists in the province which, according to the statistics above, can be considered the epicenter of the worldwide HIV pandemic. In the course of their four year degree programme UKZN physiotherapy students are introduced to the theory of HIV pathology and treatment and, in their third and final years, are involved in the hands on treatment on PLHIV in both clinical and community settings (UKZN, 2012).

There is a body of research focusing on the effects of exercise and rehabilitation interventions on the health and quality of lives of PLHIV in resource-rich settings (Dudgeon et al, 2004; Cade et al, 2004; Fillipas et al, 2006), where the access to resources and treatment for PLHIV was available since the 1990s, well before resource-poor settings like South African. This study aimed to explore both the experiences of PLHIV who experience disability in KwaZulu-Natal as well as their perceptions of the impact that a physiotherapy rehabilitation programme had on their respective impairments, their activities of daily living and their participation in social, recreational and occupational pursuits.

The study used the International Classification of Functioning, Disability and Health or ICF (WHO, 2001) as its guiding framework theory. It aimed to explore and describe the participants' experiences of a physiotherapy rehabilitation programme on their impairments, activity levels and participation restrictions. This was achieved through the use of a specific screening tool, the World Health Organisation Disability Assessment Schedule or WHODAS 2.0 (WHO, 2010), as well as interviews conducted with individual participants. It is hoped that this will provide information on how physiotherapists can better respond to the needs of PLHIV who experience disability on a daily basis. This information can, in turn, inform the development and design of adapted and enhanced rehabilitation programmes for PLHIV and disability.

1.3 Problem statement

While PLHIV are living longer with the advent of greater access to HAART, there been a concomitant increase in the observation of HIV-related disabilities and adverse events experienced by this population (Rusch et al, 2004). This has led to a parallel increase in

the number of PLHIV who require rehabilitation provided by physiotherapists. There is minimal research focusing on the physiological and psychological effects of rehabilitation on PLHIV in resource-poor settings (Mutimura et al, 2008a; 2008b) and no research focusing specifically on PLHIVs' experiences of receiving physiotherapy rehabilitation in a resource-poor South African public health setting.

1.4 Research Question

What impact does the provision of physiotherapy rehabilitation have on the lives of PLHIV with respect to their body function, activity levels and participation restrictions?

1.5 Study aim

The researcher aimed to explore the perceived effects of a physiotherapy rehabilitation programme on the participants' impairments, activity levels and participation restrictions, in order to inform future physiotherapy practice.

1.6 Study objectives

1.6.1. To describe the demographics and level of disability of each study participant using the WHODAS 2.0.

1.6.2. To explore the participants' perceived experiences of undergoing physiotherapy rehabilitation at a public-funded South African hospital.

1.6.3. To describe the perceived effects of the rehabilitation programme on participants' body function, activities of daily living and participation in their work, social and recreational environments.

1.6.4. To reveal any potential barriers and challenges that participants experienced regarding their continued access and adherence to physiotherapy rehabilitation.

1.7. Significance

As far as the researcher's knowledge is concerned, no study has been conducted focusing on PLHIVs' experiences of undergoing physiotherapy rehabilitation, in a resource-poor South African public health setting. By employing a qualitative research methodology, the researcher was better able to understand the participants' perceptions of the impact that this rehabilitation had on their body function, activity levels and participation in their work, social and recreational environments. This served to highlight the positive effects of this rehabilitation on the participants' lives and shed some light on the potential barriers to accessing this rehabilitation. It is hoped that this study can stimulate further research into this area and inform both the design of improved rehabilitation programmes as well as a wider range of rehabilitation options for PLHIV in South Africa.

Chapter 2: Literature review

2.1. Introduction

This literature review outlines the pathological effects of HIV with specific reference to the three primary systems that physiotherapists treat, namely the neurological, musculoskeletal and respiratory systems. The effects of cardiovascular and resistance exercise on the physical and emotional well-being of PLHIV are explored in detail. The concept of disability is discussed, using the ICF framework as a primary conceptual paradigm, followed by a discussion of the close interrelationship between disability and HIV, as well as the relative lack of access to services for PLHIV and disability in South Africa. Published literature related to the specific research tool that was employed in this study, the WHODAS 2.0, is reviewed and discussed. Finally, this review explores the rights of people living with disabilities, as ratified by the South African government.

2.2. HIV pathology

In 1990 the World Health Organisation (WHO) introduced a system for defining the clinical stages of HIV disease progression. This staging relies on a clinical judgment of the presenting conditions and symptoms, rather than merely classifying the stage of the disease based on a CD4 cell count (Jenkins, 2009). The CD4 cell count is a measure of an individual's immune function and historically a person has been said to have progressed from having HIV to AIDS when their CD4 cell count falls below 200 cells/uL of blood, with normal values ranging from 800 to 1200 cells/uL (Basta et al, 2008). Jenkins (2009) summarises the WHO clinical staging in a concise, accessible manner. Following primary HIV infection, infected individuals may be asymptomatic or have flu-like symptoms weeks after actual infection. In clinical stage 1, individuals may have persistent lymphadenopathy but otherwise remain asymptomatic. In clinical stage 2, moderate weight loss (less than 10 percent of body weight) is accompanied by a number of relatively mild infections including sinusitis and herpes zoster. Clinical stage 3 is defined by severe weight loss (more than 10 percent of body weight) and additional complaints such as chronic diarrhea, pulmonary tuberculosis (TB) and persistent oral

candidiasis. Clinical stage 4 is characterised by specific opportunistic infections that only attack the body when an individual's immune system is particularly compromised. These infections include pneumocystis carinii pneumonia, extrapulmonary TB, cryptococcal meningitis and Kaposi's sarcoma. The progression through these stages varies from individual to individual and can be attenuated by a number of interventions, perhaps the most important of which is access to HAART (Jenkins, 2009). These medications have dramatically improved life expectancy by altering the features and complications of the disease, effectively converting HIV into a chronic disease (Mars, 2003; Worthington et al, 2005; Meintjies, 2012).

There are a number of textbooks (Murphy et al, 2000; Jenkins 2009) that outline the wide-ranging effects that HIV has on the human body, but in order to be relevant to the scope of this study, this review will only discuss the effects specific to the field of physiotherapy. In the early years of the HIV pandemic, physiotherapists' roles were limited to palliation, particularly in South Africa where the government of the time resisted the widespread implementation of HAART provision against prevailing scientific opinion (Chigwedere et al, 2008). This palliative care had its focus on respiratory care and pain management in order to make patients comfortable in their inevitable decline towards an early death. As discussed above, with the improved care for PLHIV in general and specifically the advent of HAART, HIV is being increasingly viewed worldwide as a chronic, manageable disease. In the United States of America, for example, Gale (2008) describes how physiotherapists have moved from focusing on short-term outcomes and decreasing the discomfort experienced by PLHIV to a greater emphasis on long-term function. With this increased longevity, however, PLHIV are at risk of a number of health challenges. The profession of physiotherapy is concerned with the assessment and rehabilitation of people who experience problems with the neurological, musculoskeletal and respiratory systems, all of which may be adversely affected by HIV (Myezwa et al, 2007). These specific impairments will be discussed in more detail below.

The neurological deficits related to HIV include physical problems such as altered muscle tone, weakness or paralysis of muscles, poor balance and impaired sensation

as well as cognitive and behavioural problems, such as memory loss and personality disorders (Nixon and Cott, 2000). These can result from damage to the central nervous system by opportunistic infections such as TB, meningitis and toxoplasmosis and further manifest as a variety of peripheral neuropathies causing considerable pain and discomfort (Myezwa et al, 2007). Furthermore, the neurological impact of HIV can result in loss of sight, hearing and the ability to speak (Murphy et al, 2000), all of which may influence the interaction between the HIV patient and their physiotherapist. This relationship may be further hindered by the presence of AIDS dementia complex which, according to Hwang and Nochajski (2003) is one of the most common central nervous system complications related to HIV infection. The features of this disorder include loss of concentration, poor memory and social withdrawal. Similarly, PLHIV are prone to various mental health problems, with depression being the most commonly experienced disorder of this description (Brandt, 2009). While physiotherapists are not trained to treat psychological and behavioural impairments, it is important that they are aware of the potential impact that these problems may have on rehabilitation programmes, in order to make appropriate referrals when necessary.

According to Tehranzadeh (2004) there are numerous musculoskeletal manifestations of HIV which include conditions that affect muscles (such as muscle atrophy and myositis), joints (for example arthritis) and bones (for example spondylitis). These can result directly from specific opportunistic infections that attack the above bodily tissues, but can also be a secondary result of disuse. Thus, a patient who is extremely ill due to one of these infections and suffering from pain may be unable or unwilling to get out of bed and walk or perform specific rehabilitative exercises. The result of this may be further muscle wasting, joint and bone pain as well as other potentially life-threatening complications such as ulcerous pressure sores and deep vein thrombosis.

The third bodily system that physiotherapists treat, and that is severely affected by HIV and the opportunistic infections associated with HIV, is the respiratory system. A common respiratory manifestation of HIV is pneumocystis carinii pneumonia. This, in 1981, was the first opportunistic infection that alerted the public health authorities in the United States to the presence of a new immune-compromising syndrome, soon to be

labeled AIDS (Centre for Disease Control, 1981). Other respiratory infections more prevalent in the HIV immune-compromised patient are Kaposi's sarcoma, a cancer which can impair lung function, and pulmonary TB. TB is a bacterium that can attack the entire body, but its effects on the lung are particularly prevalent (Jenkins, 2009). TB is a leading cause of death among people living with HIV (UNAIDS, 2010). In 2009, there were an estimated 380 000 deaths world-wide from TB among people living with HIV, while in sub-Saharan Africa the HIV prevalence among people with TB is as high as 80% (UNAIDS, 2010). Common physiotherapy treatments for respiratory conditions include postural drainage, deep breathing exercises and manual techniques to mobilise bronchial secretions and improve oxygenation of the lung (Pryor and Prasad, 2002).

Central to all the neurological, musculoskeletal and respiratory impairments outlined above is the common prevalence of pain of varying intensity suffered by PLHIV (Hughes et al, 2004). In a survey of 762 HIV positive individuals by Rusch et al (2004), over half of all respondents with CD4 cell counts below 200 cells/uL reported moderate to severe pain. Physiotherapists commonly treat pain via a number of methods, including massage (Lee et al, 2009) and electrotherapeutic modalities (Pons and Shipton, 2011). Other common problems experienced by PLHIV and recorded in the study by Rusch et al (2004) were fatigue and decreased endurance, which can be improved by a number of exercise interventions, discussed in the following section.

2.3. HIV and exercise

In the early years following the discovery of the human immunodeficiency virus, medical professionals were reluctant to prescribe exercise for PLHIV (Nixon and Cott, 2000, Hanass-Hancock and Nixon, 2009). Bopp et al (2003) believe that due to the fact that prolonged high-intensity exercise has been well documented to negatively affect immune function, physicians were understandably concerned about the impact of exercise on the health status of their HIV patients. This attitude has changed in recent years, primarily due to a large body of research extolling the benefits of both cardiovascular resistance exercise for PLHIV, which includes studies conducted in resource-poor settings (Mutimura 2008a; 2008b; Myezwa et al, 2012).

Although this study will focus specifically on HIV positive individuals who experience disability, there are a number of studies that have examined the impact of exercise on PLHIV, regardless of their level of infection or ability. These studies have tended to examine either the effects of aerobic exercise or resistance exercise on PLHIV and are well summarised by O'Brien et al (2009a; 2010). Aerobic exercise is also known as cardiovascular exercise and includes activities that stress the cardiovascular system such as running, cycling or swimming (Brukner and Khan, 2001). Resistance exercise is also known as strength training and is aimed at using progressive resistance to strengthen the musculoskeletal system. This type of exercise includes weight-training and body weight exercises such as pull-ups and push-ups (Brukner and Khan, 2001). O'Brien et al (2009a; 2010) have carried out two comprehensive systematic reviews, critically assessing the various studies that have been published on the effects of aerobic exercise and resistance exercise on PLHIV, respectively. Both these systematic reviews were published by the Cochrane Collaboration, which demands a high level of methodological quality. These two reviews will be discussed in greater detail below.

The first of the systematic reviews by O'Brien et al (2009a) included studies of randomised controlled trials (RCTs) comparing aerobic exercise interventions with no aerobic exercise interventions or another exercise or treatment modality, performed at least three times per week for at least four weeks among adults (18 years of age or older) living with HIV. A total of 14 studies met the specified inclusion criteria for this review and an extensive meta-analysis of the chosen studies' data was performed. The results of the review suggest that PLHIV who perform constant or interval aerobic exercise, or a combination of constant aerobic exercise and progressive resistive exercise, for at least 20 minutes at least three times per week for at least five weeks may benefit from significant improvements in certain measures of cardiopulmonary fitness, body composition and psychological status (O'Brien et al, 2009a). Furthermore, this form of exercise appears to be safe, incurring no additional health risks to participants. Overall, no significant improvement in immunological status (as evidenced by CD4 count and viral load) was noted. A total of 454 participants between the ages of 18 and 58 were included in this review. Reported limitations of the selected studies for

this review include lack of assessor blinding, small sample sizes, high drop-out rates and lack of adherence to prescribed exercise interventions. Furthermore, the studies tended not to look at the long-term effects of aerobic exercise (beyond 15 weeks) and the benefits of exercise for older PLHIV (older than 58 years).

The second of the systematic reviews by O'Brien et al (2010) analysed RCTs comparing progressive resistive exercise interventions with no progressive resistive exercise or another exercise or treatment modality, performed at least three times per week, and lasting at least four weeks among adults living with HIV. A total of seven studies met the inclusion criteria. The results of this review indicated that performing progressive resistive exercise or a combination of progressive resistive exercise and aerobic exercise is safe and leads to increases in body weight and improvements in cardiopulmonary fitness (O'Brien et al, 2010). Individual studies also suggest that progressive resistance exercise may lead to strength increases and improved psychological status of PLHIV. There were no significant changes seen in immunological or viral status. This systematic review was limited by the small number of included studies and small sample sizes of individual studies. The authors recommended that future research of this nature should include intention to treat analyses, as a number of the selected studies failed to include results of participants who withdrew from the study before completing the prescribed training programme. This raises potential concerns about the safety of exercise among those participants that withdrew.

These two systematic reviews provide evidence that both aerobic exercise and progressive resistance exercise interventions appear to be safe and may confer a wide range of health benefits to PLHIV. Bopp et al (2003) support these findings by stating that therapeutic exercise has the potential to improve physiological and psychological measures in PLHIV, without incurring the expense and potentially severe side effects of medical and pharmacological interventions. The benefits of exercise are similar to those seen in adults who are not infected with HIV and it appears reasonable to assume that disabled PLHIV will also benefit from safe, specific and well-planned aerobic and resistance training programmes. With specific reference to the profession of

physiotherapy, the results of a summary of systematic reviews by Taylor et al (2007) demonstrate that therapeutic exercise is beneficial for patients across broad areas of physiotherapy practice, with few adverse events reported.

2.4. The International Classification of Functioning, Disability and Health

This study used the ICF as its primary conceptual paradigm, in understanding the concept of disability. The ICF (WHO, 2001) offers a useful framework for studying disablement and health-related consequences of disease based on the following three concepts: impairments, activity limitations and participation restrictions. Impairments are understood to be problems with physiological functioning or anatomical (for example organs, limbs) structure of the body. Activity limitations are defined as difficulties in executing a task or action, such as walking or dressing. Finally, participation restrictions are problems relating to involvement in life situations. For example, in a physiotherapy clinic, a female patient who has HIV may present with impairments such as weak lower limbs, tingling in her hands and feet and poor dynamic balance. These impairments may negatively affect activities such as walking, standing and lifting up objects which may further limit her participation in the work, social and recreational environments.

According to Van As et al (2009) the ICF adopts a bio-psychosocial approach that views impairments, activity limitations, participation restrictions in relation to associated contextual factors, which are further divided into environmental and personal influences. This allows disability to be defined in broader terms than a mechanistic, purely medical model and places the experience of disability in a socially constructed realm dependent on interrelated social, environmental and personal factors. PLHIV may experience both the physical impairments caused by this immune-compromising virus, but also the social challenges particular to this condition, such as shame and stigma. The combination of these physical and psychosocial barriers will affect the activities and participation of each individual in different ways. While the physical disabilities may be universal, the social experience of living with HIV will differ markedly in Southern Africa as compared to the Western World, where the disease has been viewed in a far more positive light in recent years, and where it is now largely considered a chronic,

controllable condition (Parry et al, 2004). Conversely, in South Africa there remains a high level of stigma (Visser et al, 2006, Kalichman and Simbayi, 2003) which further hinders efforts to prevent, control and treat HIV. The interrelationship between body impairments, activity limitations and participation restrictions with environmental and personal contextual factors is well illustrated in Figure 1.

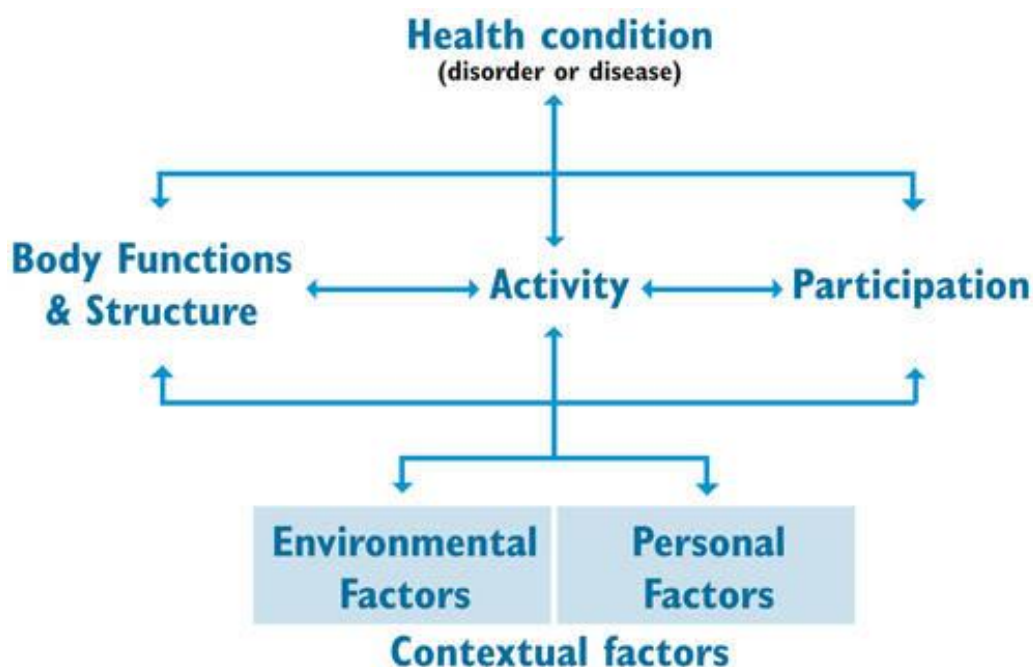


Figure 1: Graphic representation of the ICF framework

The World Health Organisation (WHO, 2003) published a checklist that can be used by health professionals to classify a patient's individual impairments, activity limitations and participation restrictions, as well as the environmental factors and other contextual information that can influence their experience of disability. This can be used to assess disability caused by any disease process, but for the purpose of this review it is pertinent to highlight studies that have investigated its use in HIV populations. Hwang and Nochajski (2003) highlight the ICF's usefulness in illustrating the interrelated clinical and social dimensions of HIV disablement, while Rusch et al (2004) found extremely high rates of impairments, activity limitations and participation restrictions among PLHIV in Canada. The first study to utilise the ICF checklist for PLHIV in South Africa was

undertaken by Jelsma et al (2006). Apart from highlighting areas of physical disability, this small pilot study also found that the participants suffered from emotional disturbances and decreased energy levels. O'Brien et al (2011) broadly define rehabilitation, in the context of HIV and the ICF, as any services and activities that address or prevent impairments, activity limitations, and social participation restrictions experienced by any individual PLHIV. Physiotherapy, as a profession, is one that provides rehabilitation services focused on addressing these various challenges (Myezwa, 2012). For this reason, this thesis will use the more holistic term “rehabilitation” rather than the more narrow description “treatment” when discussing physiotherapy interventions described in this study.

Myezwa et al (2009) conducted an extensive survey of eighty HIV in-patients at the Chris Hani Baragwanath Hospital in Gauteng province, South Africa. They used the ICF checklist to assess the impairments, activity limitations and participation restrictions experienced by these patients. Over 70% of the participants in this study reported impairments related to digestive, neuromuscular, respiratory and sensory function as well as emotional and mental problems and a decrease in energy levels and sleep quality. These impairments led to activity limitations such as decreased mobility and problems with self-care as well as participation restrictions, including difficulty engaging fully in community, social and civil life. Interestingly the researchers also analysed specific associations found among impairments, activity limitations and participation restrictions. An example of these associations was the finding that patients with sensory problems were five-times more likely to have problems in self-care than people without sensory problems (Myezwa et al, 2009). This is just one example of how the ICF framework can begin to reveal the myriad of problems that PLHIV face.

2.5. Disability and HIV

There are a number of definitions for the word “disability”, ranging from the general (“a lack of ability” – Oxford English Dictionary, 2012) to the very specific, for example the decreased ability of an individual to run, see or work. The ICF framework mainstreams the experience of disability and recognises it as a universal human experience (WHO,

2002). All people experience physical impairments that at one time or another have adversely affected their activities and limited their participation in one or more aspects of their lives. According to Hanass-Hancock and Nixon (2009) the assumption that only a small minority of people worldwide live with disability is incorrect. The recent World Health Organisation global report on disability (WHO, 2011) reveals that 15% of people worldwide live with at least one disability and that this percentage is higher in resource-poor settings. South Africa, for example has an estimated prevalence of disability of 24.2%, while Swaziland, a country neighbouring KwaZulu-Natal, has the world's highest estimated prevalence of disability of 35.9% (WHO, 2011).

Similarly, Groce (2004) exposed the myth that people living with disabilities are at little or no risk of becoming infected with HIV. In a survey of 57 countries the researchers concluded that the opposite is indeed true. The fact that people living with disabilities are at an increased exposure to nearly all of the risk factors associated with HIV, necessarily results them being at a higher risk for becoming infected with HIV. These risk factors include poverty, decreased access to health care and education, an increased risk of rape and violence, increased levels of substance abuse and the stigma attached to being disabled. Rohleder et al (2009) state that the increased risk of people with disabilities becoming infected with HIV is even more pronounced in Southern African countries. Hanass-Hancock and Nixon (2009) illustrate the cyclical relationship between HIV and disability, with PLHIV at increased risk of disability and people with disabilities being at an increased risk of contracting HIV. Interestingly, Elliott et al (2009) even argue that HIV should be recognized as a disability for at least some purposes, including the implementation of anti-discrimination laws, due to the high level of stigma and discrimination faced by PLHIV.

Disability is often viewed as a permanent static phenomenon. For example, if somebody is blind or paralysed, it is presumed they will remain blind or unable to walk for the remainder of their lives. The reality of peoples' experiences of disability is far more fluid and transitory and this appears to be particularly true of PLHIV and disability. O'Brien et al (2009b) proposed an adapted framework of viewing disability in the context of HIV. This is based on the experiences of adults living with HIV and has been termed the

Episodic Disability Framework. This framework reveals how the experience of disability varies markedly over time for individual PLHIV and this variation, or episodic disability, is dependent on a number of factors. Particularly relevant to these variations are what the researchers (O'Brien et al, 2009b) have defined as contextual factors. These are both intrinsic factors (for example personal attributes) and extrinsic factors (such as level of family support or stigma) that shape the individual experience of disability. Being aware of these factors can help both the individual and others, such as family members or health professionals, assist in mitigating the effects of these episodes of disability.

2.6. World Health Organization Disability Assessment Schedule

According to Ustun et al (2010) the first WHODAS version allowed disability and health to be measured in a manner that was operationally and conceptually linked to the ICF framework. The second version (WHODAS 2.0) was developed by the World Health Organisation (WHO 2010) in response to calls for improving the scope and cultural adaptability of the original tool. The WHO (2010) states that as well as being short and simple to administer, the WHODAS 2.0 has the added advantage of being applicable across all adult population groups and all disease types, including cognitive disorders. The WHODAS 2.0 assesses an individual's level of functioning in six major life domains, namely cognition, mobility, self-care, getting along with people, life activities and participation. Ustun et al (2010), with over 65000 respondents and Garin et al (2010), in a study of 1119 patients, found the tool to be a valid measure of disability across different populations. Nyirenda et al (2012) conducted a study in rural KwaZulu-Natal assessing the health and well-being among 422 HIV-infected and HIV-affected adults over the age of 50 years. The WHODAS 2.0 was used as one of the outcome measurement tools, specifically to assess the level of participants' disability. Interestingly, this study concluded that the female participants were significantly less likely than the males to have good levels of functional ability.

Amongst the cognitive deficits (first domain) that the WHODAS 2.0 examines are three specific questions exploring the emotional difficulties associated with disability. These focus on living with dignity, emotional effects and relaxation respectively (WHO, 2010).

Luciano et al (2010) found that the WHODAS 2.0 is an effective tool for measuring overall disability, in a study questioning 3615 adult participants who had been diagnosed with a major depressive episode. The emotional burden of living with HIV is significant, with increased signs of depression evident amongst PLHIV (Brandt, 2009.) According to Nakimuli-Mpungu et al (2011) untreated depressive disorders tend to increase HIV risk behaviours, can lower immune status and decrease adherence to antiretroviral therapy, thus negatively impacting clinical outcomes and potentially increasing the development of drug resistance. This is compounded by the increased levels of stress experienced by care-givers of PLHIV (Abasiubong et al, 2011), which has a further negative impact on the health of HIV positive individuals and their adherence to treatment. It is vital that health professionals are aware of the psychological and emotional burden of HIV on both PLHIV and their care-givers, in order to refer these patients for further counseling, when necessary. The WHODAS 2.0 can thus be employed as a useful tool to assist in the screening of conditions outside the scope of practice of physiotherapists. Similarly other health professionals using this tool may become aware of physical problems facing patients and refer them to a physiotherapist or other rehabilitation professionals.

2.7. The rights of people living with disabilities

South Africa is one of 82 signatories of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2008), which according to Nixon et al (2011) is shining a long-overdue spotlight on issues of disability. Article 26 of this convention recognises people's right to rehabilitation and requires the signatory states to take steps to allow people with disabilities to achieve maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life including through comprehensive habilitation and rehabilitation services and programmes, particularly in the area of health (United Nations, 2008).

It is commendable that South Africa has ratified the above convention but there is little research conducted in this country focusing on the access that people living with disability have to rehabilitation and treatment. Hanass-Hancock (2009) completed a

systematic review of all studies undertaken in Africa that focused on both HIV and disability over the previous decade. The review selected 36 studies following the exclusion of all studies using non-empirical methods. The findings underline the phenomenon that people living with disability are at least as likely, if not more likely, to be exposed to HIV as their non-disabled peers. Furthermore, they are less likely to access programmes focused on HIV prevention, testing and treatment. The reviewer highlighted the need for more research into the area of HIV and disability in Africa and an increased need for service delivery, particularly to communities who have difficulty accessing these services. The design and implementation of these programmes should actively involve people with disabilities in order to make them more relevant.

Access to services for people living with disability is particularly relevant in light of the South African Department of Health's (DOH, 2001) vision of public health care delivery in South Africa moving towards community-based rehabilitation (CBR) and home-based care (HBC) models. According to a widely distributed document, (DOH 2001) these models promote the rehabilitation of people in or near their homes and encourage participation by people, respond to the needs of people and encourage traditional community life. This call for improved CBR delivery is echoed by the World Confederation for Physical Therapy (WCPT), who announced their commitment to delivering accessible and appropriate rehabilitation services to persons living with disability (Bury, 2005). A primary focus of the recently published South Africa government's National Strategic Plan on HIV, STIs and TB (2012-2016) is to achieve significant reduction in disability as a result of HIV and TB through universal access to affordable and good quality diagnosis, treatment and care (Strategic Objective 3, SANAC, 2011).

The reality, however, is often different from the admirable goals stated above. Chappell and Johannsmeier (2009) conducted a study exploring the impact of CBR on people living with disabilities and their families. The study describes how the majority of CBR programmes in South Africa employ mid-level rehabilitation workers (also known as community rehabilitation facilitators or CRFs), due to the difficulty of and expense of getting professionals, such as physiotherapists, to work in the community. At the time of

the study, there were approximately 200 CRFs working in over 100 communities in six of the nine South African provinces, including KwaZulu-Natal. Although the results of this qualitative study showed a positive impact on individuals living with disabilities, certain gaps were identified, including the ability of individual CRFs to carry out certain tasks related to their work. This is understandable given the fact that these mid-level workers receive only two years of post-school training as compared to the four years of undergraduate training undertaken by South African physiotherapy students.

2.8. Summary

This review has highlighted some of the impairments, activity limitations and participation restrictions experienced by PLHIV. Cardiovascular and resistance exercise have been shown, by extensive research, to be both safe and beneficial for PLHIV. As experts in the design and prescription of exercise programmes, physiotherapists are ideally suited to providing rehabilitation services to PLHIV who experience the disabling effects of this disease. This review has demonstrated the relative lack of literature investigating the impact of rehabilitation on PLHIV and disability in resource-poor settings. By adding to this growing body of research in the area of HIV and disability in a specifically South African context, it is further hoped that policy makers and stakeholders in the public health service will be alerted to the growing need for services and programmes specifically catering for this vulnerable subsection of the population.

Chapter 3: Methodology

3.1. Study design

In order to describe the experiences of the study participants, a qualitative research design approach was used in this study, obtaining information from both the WHODAS 2.0 (Appendix 1), and from semi-structured participant interviews following a period of physiotherapy rehabilitation. The development of the interview schedule (Appendices 2 and 3), was guided by the ICF framework. Strauss and Corbin (1998) describe qualitative research as any research that strives to obtain intricate details regarding observed and reported phenomena, rather than employing pure statistical procedures used in quantitative research methodology. The *data* described in qualitative research can come from various sources, including documents and interviews, similar to those described in this study. While qualitative research is often believed to provide a deeper understanding of social phenomena than pure quantitative data, Silverman (2000) points out that it is not a faultless methodology. Criticisms of this approach include the fact that by being immersed in the research process, the researcher may be speculative in the reporting of phenomena and be further influenced by his or her own background and socio-political values. In short, critics of qualitative researchers would say that they are too subjective in their interpretation and reporting of data (Silverman, 2000). This view is nullified by constructivist theories that firmly believe that neither objective reality nor objective truth is possible in practice and any *reality* is thus necessarily constructed by the observer (Sarantakos, 2005).

3.2. Research setting

The study was located at a public hospital in a semi-urban area of the eThekweni district in the province of KwaZulu-Natal, South Africa. The facility is a 200 bed hospital serving a population of 750 000 people in Mariannhill, which is an impoverished rural and peri-urban area on the outskirts of Durban. The hospital provides a service for 4500 PLHIV. It is estimated that more than 250 000 people (33%) living in the hospital's catchment

area are HIV positive. The hospital is the only public-funded Roman Catholic mission hospital in South Africa (About us, 2012).

Although this hospital receives a government grant, this only covers just over half of the its operational costs. The shortfall is covered by generous donations from individuals, corporates and partners. This ensures that patients who are unable to pay for treatments are seen at no cost to themselves. Amongst the various services this hospital offers a rehabilitation department, which provides physiotherapy for both in- and out-patients and palliative care wards for terminally ill patients, many of whom are dying of HIV-related illnesses (About us, 2012).

The hospital has recently engaged with UKZN and the Health Economics HIV/AIDS Research Division (HEARD) to address HIV-related disability as experienced by their staff and patients (Hanass-Hancock et al, 2012)

3.3. Study population

All HIV positive adults who were referred to the physiotherapy department at the study facility during a five week UKZN clinical block were considered for recruitment for the study, subject to the inclusion and exclusion criteria below.

3.4. Inclusion criteria

- Must be HIV positive.
- Males and females.
- Any racial or language group.
- Over the age of 18.
- Referred for physiotherapy rehabilitation at the study facility.
- Deemed suitable by the researcher (who is a UKZN physiotherapy clinical supervisor) to be treated by fourth year UKZN physiotherapy students.

3.5. Exclusion criteria

- Unable to communicate with, or understand, the researcher or research assistants (for example due to advanced HIV dementia).
- Unwilling to participate in the study.

3.6. Sampling strategy

The study used a convenient sampling method dependent on who was referred to the physiotherapy department during the period of the study. HIV positive adult patients who were referred to the physiotherapy department at the study facility, satisfied the inclusion criteria and agreed to participate were recruited for the study. The researcher or research assistants informed potential participants about the opportunity to take part in this study. Participation was completely voluntary and a patient's refusal to participate in the study did not influence their ongoing physiotherapy and treatment.

At baseline, 14 participants completed the WHODAS 2.0. Four participants were lost in the follow up as they did not return for the post-rehabilitation interview nor were they contactable using the telephone numbers recorded in their patient files. One participant had passed away since being discharged from the study facility, while another participant did not arrive for the interview after already having missed a number of scheduled appointments. Thus a total of eight participants, who completed both the WHODAS 2.0 and the interview, were considered for discussion in this study.

3.7. Data collection

Participants received physiotherapy rehabilitation over the course of a standard five week clinical block at the study facility, one of the fourth (and final) year clinical placements undertaken by UKZN physiotherapy students. After reading the study information sheet (Appendices 4 or 5), individuals who agreed to participate in the study were requested to sign an informed consent form (Appendix 6). Participants then filled in the WHODAS 2.0 form with either the researcher or one of the research assistants

before beginning their rehabilitation. This tool was translated into isiZulu and completed with the assistance of an isiZulu-speaking research assistant, where necessary.

Each participant received an individualised rehabilitation programme, designed and supervised by their designated physiotherapist. This is standard practice for any patient referred for physiotherapy rehabilitation in a hospital setting. The number of days each participant was seen by their designated physiotherapist varied depending on the specific nature of their presenting complaint. Where necessary, participants were referred for on-going out-patient physiotherapy rehabilitation, provided by the hospital's physiotherapy staff. A detailed description of each participant's prescribed rehabilitation programme is beyond the scope of this study.

On completion of their period of rehabilitation, individual participants participated in an interview with the principal investigator and, where necessary, a research assistant who was fluent in isiZulu. This interview consisted of 14 open-ended questions related to their health condition and their experiences of receiving physiotherapy rehabilitative. A semi-structured interview approach was employed in this study. Sarantakos (2005) defines semi-structured interviews as lying between structured interviews, which stick rigidly to a pre-defined order, and unstructured interviews, where the order and wording of questions can be changed at will. All interviews began with the same unchallenging question ("When were you admitted to hospital?"), an approach Trochim (2001) endorses as a way of putting the respondent at ease and building trust and rapport between the interviewer and respondent. Thereafter, questions were guided by the ICF framework, but the interviewers were encouraged to probe with further questions when appropriate (see Appendices 2 and 3).

Two research assistants (fluent in isiZulu) were employed on a part-time basis. Prior to the data collection phase of this study described above, the research assistants received thorough training on the questioning of participants using the WHODAS 2.0 forms, as well as the conducting of participant interviews. When training the research assistants, the researcher followed the advice of Trochim (2001) which includes describing the background of the study to research assistants, explaining the pitfalls of

interviewer bias and rehearsing the interview schedule prior to the commencement of interviewing. The research assistants were also required to sign consent forms, with the understanding that they could have withdrawn from the study at any time should they have so wished (see Appendix 7). The researcher conducted the interviews alone with the three participants who spoke fluent English. The researcher was also present at all of the other five interviews, with the participants who spoke isiZulu, and thus participated in the delivery of open-ended questioning, via translation provided by the research assistant present. This ensured that the researcher remained an integral part of the data collection phase at all times.

This data collection took place either on the patient's hospital ward or in the physiotherapy department at the hospital, with privacy ensured at all times. Patients who were considered to require on-going treatment were referred for further out-patient physiotherapy rehabilitation at the study facility.

3. 8. *Data analysis*

Participants' identities were coded by the researcher to ensure participant anonymity. The first participant was given the code P1, the second participant P2, and so forth. Data from the WHODAS 2.0 was summarised using Microsoft Excel (Microsoft, 2010). This data is presented in tabular form (see Chapter 4) in order to better illustrate the types of physical, mental and emotional challenges facing these participants.

Recorded data from patient interviews was transcribed by the researcher in cases where the interview was conducted in English (for the three interviews with P1, P2 and P5). For the remaining five isiZulu-speaking participants, the research assistants transcribed and then translated the interview data into English. Each research assistant checked the transcriptions and translations of the other assistant in order to improve the validity of the reviewed data. Any non-verbal communication (for example lengthy pauses or laughter) was also transcribed.

The interview data was then subject to thematic qualitative analysis, in order to identify any common categories and themes that emerged from the participants' responses to

the interview questions regarding their experiences of the physiotherapy rehabilitation. Coding of data was employed in order to both organise and interpret the recorded data. This process was facilitated by the use of NVIVO 10 software (QSR International, 2011). The results of this data collection are displayed in Chapter 4, while the identified themes and categories are discussed in Chapter 5.

There are a number of techniques used to interpret meaning from qualitative research data. The approach used in this study was that of content analysis. Hsieh and Shannon (2005) define content analysis as “the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns”. More specifically, a combination of directed and conventional content analysis was used. By using the ICF framework as an existing theory to guide the identification of key concepts and the coding of thematic categories, the analysis followed what Hsieh and Shannon (2005) refer to as a directed approach to content analysis. The analysis and coding, however, also allowed for a more conventional form of content analysis, which allows the flexibility to identify additional coding categories directly from the data (Hsieh and Shannon, 2005). A hallmark of this approach is the use of open-ended questions, of the type included in the interview schedule for this study (see Appendices 2 and 3). Although questions are designed to reflect an overarching paradigm (in this study’s case, the ICF), the fact that they are open-ended allows the researcher to probe and further explore participant’s experiences. This was, indeed, what transpired during the participant interviews in this study.

3.9. Ethical considerations

- Permission to conduct the study was granted on the 30th May 2012 by the chief executive officer of the study facility for the overarching proposal, which includes this research project (See Appendix 8 – Subproject 1).
- The research proposal was submitted to the University of KwaZulu-Natal, School of Health Sciences Research Committee and then forwarded to the Human and Social Sciences Research Ethics Committee (together with the completed ethical

consideration form) for ethical approval. Approval (HSS/0325/12M) was obtained on the 5th September 2012 (see Appendix 9).

- Participants were given an information sheet outlining the nature and requirements of the study and their completely voluntary participation, with the right to withdraw at any point during the study. Following this, they were required to sign a consent form to participate in the study.
- Participants were assigned codes in order to maintain their anonymity. No information regarding the participants' involvement in this study was divulged at any point.
- All information obtained from participants will be kept confidential under lock and key and electronically on a password protected computer at the UKZN department of physiotherapy for 5 years, after which time all documentation will be destroyed.

3.10. Conclusion

This chapter explained in detail the methodology employed by the researcher in the design and implementation of this study. A qualitative research design was used in order to describe the experiences of participants who underwent a period of physiotherapy rehabilitation. Adult PLHIV who were referred for physiotherapy rehabilitation at the study facility and who satisfied the specific study inclusion criteria were requested to answer the WHODAS 2.0 questionnaire and participate in an interview following the rehabilitation period. A total of eight participants completed both the WHODAS 2.0 and the interview process and were included in the final analysis and discussion. The transcribed interview data was subjected to content analysis in order to identify themes that emerged from the participants' responses. NVIVO 10 software was used to assist in the coding of this transcribed data. All stages of the research process were guided by rigorous ethical principles.

Chapter 4: Results

4.1 Introduction

This chapter presents the participants' demographic data and domain scores obtained from the WHODAS 2.0. Medical diagnoses were obtained from the individual participant's patient files. The eight categories identified via the coding of the transcribed interview data are then displayed, followed by examples of participants quotes that serve to illustrate each of these categories.

4.2 WHODAS 2.0 data

Table 1 displays the summarised demographic data for all eight participants, obtained from the individual WHODAS 2.0 forms. Mean values are used to represent the age of participants and their total years of school and post-school study, with minimum and maximum values displayed in brackets.

Table 1: Participants' grouped demographic data

<i>Demographic</i>	<i>N = 8</i>
<i>Gender</i>	Male: n=4 Female: n=4
<i>Mean age</i>	38 (26-48)
<i>Marital status</i>	Married: n=3 Never: n=4 Separated: n=1
<i>Mean years of study</i>	9 (3-14)
<i>Work status</i>	Paid work: n=2 Volunteer work: n=1 Part-time work: n=1 Unemployed: n=4

The demographic data shows an even gender split, with four male and four female participants included in this study. Four of the participants had never married; while the other four had married (one had separated at the time of the study). The mean age of the eight participants was 38 years, with the youngest participant 26 and the oldest participant 48 years old. The total number of years that each participant has studied (including school and post-school education) varied greatly. Two of the participants left school after only three years, at the age of approximately nine years. In marked contrast, one participant had studied for 14 years, including two years of post-school education at college. This participant (P1) was involved in charity work, one participant was working part-time, two were working full-time and four were unemployed.

Table 2 provides a brief summary of pertinent demographic and diagnostic information related to each of the eight participants. This serves to provide background regarding each participant, which may be helpful to the reader, when considered together with their responses obtained from the participant interviews. This information was extracted from both the WHODAS 2.0 forms as well as the medical and physiotherapy notes in their individual patient files.

Table 2: Individual participant data

<i>Code</i>	<i>Gender</i>	<i>Age</i>	<i>Years of study</i>	<i>Marital status</i>	<i>Work status</i>	<i>Health condition</i>
<i>P1</i>	Male	40	14	Married	Volunteer	Hemiparesis
<i>P2</i>	Male	35	12	Never	Unemployed	Hemiparesis
<i>P3</i>	Male	31	12	Never	Paid work	PTB
<i>P4</i>	Female	35	12	Never	Unemployed	PTB
<i>P5</i>	Female	48	8	Married	Self-employed	PN
<i>P6</i>	Male	45	3	Never	Unemployed	PTB
<i>P7</i>	Female	26	9	Married	Paid work	Body Pain
<i>P8</i>	Female	40	3	Separated	Unemployed	PTB

Note: PTB = pulmonary tuberculosis; PN = peripheral neuropathy

Table 2 includes the presenting health condition or diagnosis written in the participants' hospital medical files by the attending doctor on their admission to the hospital. Two of the participants presented with acute-onset hemiparesis (weakness of one side of the body), presumed to be caused by a cerebrovascular accident or stroke. Four of the participants presented with complications related to suspected pulmonary TB. One participant had signs and symptoms indicating peripheral neuropathy of both hands. One participant was admitted complaining of general widespread body aches and pains, with the attending doctor writing "body pain" in the admission notes. All of these patients were referred by the doctors for physiotherapy rehabilitation, illustrating the wide range of health conditions that physiotherapists are trained to treat.

Table 3 shows the scores all eight participants for each of the six domains assessed by the WHODAS 2.0. A score of one indicates that the patient has no difficulty at all with the task or activity assessed in each question. A score of two indicates mild difficulty, three moderate difficulty, four severe difficulty, while a score of five indicates extreme difficulty or an inability to do the specified task. Note that the score given for each domain is an average of the scores given for the questions asked for each of the six domains. The number of questions asked for each domain varies (see Appendix 1).

Table 3: WHODAS 2.0 domain scores

	<i>Cognition</i>	<i>Mobility</i>	<i>Self-care</i>	<i>Getting along</i>	<i>Life activities</i>	<i>Participation</i>
<i>P1</i>	2.7	4.8	3.5	3.0	5.0	4.9
<i>P2</i>	1.2	5.0	4.3	1.8	5.0	2.6
<i>P3</i>	1.7	4.2	2.8	1.2	4.5	3.3
<i>P4</i>	1.3	2.2	4.0	2.8	2.9	1.9
<i>P5</i>	1.3	1.6	1.0	1.4	1.6	1.3
<i>P6</i>	3.8	4.6	2.8	1.8	5.0	4.1
<i>P7</i>	1.2	1.2	1.3	1.2	2.5	2.0
<i>P8</i>	1.5	3.2	1.8	1.0	4.5	2.5

With the exception of participants 1 and 6, most of the participants scored between one (no difficulty) and two (mild difficulty) for the questions in the cognitive domain (Domain 1). This shows that they had little difficulty in tasks related to concentration, memory, conversing and understanding.

Domain 2 (mobility) shows considerably higher scores, with five of the participants scoring between three (moderate difficulty) and five (extreme difficulty or an inability to perform the specific task). Indeed participant 2 scored a maximum of five for all five of these questions, which explored the participants' ability to stand up, remain standing, move around inside and outside and walk long distances.

Domain 3 focuses on self-care activities such as washing, getting dressed, eating and staying on one's own. The lowest average score recorded in this domain was 1.3, while the highest score was 4.3, representing a wide range in the ability of participants to look after themselves.

Domain 4 questions participants' ability to get along with other people. Like the first domain (cognition) the participants in this study recorded generally low scores for this domain, with the exception of participant 1 who scored an average of three in this domain, indicating a moderate difficulty in this area.

Domain 5 questions participants on household activities, such as cooking and cleaning, as well as work or school activities such as the ability to get all one's work tasks done well and in time. Five of the participants showed very high average scores (above 4.5) in this domain, with three of the participants (P1, P2 and P6) scoring a maximum of five for all eight of the questions included in this domain.

Finally, domain 6 explores one's ability to participate fully in society, including community activities, as well as one's ability to be able to relax and live with dignity. Scores for this domain varied considerably for all eight participants, with a lowest score of 1.3 and a highest score of 4.9.

4.3 Interview data

As described in the methodology, the eight participants attended interviews following the rehabilitation period. Coding of data was employed in order to both organise and interpret the recorded. This process was facilitated by the use of NVIVO 10 software (QSR International, 2011). The following nodes (shown in alphabetical order) were created in NVIVO 10, reflecting both the ICF framework as well as the emergence of repeated participant responses: activities, barriers, cognitive, diagnosis, disability, environment, HIV, impairments, medication, participation, personal factors and rehabilitation. Analysis of the responses contained within these nodes resulted in the identification of the categories and themes displayed in Table 4. Examples of participant statements that illustrate each of these categories are shown thereafter.

Table 4: Interview coding: categories and themes

<i>Category</i>	<i>Themes</i>
Knowledge of health condition	Diagnosis Acceptance of HIV status
Medication	Knowledge of medications Impact on health
Impairments	Physical deficits Cognitive deficits
Activities	Difficulty in executing a task/action
Participation	Involvement in life situations Work and social participation
Contextual factors	Environmental and personal influences on health
Rehabilitation experience	Experience of physiotherapy Positive and negative responses
Barriers to rehabilitation	Access to rehabilitation Cost implications

4.3.1 Knowledge of health condition

It was evident from the participants' responses that few of them knew the actual reason for their admission to hospital. Most of them described the various symptoms related to their illness, with only one participant (P1) giving an actual medical diagnosis (stroke), that was verified in his patient file.

"So the doctor said it was the hypertension that led to the stroke." (P1)

"I had a problem for numbness for my hands, and then for my back." (P5)

"What brought me here was weakness and I couldn't walk." (P6)

"I was losing strength, trembling all over to the bone, my body was sore." (P7)

"I was ill and I did not know what was wrong with me, I was sick in such a way they ended up draining water from me." (P8)

Only three participants mentioned their HIV status, either directly (P5) or indirectly, by mentioning that they were taking antiretroviral (ARV) drugs (P2 and P8).

"No, when I was walking I made a sound in my back. I think otherwise it is the cause of the numbness, I don't know. Then I stay for about, it's about a year, I think so. Then I started my AIDS." (P5)

"What medication are you taking?" (Interviewer)

"ARVs" (P2)

"Yes I am taking medication... the ARV's and chest medication." (P8)

4.3.2 Medication

The participants' responses illustrated varying knowledge regarding both the type of medication they had been prescribed, as well as the effects of these medications. They

described when and how often they took their medications, what medications they were actually taking and in one case (P5) what the possible side-effects of the medication were.

“Yes, I am taking medication. When I was discharged I was given some drugs. So I have them at home.” (P1)

“Do you know what the drugs are?” (Interviewer)

“They are anti-hypertensive drugs.” (P1)

“There are iron, TB, pain pills” (P4)

“No I started taking pills here in the hospital, lots of things I got them from the hospital.” (P4)

“Before I drink four tablets. Then we say, you drink your tablets nicely and then you change me last month. You say you must drink three. Now I drink only three.” (P5)

“When I take the tablets I feel better, but the problem before – I was feeling my body weak, but when I start to drink the tablets I am feeling strong.” (P5)

“And that problem with the hands, the numbness, did that come after you started taking the tablets, or before?” (Interviewer)

“Ah, it's coming when I drink the tablets.” (P5)

“I took pills and took TB treatment which I am still taking and some injections I am taking.” (P6)

“I only know that they are for TB.” (P7)

“Yes, they explained that if I don't finish it, it happens that it doesn't heal then it starts all over again.” (P7)

"I was sick because I was not on medications and time was ticking and I was supposed to be on medications and at my clinic they said I must wait because I won't get my file soon and they said I must come here." (P8)

"Yes, I will need to take my medications until I get better." (P8)

4.3.3 Impairments

This includes participants' descriptions of any physical and cognitive deficits that they were faced with. The physical impairments they described included pain, weakness, numbness, swelling, shortness of breath and itching. Cognitive impairments described included participant 3's description of his difficulty with planning.

"I had a stroke." (P1)

"Like, maybe if I tried planning, things didn't work." (P3)

"It made me feel disabled." (P3)

"The problem is that I get heartache when I think about it because I used to live alone." (P3)

"Yes, she said she will help me with gyming and integrating me into the community and make me stronger. Since I am weak." (P4)

"I had a problem for numbness for my hands, and then for my back." (P5)

"Feet, it's okay. It's only in my hands. It [the numbness] started here, here, here, here, then until here [indicates various points from her hands up until the elbows]." (P5)

"The illness got me when I was in the hospital when my feet were shocked where I felt pins and needles underneath my feet and toes. Then my legs got shocked." (P6)

"But from that side to here, it was the shortness of breath and getting weak. It's like I am getting asthma because when it gets worse I use my inhaler." (P6)

"I felt pain on my knee. I don't know how to explain but, it used to be painful." (P7)

"The doctor advised that I should put it up then as time went by, the swelling decreased but the pains are back in my body." (P7)

"Yes, my body is also itchy. It's my bones, my bones are painful. They get painful especially if I have been too cold, they get painful." (P7)

"No, just weakness. I got ill in such a way I did not have power." (P8)

"I stopped because my health was not well and I discovered that it was my chest." (P8)

4.3.4 Activities

Below are examples of participants' responses related to difficulties they had in executing a specific task or action. These included problems with mobility such as walking and standing as well as difficulties with self-care activities such as bathing and toilet use.

"I was confined to my bed, I could not do things for myself, I had to be helped. Even to the toilet, even to take my baths in the morning. Some people had to come and bath me on the bed, you can imagine. Such an experience, I have never had it in my life." (P1)

"I could walk within the house, without any support. Except when I am going on a long distance, that's when I use this stick." (P1)

"Before I couldn't even afford [sic] to sit or stand up but now I do afford [sic] to." (P2)

"They show me how to wake up in bed and how to position your body, in order to get up." (P2)

"I now can wake up and walk to the toilet. I couldn't walk at all." (P4)

"She helped me, we were walking and she hold my waist because I did not have balance." (P4)

“Yes, she helped me in how to wake up, lift my legs, to blow a balloon and breathing three times.” (P4)

“Yes. It’s a problem. When I am standing like this [stands with a straight back] it’s fine. When I am walking, no problem. But when I am walking too much, in the night I am very tired.” (P5)

“When I wash I don’t want to stand, I want to sit down. To wash, you see. Then after washing, when I sleep, the numbness in the night goes worse.” (P5)

“When I’m walking I’m fit. The problem is when I want to do like this [stands up and indicates bending forward repeatedly], it’s a problem to me.” (P5)

“I easily get out of breath and I have no power, walking from OPD to here I was in trouble.” (P6)

“I can now do some activities like doing something where I get tired. You see like cleaning, I can’t clean. I can clean when I am sitting and move a bit but I can’t clean.” (P6)

“No I can’t exercise because I can walk. It’s a sin doing something you can do.” (P8)

“I did not have any problem because there are a lot of us at home. Besides they helped me and I did not defecate on myself and I did not wear any nappy.” (P8)

4.3.5 Participation

Below are responses related to the participants’ involvement in life situations, including their participation in work, social and community pursuits. All eight of the participants reported participation restrictions related to their ability to work, either in an unpaid or paid capacity.

“At least I can function in the church.” (P1)

"I tell people I was not working before, but now I am not able to go around for evangelism the way I used to before." (P1)

"Do you think the physiotherapy will help you going back to being a gardener?" (Interviewer)

"I can do some of the things but I still cannot walk." (P2)

"I couldn't just do things like work..... like, maybe if I tried planning, things didn't work." (P3)

"Could you get job opportunities?" (Interviewer)

"No, it's because when I got them I couldn't reach the expected work levels when I was employed." (P3)

"She said she will help me with gyming and integrating me into the community and make me stronger." (P4)

"I must carry on and exercise since I am self-employed." (P4)

"Because me, I'm self-employed. I'm sewing something like seat covers, you know? Here there is too much like this, this, this [stands up and indicates bending forward repeatedly] and the problem for the back. Then you say you must reduce the work. Then I reduce my work." (P5)

"The thing I survived on before hospitalization was a garden." (P6)

"At the moment I'm not even working, even at home when I try doing something, it gets painful, I stop then sit down." (P7)

"I was working and receiving those few cents but now I am not. I will just wait until I finish my medications." (P8)

"I stopped [work] because my health was not well and I discovered that it was my chest. I worked in Durban as a domestic worker." (P8)

4.3.6 Contextual factors

Participants' responses included a number of statements related to the various environmental factors that helped or hindered their recovery. These responses, shown below, described the impact that friends and family had on their experience of their illness, as well as the role that their own personal attributes played in coping with these challenges.

"The person I am staying with, the only problem he is afraid of leaving me alone, like this morning he brought me, he dropped me here." (P1)

"I did not have any problem because there are a lot of us at home. . . . my mom and my sister offered me assistance." (P8)

"Yes, something which always caused problems for me was that on one side I had a mother plus a few others from my father's side so I had problems with finances." (P3)

"Would it be easier if you had the physiotherapy treatment at your home?" (Interviewer)

"At home, I don't stay a big room. I stay a small house, you know. I'm renting." (P5)

"I don't get the social grant for my two children and that affects me psychologically." (P8)

Personal attributes also influenced some of the participants' responses to their illness. These include both responses that demonstrated a positive approach to their condition (P3) as well as responses that indicated a negative attitude to recovery (P4 and P6).

"What caused it to improve?" (Interviewer)

"It was commitment... I would [come back for treatment], since all that I want is to be better." (P3)

"I can't do it at home because I will get lazy, there are my sisters we sit and talk and eat and I won't do anything." (P4)

"No it [physiotherapy] has not helped me because I am still dying." (P6)

4.3.7 Rehabilitation experience

Five of the eight participants gave favourable responses related to their experiences of receiving physiotherapy rehabilitation. These responses show that the participants found the physiotherapy staff and students to be very helpful, caring and motivating. This enabled them to improve their ability to carry out the activities of daily living, such as walking and cooking, and provided them with encouragement to continue with their rehabilitation.

"All the physiotherapists, I have to say this because it is very important, all the physiotherapists have been very friendly and caring. And that has really helped me. They have been friendly and caring. They tell me what I am supposed to do and they teach me what I am supposed to do. They have been very friendly." (P1)

"JP [physiotherapy student] brought me here to the physiotherapy department for exercises, and while she was trying to teach me what to do, everybody in the department came out for assistance. Actually, everyone in this department has been so wonderful." (P1)

"What things have you most enjoyed about your physiotherapy?" (Interviewer)

"They show me how to wake up in bed and how to position your body, in order to get up." (P2)

"Yes [I would like to continue with exercise], so that my body is going to be motivated always." (P2)

"Yes it helped me. I now can wake up and walk to the toilet. I couldn't walk at all." (P4)

“She helped me in how to wake up, lift my legs, to blow a balloon and breathing three times.” (P4)

“I enjoyed it because you know my hands, I didn’t cook. But you say to me you must do this [open and closes the fingers of both hands]. When I am walking in the street [laughs and continues opening and closing her fingers].” (P5)

“And then I go to physio. Now you see I cook, but before I didn’t cook, someone can cook for me. But now I do everything, I cook you see. I was very happy.” (P5)

“I was helped by that sister. I complained that my legs couldn’t handle...then she came to train me.” (P6)

“I was helped in that because I can now take my food to the oven and warm it... I can now do most activities like utilizing the electric kettle and make tea.” (P6)

“They picked me up from the situation I was in, because when I got here... I cannot tell how I got here and I was unconscious but after weeks I was conscious and I walked holding the walls and going to the toilet... I couldn’t walk at all. Now I can try and they helped me a lot”. (P6)

However, not all responses were favourable regarding the participants’ rehabilitation experiences. These responses include descriptions of a delay in the delivery of a walking aid, pain caused by a specific treatment and a lack of knowledge of the goals of physiotherapy rehabilitation. Three of the participants (P3, P7 and P8) reported not actually receiving physiotherapy rehabilitation at all. Below are all the transcribed examples of negative experiences.

“Because, the walking stick that was given to me, it was the last day that I was discharged. So if it had been given to me earlier, I would have been doing a lot of things for myself, even before leaving the hospital.” (P1)

“When they tried to make my left foot stronger, I was in the wheelchair and they pulled it and it was painful under the knee here.” (P2)

“No one has come to see you, even the people who make you exercise?” (Interviewer)

“There is a lady but she only spoke to me.” (P3)

“Do you know why you were referred for Physiotherapy?” (Interviewer)

“I would be lying, I don’t know.” (P6)

“There was a lady who came to me and asked questions then wrote down but she never showed me anything. She said she would come back but never came back.” (P7)

“Do you know about physiotherapy?” (Interviewer)

“No, they treated other people. I walked on my own.” (P8)

4.3.8 Barriers to rehabilitation

It became clear throughout the eight interviews that participants experienced certain barriers with regard to accessing continued rehabilitation and treatment for their condition. These barriers included a lack of transport or a reliance on others for transport, the clashing of dates with other scheduled appointments and the prohibitive costs associated with transport and continued rehabilitation. Examples of responses highlighting these barriers are shown below.

“The person I am staying with, the only problem he is afraid of leaving me alone, like this morning he brought me, he dropped me here.” (P1)

“I don’t have it [transport], but if the physiotherapy can have it, they can reach that home. Then I will be glad for them to come.” (P2)

“You give me a date to come again, but I didn’t come because my date to take the tablets in Mophola and here, it is the same date.” (P5)

“Yes, I want it [continued treatment]. But the problem, otherwise you know what? You say I must pay. When I come, I pay R40 for physio. Then I pay taxi. It’s R9 to come here, R9 to go back, you see?” (P5)

““With exercises I would like to have them but the problem is I live very far. . . . From home I get strained by the money because even this one I borrowed it.” (P6)

“I can come to the hospital only that my problem is money because my husband is also not working. From home it’s R12 to Pinetown, then to here is R8.50.” (P7)

“If you are able to see a doctor, as we were arriving for the first time, we were told that it is R230.00. The one for admission as they counted everything, so when it was added it came to one thousand eight hundred and fifty something.” (P7)

“I was sick because I was not on medications and time was ticking and I was supposed to be on medications and at my clinic they said I must wait because I won’t get my file soon and they said I must come here.” (P8)

4.4 Conclusion

This chapter presented the data obtained from the WHODAS 2.0, diagnoses from the participants’ medical files and the transcribed data from the eight participant interviews. Coded analysis of the interview transcript data resulted in the emergence of a number of thematic categories. Participant quotes are displayed in this chapter to better illustrate these categories. A closer inspection of these categories shows that the participants had varied knowledge of their health condition and prescribed medication. They reported a number of physical and cognitive impairments, activity limitations and participation restrictions related to their respective health conditions. These challenges were impacted upon by both environmental and personal factors. Five of the participants reported largely favourable experiences of physiotherapy rehabilitation while three participants reported negative experiences. All eight of the participants described the barriers limiting their continued access to rehabilitation. These various issues will be discussed in greater detail in Chapter 5.

Chapter 5: Discussion

5.1 Introduction

This chapter discusses the results from the WHODAS 2.0, diagnoses from their patient files and the responses from the participant interviews outlined in Chapter 4. The data from these sources are considered concurrently in order to achieve a deeper understanding of the various themes and issues uncovered by this study. Where possible, this information is related to the available literature specific to HIV and disability, so as to better illustrate the relevance and position of this study in a wider research context. The participants' recorded demographics and diagnoses are discussed, as well as their individual knowledge of their respective health conditions and prescribed medication. The impact that these illnesses have on their impairments, activity limitations and participation restrictions is explored, with subsequent reflection on the contextual factors that shape their experiences of these challenges. The participants' recorded experiences of physiotherapy rehabilitation, both positive and negative, are discussed in detail. Finally, the potential barriers to the participants' continued access to physiotherapy rehabilitation are discussed, in relation to current South African government policies.

5.2 Participants' demographics and diagnoses

There were eight adult PLHIV selected for this study. The demographic data displayed in Tables 1 and 2 illustrates the fact that this relatively small study population was heterogeneous in nature, with respect to gender, marital status, age, mean years of study and work status. This reflects the reality that HIV is prevalent worldwide across age groups and genders and infects people regardless of their education, marital or employment status (WHO, 2011).

The presenting health condition or diagnosis of each participant (shown in Table 2) is indicative of the wide range of opportunistic infections and complications associated with HIV infection. Hemiparesis, or weakness of one side of the body, and peripheral neuropathy are neurological deficits related to HIV and are amongst the diagnoses

reported by Myezwa et al (2007) in the patient population at Chris Hani Baragwaneth Hospital in Johannesburg, South Africa. Participant 1, who was diagnosed with hemiparesis as a result of a stroke, described how the disabling effects of his condition changed him from an active individual to somebody who depended on care-givers for the most basic of functions.

“I am a very active and agile person. I was confined to my bed, I could not do things for myself, I had to be helped. Even to the toilet, even to take my baths in the morning. Some people had to come and bath me on the bed, you can imagine. Such an experience, I have never had it in my life.” (P1)

Participant 5's description of her peripheral neuropathy raises the possibility that this condition may have been caused by either the HIV infection or the HAART medication she began taking.

“It [the numbness] is coming when I drink the tablets.”(P5)

The possibility that her peripheral neuropathy may have been caused by HAART is supported by research. According to Keswani et al (2002) peripheral neuropathies are known to occur as side-effects in patients taking nucleoside reverse transcriptase inhibitors (NRTIs). Participant 5 was taking Lamivudine, a NRTI commonly prescribed in South Africa, at the time of her interview, as confirmed by her interview response regarding the medication she was taking.

In the study by Myezwa et al (2007) described above, 27 out of 132 (or about 25%) of patients considered suitable for physiotherapy treatment were diagnosed with TB, while in this study exactly half (50%) of the patients had pulmonary TB as their primary diagnosis. According to Pope et al (2010) TB is the leading cause of death amongst PLHIV in South Africa, with a TB-HIV co-infection rate in this country at approximately 44%. This percentage is similar to the percentage (50%) reported in this study. Interestingly, only one of these participants alludes to any respiratory complications, in this response shown below.

“I was sick in such a way they ended up draining water from me.” (P8)

What is described above (and confirmed in this patient’s medical file) is the insertion of an intercostal drain (ICD), a technique used to enable re-expansion of lung tissue that has been deflated or compressed by thoracic conditions (Pryor and Prasad, 2002). Patients with an ICD inserted are commonly referred for physiotherapy treatment that facilitates drainage of air and/or fluids from the lung (Pryor and Prasad, 2002).

Participant 7’s health condition was only given as “body pain” in her patient file. In the interview with this participant, she puts this diagnosis into her own words.

“I was losing strength, trembling all over to the bone, my body was sore.” (P7)

Pain, weakness and fatigue are examples of impairments that, according to Nixon and Cott (2000), result from a myriad of disease processes associated with HIV infection. As discussed in Chapter 2, physiotherapists commonly treat pain via a number of methods, including massage (Lee et al, 2009) and electrotherapeutic modalities (Pons and Shipton, 2011). It is important that physiotherapists are aware of the pain associated HIV opportunistic infections and help patients to manage their pain, so as to ensure improved rehabilitation outcomes.

The diagnoses outlined above resulted in the participants experiencing a wide range of cognitive and physical challenges that impacted on their activities of daily living and their participation in household, occupational and community pursuits. While they were not always aware of their actual medical diagnosis, the participants spoke at length about the various impairments, activity limitations and participation restrictions that resulted from their respective health condition. These challenges are illustrated by the WHODAS 2.0 scores and further elaborated upon by the individual participants in their interviews. The eight identified interview categories will be discussed in greater detail in the following sections and, where appropriate, related to the individual participants’ WHODAS 2.0 scores.

5.3 Knowledge of health condition

The fact that very few of the participants knew the actual medical reason for their admission to hospital is of significance to physiotherapists.

“I was ill and I did not know what was wrong with me.” (P8)

Interdisciplinary teams of healthcare professionals involved in rehabilitation can offer a range of rehabilitative services through a comprehensive, coordinated and collaborated programme (Jelsma et al, 2002). As members of the multidisciplinary health-care team, physiotherapists play a role in educating patients about their condition. According to Atwal and Caldwell (2005) poor communication within the multidisciplinary team can influence quality of care for the patients. It is thus vital that physiotherapists find out the exact nature of each of their patients' diagnoses from the attending doctor or nurse, so as to assist in reinforcing patients' knowledge of their health condition.

Another interesting phenomenon in the participants' interview responses was the fact that only three of the participants alluded to their HIV status at all, with only one of the participants directly referring to the disease.

“Then I started my AIDS.” (P5)

This is despite all participants having been counseled regarding their positive HIV status, a fact confirmed by their medical files. This denial of one's HIV status is common amongst PLHIV throughout the world (Parker and Aggleton, 2003) and may be further fueled in South Africa by the prevailing stigmatisation of PLHIV in their own communities (Kalichman and Simbayi, 2003, Visser et al, 2006). Rohleder et al (2009) describes how the stigma associated with HIV/AIDS further compounds the stigma of disability. From their interview responses, it would appear that the participants were far more comfortable talking about the impairments associated with HIV than they were discussing the disease itself. Physiotherapists need to be aware of, and sensitive to, these issues of denial and stigma when treating PLHIV, in order to gain their trust and further improve the effectiveness of prescribed treatments.

5.4 Medication

In contrast to the relative silence regarding their HIV status, most of the participants readily discussed issues relating to their prescribed medication, although only two participants actually mentioned the phrase “ARVs” (P2 and P8). This is despite the fact that all of the participants, with the exception of participant 1, had been initiated on ARVs at the time of the interviews, according to their patient files. While physiotherapists are not involved in prescribing or dispensing medication, they should be aware of the potential side effects of HAART medication. It may be that the physiotherapist is the first health care professional to hear of a known side-effect of a prescribed drug, for example the peripheral neuropathy experienced by participant 5, described above.

In a case like this, the physiotherapist could alert the doctor regarding this condition, who may then decide to change the drug regimen, if the side-effect is confirmed and deemed to be of serious enough a nature. Physiotherapists can also play a key role, as members of the wider multidisciplinary team, in reminding and encouraging PLHIV to adhere to taking their tablets on time, every day. Non-adherence to HAART is, according to Dudgeon et al (2004), a major concern as it leads to faster disease progression as well as the development of resistant strains of HIV. The onus is on all members of the multi-disciplinary team to ensure that this does not happen.

5.5 Impairments, activity limitations and participation restrictions

The ICF adopts a bio-psychosocial approach that views impairments, activity limitations, participation restrictions in relation to associated contextual factors, which are further divided into environmental and personal influences (Van As et al, 2009). This framework for understanding disability is well illustrated by Figure 1 (see page 15). Bearing this in mind, the four interview categories directly related to the ICF (namely impairments, activities, participation and contextual factors) will be discussed in relation to one another in this sub-section of the discussion.

All eight of the participants in this study reported a wide range of impairments, of both a physical and cognitive nature. The physical impairments related to HIV are well documented and include weakness or paralysis of muscles (Nixon and Cott, 2000), peripheral neuropathy (Myezwa et al, 2007), inflammatory joint conditions (Terenzedah, 2004), impaired lung function (Myezwa et al, 2007) and the widespread prevalence of pain (Rusch et al, 2004). The various responses related to body impairments are shown in the results (section 4.3.3) but below is an example which serves to illustrate some of these physical challenges.

“Yes, my body is also itchy. It’s my bones, my bones are painful. They get painful especially if I have been too cold, they get painful.” (P7)

As discussed in detail in Chapter 2, physiotherapists are directly concerned with treating the impairments related to the neurological, musculoskeletal and respiratory complications of HIV infection. What is perhaps more challenging to physiotherapists is the frequent presence of cognitive deficits related to HIV. These deficits may include loss of concentration, poor memory and social withdrawal (Nixon and Cott, 2000). One of the participants, in his interview, directly alluded to difficulty with planning.

“Like, maybe if I tried planning, things didn’t work.” (P3)

Two of the participants (P1 and P6) reported mild to moderate difficulties with tasks related to cognition. Of more concern was the following statement by participant 6.

“No it [physiotherapy] has not helped me because I am still dying.” (P6)

This could either point to a lack of patient understanding of the medical prognosis of HIV or possibly be indicative of depression experienced by this individual. According to Ciccolo et al (2004), up to 80% of PLHIV experience symptoms of anxiety or depression, which may be a result of the infection itself or related to the side-effects of HAART. With the ICF framework in mind, one cannot ignore the impact of environmental and personal factors on the individual experience of living with HIV. The increased stigma of living with HIV and disability in Southern Africa is described by

Kalichman and Simbayi (2003), Visser et al (2006) and Rohleder (2009). This may well result in this individual, who lives in a poor, semi-urban community, having a markedly different experience of living with HIV, than equivalent PLHIV in the Western world. However, one should also bear in mind the strong influence that personal factors, such as motivation, can have on one's experience of living with HIV and disability. Whereas participant 6 sounds dejected and lacking in hope, participant 3 is intent on returning for treatment and feels strongly that his health condition can improve, as shown by this exchange with the interviewer below.

“What caused it to improve?” (Interviewer)

“It was commitment. . . Yes I would [come back for treatment], since all that I want is to be better.” (P3)

Physiotherapists are not qualified to give psychological counseling, but it should be noted that the two systematic reviews by O'Brien et al (2009a; 2010) conclude that both aerobic exercise and resistance exercise interventions are linked to improvements in the psychological status of PLHIV. This again points to the importance of the multi-disciplinary team working together, in this case the professions of physiotherapy and psychology, in an effort to improve both physical and cognitive treatment outcomes. Physiotherapists, however, must be aware of the limits of their scope of practice and be prepared to refer patients for counseling where necessary. O'Brien et al (2010) name a number of screening tools, used in previous studies of PLHIV, which include questions related to psychological well-being. These include the Montgomery-Asberg scale for depression, the Quality of Life questionnaire the Profile of Mood State Scale (POMS), and various versions of the Short Form questionnaire (SF-12, SF-20, SF-21 and SF-36). It would be prudent for physiotherapists to meet with psychologists in their hospital or local area to discuss the most appropriate screening tool as well as mutual indications for referral.

As well as being involved in the treatment of the impairments related to HIV and disability, physiotherapists are trained to assist patients in overcoming, or managing, the

limitations in activity resulting from these impairments (Myezwa, 2012). A number of participants recorded very high average scores in the mobility and self-care domains of the WHODAS 2.0. For example, participant 1 reported extreme difficulty or an inability to do any of the tasks outlined in the mobility domain and moderate to severe difficulty in the self-care domain. This is confirmed by one of his interview responses.

“I was confined to my bed, I could not do things for myself, I had to be helped. Even to the toilet, even to take my baths in the morning. Some people had to come and bath me on the bed, you can imagine. Such an experience, I have never had it in my life.” (P1)

Participant 5 described her difficulty standing up, which limited her ability to wash clothes for her family and exacerbates the symptoms of her peripheral neuropathy.

“When I wash I don’t want to stand, I want to sit down. To wash, you see. Then after washing, when I sleep, the numbness in the night goes worse.” (P5)

The above statement highlights the close inter-relationship between impairment (peripheral neuropathy) and activities (both standing and washing), thus confirming the value of considering a patient’s overall health holistically via the use of the ICF framework. In addition to this, it is vital that rehabilitation professionals do not forget to ask about any restrictions that their patients may experience in their participation in school, work or community pursuits. Consider the interview response below.

“I tell people I was not working before, but now I am not able to go around for evangelism the way I used to before.” (P1)

Participant 1 stated that he was not employed, but his voluntary work as an evangelist is extremely important to him. In the WHODAS 2.0, he scored an average of 4.9 for the participation domain (indicating an extreme difficulty or inability to do the specified tasks). This is confirmed by the interview response above. For this individual, the fact that he could not walk for long distances was a severe set-back, reducing his participation in his community and impacting on his spiritual duties. In a study validating the WHODAS 2.0, Garin et al (2010) propose that the participation domain is reflective

of the way in which disability is manifested in the societal context. In other words, being unable to walk properly has very different meanings for different individuals. Without understanding the greater societal and occupational context in which each patient lives, it is unlikely that physiotherapists will be able to help patients achieve all their rehabilitation goals.

As well as identifying the individual patient's needs, it is imperative that physiotherapists attempt to understand the patient's social support network. An individual's family and friends can play a significant role in helping them cope with health problems. According to Nair and Muthukrishna (2009), who conducted a study of 133 HIV-positive women in KwaZulu-Natal, social support was found to decrease the risk of suicide. Conversely, a lack of supportive networks is linked to decreased participation in society; with the additional physical and psychological drawbacks this withdrawal entails (O'Brien and Nixon 2004). An example of positive support family is shown below.

"I did not have any problem because there are a lot of us at home. . . my mom and my sister offered me assistance." (P8)

From this response, it is clear that participant 8 is receiving sufficient assistance from her family, improving her ability to cope with her health problems. However, at times family may actually cause a patient to have additional concerns, as evidenced by the statement by participant 3 below (note that he was in full-time paid work prior to being hospitalised, and thus a primary breadwinner for his extended family).

"Yes, something which always caused problems for me was that on one side I had a mother plus a few others from my father's side so I had problems with finances." (P3)

While it is clear that PLHIV are faced with a number of challenges, physiotherapists should also be aware of the difficulties that face the caregivers of PLHIV. According to Abasiubong et al (2011) the burden associated with this care often results in high level of stress among caregivers, usually manifesting as anxiety and/or depression. It is therefore important to involve these caregivers, where possible, in the holistic rehabilitation of PLHIV. This may further improve rehabilitation goals, as well as assist

in alleviating some of the concerns and difficulties faced by patients' families, friends and caregivers.

5.6 Rehabilitation experience

This study aimed to explore the effects of a physiotherapy rehabilitation programme on the participants' impairments, activity levels and participation restrictions. The interview responses by the eight participants included both positive and negative experiences of the rehabilitation process. One of the positive responses is shown below.

"Yes it helped me. I now can wake up and walk to the toilet. I couldn't walk at all." (P4)

These positive responses describe how physiotherapy rehabilitation benefitted the participants with respect to specific activity limitations. A positive treatment effect would concur with the evidence revealed by the two systematic reviews by O'Brien et al (2009a; 2010). By employing a combination of resistance and aerobic exercise interventions, the physiotherapy students had a largely positive impact on the overall health of five of the eight participants. Indeed, participant 1 was effusive in his praise.

"JP [physiotherapy student] brought me here to the physiotherapy department for exercises, and while she was trying to teach me what to do, everybody in the department came out for assistance. Actually, everyone in this department has been so wonderful." (P1)

Unfortunately, not all the interview responses were positive regarding individual experiences of physiotherapy. Despite recounting mostly positive experiences, participant 2 also experienced pain, caused during one of the treatment sessions. Of more concern, three of the participants (participants 3, 7 and 8) appeared, from their responses, not to be aware of having received any physiotherapy rehabilitation at all. One of these responses is shown below.

"There was a lady who came to me and asked questions then wrote down but she never showed me anything. She said she would come back but never came back." (P7)

These responses are directly contradicted by information contained within these participants' patient files, which contain written evidence that all three of them were in fact treated by the physiotherapy students on two or more occasions. It is possible that participants simply forgot receiving any physiotherapy rehabilitation, which in some cases was a month before the interviews took place. Alternatively this memory loss may indicate possible HIV-related cognitive deficit. Research conducted in a Southern African context (Joska 2010; Lawler 2010; 2011) has outlined the neurocognitive deficits related to HIV, which include problems with memory. A further possible explanation is that patients in hospital wards are often seen by a variety of health care professionals over a short period of time and may actually have no idea which individual represents which particular profession.

Whatever the explanation for this apparent anomaly, the onus rests on physiotherapists to continually educate patients regarding both a wider explanation of the profession itself as well as the specific goals of each individual rehabilitation programme. With respect to any possible difficulties with memory and understanding, physiotherapists should also provide patients with a simple ward and/or home exercise programme, containing clear diagrams of selected exercises. Where possible, caregivers should also be included in this education process, as discussed above.

5.7 Barriers to rehabilitation

A prevailing theme emerged throughout each of the eight interviews, namely the barriers or obstacles each of these participants faced with regard to accessing further rehabilitation and healthcare services. Some of these may seem relatively insignificant, such as the response by participant 2 below:

“What problems do you think you may have getting to the hospital?” (Interviewer)

“Like I don’t have the hospital’s telephone number.” (P2)

In the modern Western world, this problem would be easily solved by phoning directory services, or accessing the hospital telephone number on-line. However, only two of

these eight participants actually owned their own mobile phone, and none of them had personal internet access. The researcher had great difficulty calling the participants back for interviews, in most cases having to phone family members or friends of the participants to arrange a suitable date and time to meet. Even the cost of making a phone call was beyond many of these participants, with their poverty compounded by their difficulties in returning to work. These financial barriers were further illustrated by their difficulty in paying for transport to get to and from hospital. None of these participants owned their own car. Consider this response from participant 5, describing the financial cost of her attending one physiotherapy session.

“When I come, I pay R40 for physio. Then I pay taxi. It’s R9 to come here, R9 to go back, you see?” (P5)

Patients at the study facility are requested to pay a nominal amount of R40 for each physiotherapy treatment session. This may seem a small amount of money, compared to private physiotherapy rates, which can be ten times that amount, depending on the type of treatment provided (HealthMan, 2012). However, R40 is still beyond the means of a large number of unemployed South Africans. This amount, as well as the cost of her return taxi fare, would also be multiplied by the number of times patients return for regular physiotherapy treatment, as is often required for satisfactory rehabilitation outcomes. Participant 7’s response, shown below, sums up the potential burden of spiraling medical costs, even at a government-funded hospital such as the study facility.

“If you are able to see a doctor, as we were arriving for the first time, we were told that it is R230.00. The one for admission as they counted everything, so when it was added it came to one thousand eight hundred and fifty something.”

These financial difficulties were further exacerbated, in some cases, by the physical difficulties that participants had in walking from their home to a taxi and then from where the taxi dropped them to the hospital. Participant 6 described the difficulty he had walking a short distance of about 50 meters from the outpatient department to the physiotherapy department at the study facility. One can only imagine the difficulty he

may have getting from his home to the hospital and back to his home. It is clear then that the physical burden of just getting to the hospital for treatment is a significant factor dissuading patients from returning for further care. Other barriers expressed in the interviews included logistical difficulties, as in the statement by participant 5 below, which could have been resolved telephonically, if this individual owned a mobile phone.

“You give me a date to come again, but I didn’t come because my date to take the tablets in Mophola and here, it is the same date.” (P5)

Participant 1 also made an interesting comment below, revealing another potential barrier to his continued rehabilitation that is not immediately apparent.

“The person I am staying with, the only problem he is afraid of leaving me alone, like this morning he brought me, he dropped me here.” (P1)

While, on the one hand, this shows the positive effect of having a friend who is prepared to drive him to hospital, this also highlights the concern that participant 1 has of being dependent on others for his transport. This concern for his friend, or his friend’s future unavailability, may potentially prevent him from attending further physiotherapy sessions.

The barriers discussed by the eight participants in this study reflect a reality that appears contrary to the vision of the South African Department of Health (DOH) that promotes the treatment of people in or near their homes, responds to the needs of people and encourages traditional community life (DOH, 2001). The DOH wrote these guidelines on community-based care in 2001. Now, eleven years later, this study shows that in this semi-rural KwaZulu-Natal hospital patients still have to commute considerable distances, at great financial and physical cost, in order to access the rehabilitation they require. These barriers also contrast starkly with the South African government’s recently published National Strategic Plan on HIV, STIs and TB (2012-2016). The reader is reminded of Strategic Objective 3 in this document which states the goal of significantly reducing disability as a result of HIV and TB through universal access to affordable and good quality diagnosis, treatment and care (SANAC, 2011).

The fact that these eight participants experience such difficulties with regard to accessing continued physiotherapy rehabilitation shows that significant work still needs to be done to achieve the admirable goals outlined in the above policies.

To this researcher's knowledge, of the 200 community rehabilitation facilitators working in over 100 communities in South Africa, described by Chappell and Johannsmeier (2009), none of them work in the geographical area served by the study facility. One should be reminded that this area has a population of over 750 000 people (About us, 2012). It is important to describe, however, the commendable work in this area performed by the Community Outreach Centre (COC), a non-governmental organization based at the hospital. The COC, staffed mainly by volunteers, offers basic nursing care, food parcels and promotes income-generating projects to approximately 600 adults in this area every month. They further provide food and drop-in care facilities for up to 2500 orphans and vulnerable children (COC, 2012). Due to the fact that COC has no trained rehabilitation staff, the UKZN physiotherapy department, in 2012, began sending its fourth year students into the Marianhill community to treat disabled patients identified by the volunteer staff at COC and to assist with the work done at the drop-in care facilities. This researcher was one of the academic staff supervising physiotherapy students in the first year of this initiative. While the work that COC and other similar organisations perform is commendable, non-governmental organisations still require the assistance of government services and resources to even come close to meeting the rehabilitation requirements required for effective home-based care. According to Ogden et al (2006), public, private and non-governmental sectors need to work with common purpose to ensure that households affected by HIV and AIDS are enabled to survive.

The above access to effective rehabilitation should not be viewed as a luxury, enjoyed by a select few individuals. As a signatory of the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2008), South Africa has pledged to recognise every individual living with disability's right to rehabilitation. The UNCRPD explicitly states (in Article 26) that all signatory countries take steps to allow people with disabilities to achieve maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. It is important

that health care professionals are aware of these rights and endeavour to ensure that the patients they treat have access to the holistic care described by this convention.

Although the systematic reviews conducted by O'Brien et al (2009a; 2010), clearly show the positive physical and psychological effects of exercise for PLHIV, it should be noted that these reviews included studies mostly conducted in the Western World. People living in the Western World have improved access to rehabilitation professionals, as compared to their Southern African counterparts, simply as a result of there being significantly more qualified rehabilitation professionals in the West, per head of population. Recent WHO statistics (WHO, 2011) reveal that there are more than 20 physiotherapists per 10 000 population in Finland as compared to fewer than two physiotherapists per 10 000 population in South Africa. Denmark has approximately 11 occupational therapists, compared to fewer than one occupational therapist in South Africa, per 10 000 population. While those responsible for the allocation of funding and resources may argue that the South African government can't afford to train and place more rehabilitation professionals, it may be that in doing so they can actually save money in the long-term. In a recent review article, Green et al (2012) state that improving the delivery of services to PLHIV not only makes clinical sense, it also has the potential to save healthcare systems money they would have otherwise spent on hospitalisation due to acute illness and the provision of second- and third-line HAART regimens. Thus, by improving rehabilitation for PLHIV it may be possible to decrease the number of hospital visits that PLHIV are required to make due to exacerbation of any of their physical impairments. O'Brien et al (2009b) describe the episodic nature of disability experienced by PLHIV. It should be the goal of physiotherapists and other rehabilitation professionals to decrease the frequency of these episodes of disability. Not only will this decrease the need for acute care, but in doing so it may well increase the life expectancy and quality of life of PLHIV. This has the potential to influence a number of social and economic challenges facing South Africa. More research is required to ascertain what exactly these effects may be.

5.8 Summary

This chapter has discussed the data obtained from the WHODAS 2.0, patient files and participant interviews in relation to the reviewed literature specific to the area of rehabilitation for PLHIV and disability. This information is useful in informing physiotherapists on how to improve their own practice when treating these patients. Physiotherapists, as part of the wider multi-disciplinary team, should assist PLHIV to understand their health condition, the associated complications, the importance of adherence to chronic medications and the potential side-effects of these medications. The responses provided by the participants in the interviews describe their impairments, activity limitations and participation restrictions. It is important that physiotherapists are aware of the difficulties facing patients as well as the personal and environmental factors that influence their response to these challenges. It is hoped that this knowledge will allow for the provision of a variety of improved rehabilitation options. One of these options should include the provision of community based rehabilitation in or near to patient's homes, in line with South African governmental policy. This is vital as a means of responding to the numerous barriers that limit PLHIV's access to continued physiotherapy rehabilitation in this peri-urban district of KwaZulu-Natal.

Chapter 6: Conclusion

6.1 Conclusion

This study aimed to explore the experiences of eight PLHIV who received physiotherapy rehabilitation in a public-funded hospital in a resource-poor area of Kwazulu-Natal province, South Africa. The participant's physical and cognitive difficulties were documented using the WHODAS 2.0 while their experiences of rehabilitation were examined using an interview schedule guided by the ICF framework on disability.

The results of this study showed that these participants experienced similar impairments, activity limitations and participation restrictions to those experienced by PLHIV worldwide. While a majority of participants found the physiotherapy rehabilitation they received to be beneficial, they also reported a number of barriers that they faced with regard to receiving continued rehabilitation. These barriers included a lack of transport to get to their nearest hospital, a lack of money to pay for transport and continued rehabilitation, physical difficulties in accessing rehabilitation services as well as a dependence on others to access this care.

The reader is reminded of the cyclical relationship between HIV and disability, with PLHIV at increased risk of disability and people with disabilities being at an increased risk of contracting HIV (Hanass-Hancock and Nixon, 2009). This study has clearly outlined the physical and cognitive difficulties experienced by eight PLHIV. Unfortunately, the barriers that prevent them from accessing and experiencing effective rehabilitation services also prevent these individuals from achieving maximum independence and dignity and may increase their individual risk of developing further disabilities.

This study serves to inform physiotherapists and other rehabilitation professionals working in the South African public health care service about both the challenges PLHIV face, and provides these professionals with some ideas about how to improve their delivery of effective rehabilitation services. These strategies should include close cooperation with the multi-disciplinary team regarding on-going care and referral,

improved patient education with respect to the description and goals of each profession, reinforcement of advice related to medication side-effects and adherence, as well as a concerted effort to take rehabilitative services into patients' communities and homes.

It is hoped that the information and knowledge gained from this study will inspire further research into the area of rehabilitation for PLHIV and ultimately assist in the improved design of rehabilitation programmes for this vulnerable population. To paraphrase Nixon et al (2011), while medicine (in the form of HAART) may add years to the life of PLHIV, it is rehabilitation that can add life to years. The responsibility of spreading this message and implementing it into practice lies squarely on the shoulders of those professionals involved in the field of rehabilitation.

6.2 Limitations

Of fourteen individuals who satisfied the inclusion criteria for this study and completed the WHODAS 2.0, only eight participants were able to attend the post-rehabilitation interviews. Large sample sizes are not necessarily an important feature of qualitative research methodology, which can even derive valuable data from just one case (Silverman, 2000). Indeed, this study identified a number of experiences and concerns common to the majority of the participants. Sarantakos (2005) proposes that qualitative sampling should be directed towards typical cases rather than large numbers of participants. It is hoped that this study achieved this aim. However, Trochim (2001) states that the detail portrayed by most qualitative research can be both a blessing and a curse. On the positive side, qualitative research describes phenomena with great richness and depth, but on the negative side, it is very difficult to generalise the identified themes to a larger population. While this study does not aim to be representative of all PLHIV in South Africa, more value may have been added to the findings had it been possible to interview all fourteen of the original participants.

Five of the eight participants were interviewed by the isiZulu-speaking research assistants. While this researcher was present at all five of these interviews and participated in the asking of questions, via translation, it is possible that some of the meaning may have been lost in the translation and transcription of the interview data.

Although this was unavoidable due to the language barrier between the researcher and these participants, it should also be noted as a limitation to this study. To attenuate this potential limitation, the research assistants received thorough prior training to help ensure the quality of the interview delivery.

Qualitative research should, according to Sarantakos (2005), be reflexive and thus derive value from the interaction between the participants in the study and the researchers conducting the study. Although it was important that the researcher was present in all the interviews for this very reason, it is possible that this may have caused the participants to mainly respond positively regarding their experiences of physiotherapy, as they knew that the researcher and research assistants were involved in their previous and possible future rehabilitation. In an attempt to allay this potential drawback, participants were encouraged to be completely honest at all times and were assured that their on-going care would not depend upon their responses. It is hoped that the negative experiences reported in this study are a reflection of this honesty.

6.3 Recommendations

According to Heidari and Kippax (2009), research on HIV and disability with regard to both the disabling consequences of HIV infection and the subsequent treatment of these disabilities, has been sorely neglected. It is hoped that this study and others like it will inform and influence future research in this much-needed area.

This study has described the experiences of adult PLHIV in a resource-poor KwaZulu-Natal environment. Future research could examine the experiences of rehabilitation in different populations and study settings in South Africa. More important, perhaps, is the need for studies that assess the effectiveness of alternative rehabilitation programmes in influencing the lives of PLHIV and disability. These programmes may include, but should not be limited to, home-based care interventions, rehabilitation offered at step-down (or intermediate) care facilities and the provision of a block-period of rehabilitation. It can only be hoped that research that confirms the positive effects of exercise and rehabilitation for PLHIV in South Africa may also encourage the leaders and policy-

makers in the public education and health sectors to train and employ more rehabilitation professionals in this country.

From this study of eight adult PLHIV, it is apparent that the current level of rehabilitation provision is not adequate in assisting patients to reach full potential in all areas of their lives. Research that is able to demonstrate the viability and potential effectiveness of alternate, better-resourced rehabilitation solutions is vital in being able to advocate for change in the delivery of rehabilitation services in the South Africa public health care sector. It is important that South African physiotherapists working with PLHIV are familiar with and learn from the vital work that has been done in the Western World with regard to rehabilitation for PLHIV, such as the extensive research and policy development undertaken by Canadian rehabilitation professionals (CWGHR, 2011). The need remains, however, to adapt and develop these models of rehabilitation so that they are relevant and benefit PLHIV in this country. South African physiotherapists and other rehabilitation professionals should be at the forefront of research and advocacy efforts to ensure that PLHIV are provided with the rehabilitation services that they are, morally and legally, entitled to.

References

- Abasiubong, F., Bassey, E.A., Ogunsemi, O.O. and Udobang, J.A., 2011. Assessing the psychological well-being of caregivers of people living with HIV/AIDS in Niger Delta region, Nigeria. *AIDS Care*, 23(4), pp. 494-500.
- About us. 2012 Available at: <http://www.stmarys.co.za/pages/40327_aboutus.htm> [Accessed 13 November 2012].
- Actuarial Society of South Africa, 2011. ASSA 2008 model. Available at: <<http://aids.actuarialsociety.org.za/404.asp?pageid=3480>> [Accessed 07 November 2012].
- Atwal, A. and Caldwell, K., 2005. Do all health and social care professionals interact equally: a study of interactions in multidisciplinary teams in the United Kingdom. *Scandinavian Journal of Caring Sciences*, 19, pp. 268–273.
- Basta, T.B., Reece, M. and Wilson, M.G., 2008. Predictors of exercise stage of change among individuals living with HIV/AIDS. *Medicine and Science in Sports and Exercise*, 40(9), pp. 1700-1706.
- Bopp, C.M., Phillips, K.D., Fulk, L.J. and Hand, G.A., 2003. Clinical implications of therapeutic exercise in HIV/AIDS. *Journal of the Association of Nurses in AIDS Care*, 14(1), pp. 73-78.
- Brandt, R., 2009. The mental health of people living with HIV/AIDS in Africa: a systematic review. *African Journal of AIDS Research*, 8(2), pp. 123–133.
- Bruckner, P. and Khan, K., 2001. *Clinical sports medicine*. 2nd ed. Sydney: McGraw-Hill.
- Bury, T., 2005. Primary healthcare and community based rehabilitation: implications for physical therapy. *Asia Pacific Disability Rehabilitation Journal*, 16(2) 29-61.

Cade, W.T., Peralta, L. and Keyser, R.E., 2004. Aerobic exercise dysfunction in human immunodeficiency virus: a potential link to physical disability. *Physical Therapy*, 84(7), pp. 655-664.

Canadian Working Group on HIV and Rehabilitation (CWGHR), 2011. E-module for evidence-informed HIV rehabilitation. Available at:< http://cwghrcampus.hivandrehab.ca/documents/CWGHR_E-moduleEvidence-InformedHIVRehabilitationfinal.pdf> [Accessed 17 November 2012].

Centre for Disease Control, 1981. Pneumocystis pneumonia - Los Angeles. *Morbidity and Mortality Weekly Report*, 30, pp. 250-252.

Chappell, P. and Johannsmeier, C., 2009. The impact of community based rehabilitation as implemented by community rehabilitation facilitators on people with disabilities, their families and communities within South Africa. *Disability and Rehabilitation*, 31(1), pp. 7–13.

Chigwedere, P., Seage, G.R., Gruskin, S., Lee, T.H. and Essex, M., 2008). Estimating the lost benefits of antiretroviral drug use in South Africa. *Journal of Acquired Immune Deficiency Syndrome*, 49(4), pp. 410-415.

Ciccolo, J.T., Jowers, E.M. and Bartholomew, J.B., 2004. The benefits of exercise training for quality of life in HIV/AIDS in the post-HAART era. *Sports Medicine*, 34 (8), pp. 487-499.

Community Outreach Centre (COC), 2012. The work we do. Available at:< <http://coc-stmarys.com/about/overview>> [Accessed 13 November 2012].

Department of Health (DOH), 2001. National guideline on home-base care/community-based care. Available at:<<http://www.doh.gov.za/docs/factsheets/guidelines/homecare/>> [Accessed 14 November 2012].

Dudgeon, W.D., Phillips, K.D., Bopp, C.M. and Hand, G.A., 2004. Physiological and psychological effects of exercise interventions in HIV disease. *AIDS Patient Care and STDs*, 18(2), 81-97.

Elliott, R., Utyasheva, L. and Zack, E., 2009. HIV, disability and discrimination: making the links in international and domestic human rights law. *Journal of the International AIDS Society*, 12 (29), pp. 1-15.

Fillipas, S., Oldmeadow, L.B., Bailey, M.J. and Cherry, C.L., 2006. A six-month, supervised, aerobic and resistance exercise program improves self-efficacy in people with human immunodeficiency virus: A randomised controlled trial. *Australian Journal of Physiotherapy*, 52, pp. 185-190.

Garin, O., Ayuso-Mateos, J., Almansa, J., et al., 2010. Validation of the "World Health Organization Disability Assessment Schedule, WHODAS-2" in patients with chronic diseases. *Health and Quality of Life Outcomes*, 8(51), pp. 1-15.

Gale, J.R., 2008. HIV/AIDS in the 21st century: what can we learn from each other? *Physiotherapy Research International*, 13(4), pp. 201–202.

Green, K., Dix, O., Mwangi-Powell, F., Horne, C. and Luyirika, E., 2012. Where's the care in the post-ART era? *Africa Health*, pp. 19-21.

Groce, N.E., 2004. Global Survey on HIV/AIDS and disability, New Haven: Yale University. Available at: <<http://cira.yale.edu/projects/hivaids-and-disability-global-survey-hivaids-disability>> [Accessed 14 November 2012].

Hanass-Hancock, J. and Nixon, S.A., 2009. The fields of HIV and disability: past, present and future. *Journal of the International AIDS Society*, 12 (28) pp. 1-14.

Hanass-Hancock, J., 2009. Disability and HIV/AIDS - a systematic review of literature on Africa. *Journal of the International AIDS Society*, 12 (34), pp. 1-11.

Hanass-Hancock, J., Nixon, S., Myezwa, H. and Gibbs, A., 2012. "Nathi Singabanthu": an exploratory study of HIV-related disability in KwaZulu-Natal. In: Hanass-Hancock, J. (ed). Durban: HEARD.

HealthMan, 2012. Physiotherapy costing guide 2012. Available at:<
<http://www.mm3admin.co.za/documents/docmanager/419AE5A4-F8C7-11D4-9FB7-0090279A6A88/00023508.pdf>> [Accessed 13 November 2012].

Heidari, S. and Kippax, S., 2009. Special theme on HIV and disability - time for closer bonds. *Journal of the International AIDS Society*, 12 (26), pp. 1-2.

Hsieh, H.F. and Shannon, S.E., 2005. Three approaches to qualitative content analysis. *Qualitative Health Research*, 15, pp. 1277-1288.

Hughes, J., Jelsma, J., Maclean, E., Darda, M. and Tinise, X., 2004. The health-related quality of life of people living with HIV/AIDS. *Disability and Rehabilitation*, 26 (6), 371-376.

Hwang, J. and Nochajski, S., 2003. The International Classification of Function, Disability and Health (ICF) and its application with AIDS. *Journal of Rehabilitation*, 69, pp. 4-14.

Jenkins, S.K., 2009. *AIDS: education and prevention*. Indiana: Author House.

Jelsma, J., Mielke, J., Powell, G., De Weerd, W. and De Cock, P., 2002. Disability in an urban black community in Zimbabwe. *Disability and Rehabilitation*, 24 (16), pp. 851-859.

Jelsma, J., Brauer, N., Hahn, C., Snoek, A. and Sykes, I., 2006. A pilot study to investigate the use of the ICF in documenting levels of function and disability in people living with HIV. *South African Journal of Physiotherapy*, 62(1), pp. 7-13.

Johnson, L.F., Dorrington, R.E. and Mathews, A.P., 2007. An investigation into the extent of uncertainty surrounding estimates of the impact of HIV/AIDS in South Africa. *South African Journal of Science*, 103, pp. 135-144.

Joska, J.A., 2010. Clinical correlates of HIV-associated neurocognitive disorders in South Africa. *AIDS and Behavior*, 14(2), pp. 371-378.

Kalichman, S.C. and Simbayi, L.C., 2003. HIV testing attitudes, AIDS stigma, and voluntary HIV counselling and testing in a black township in Cape Town, South Africa. *Sexually Transmitted Infections*, 79, pp. 442–447.

Keswani, S.C., Pardo, C.A., Cherry, C.L., Hoke, A. and McArthur, J.C., 2002. HIV-associated sensory neuropathies. *AIDS*, 16, pp. 2105-17.

Lawler, K., 2010. Neurocognitive impairment among HIV-positive individuals in Botswana: a pilot study. *Journal of the International AIDS Society*, pp. 13-15.

Lawler, K., 2011. Neurobehavioral effects in HIV-positive individuals receiving highly active antiretroviral therapy (HAART) in Gaborone, Botswana. *PLoS*, 6(2), pp. 17-33.

Lee, A., Holdsworth, A., Holland, A. and Button, B., 2009. The immediate effect of musculoskeletal physiotherapy techniques and massage on pain and ease of breathing in adults with cystic fibrosis. *Journal of Cystic Fibrosis*, 8(1), pp. 79-81.

Luciano, J.V., Ayuso-Mateos, J.L., Aguado, J., Fernandez, A., Serrano-Blanco, A., Roca, M., and Haro, J.M., 2010. The 12-item World Health Organization Disability Assessment Schedule II (WHODAS II): a nonparametric item response analysis. *BMC Medical Research Methodology*, 10(45), pp. 1-9.

Mars, M., 2003. What limits exercise in HIV positive individuals? *International Sports Medicine Journal*, 4(3), pp. 3-13.

Meintjies, G., Maartens, G., Boulle, A., Conradie, F., Goemaere, E., Hefer, E., Johnson, D., Mathe, M., Moosa, Y., Osih, R., Rossouw, T., Van Cutsem, G., Variava, E., Venter, F. and Spencer, D., 2012. Guidelines for antiretroviral therapy in adults. *South African Journal of HIV Medicine*, 13, pp. 114-130.

- Mutimura, E., Stewart, A., Crowther, N.J., Yarasheski, K.E. and Todd Cade, W., 2008a. The effects of exercise training on quality of life in HAART-treated HIV-positive Rwandan subjects with body fat redistribution. *Quality of Life Research*, 17, pp. 377–385.
- Mutimura, E., Crowther, N.J., Todd Cade, W., Yarasheski, K.E., and Stewart, A., 2008b. Exercise reduces central adiposity and improves metabolic indices in HAART-treated HIV-positive subjects in Rwanda: a randomized controlled trial. *AIDS Research*, 24, pp. 15-23.
- Murphy, S.M., Brook, G. and Birchall, M.A., 2000. *HIV infection and AIDS*. Edinburgh: Churchill Livingstone.
- Myezwa, H., Stewart, A., Mbambo, N. and Nesara, P., 2007. Status of referral to physiotherapy among HIV positive patients at Chris Hani Baragwaneth Hospital Johannesburg South Africa. *South African Journal of Physiotherapy*, 63(2), pp. 27-31.
- Myezwa, H., Stewart, A., Musenge, E. and Nesara, P., 2009. Assessment of HIV-positive in-patients using the International Classification of Functioning, Disability and Health (ICF) at Chris Hani Baragwanath Hospital, Johannesburg. *African Journal of AIDS Research*, 8(1), pp. 93–105.
- Myezwa, H., Stewart, A., Solomon, P. and Becker, P., 2012. Topics on HIV/AIDS for inclusion into a physical therapy curriculum: consensus through a modified Delphi technique. *Journal of Physical Therapy Education*, 26(2), pp. 50-56.
- Nair, K. and Muthukrishna, N., 2009. Psychological well-being and health related quality of life among a group of low-income women living with HIV/AIDS in South Africa. *Journal of Psychology in Africa*, 19(4), pp. 517-529.
- Nakimuli-Mpungu, E., Musisi, S., Katabira, E., Nachega, J. and Bass, J., 2011. Prevalence and factors associated with depressive disorders in an HIV+ rural patient population in southern Uganda. *Journal of Affective Disorders*, 135, pp. 160-167.

- Nixon, S. and Cott, C., 2000. Shifting perspectives: reconceptualizing HIV disease in a rehabilitation framework. *Physiotherapy Canada*, 52(3), pp. 189-207.
- Nixon, S.A., Forman, L., Hanass-Hancock, J., Mac-Seing, M., Munyanukato, N., Myezwa, H. and Retis, C., 2011. Rehabilitation: A crucial component in the future of HIV care and support. *South African Journal of HIV Medicine*, 6, pp. 12-17.
- Nyirenda, M., Chatterji, S., Falkingham, J., Mutavedzi, P., Hosegood, V., Evandrou, M., Kowal, P. and Newell, M.L., 2012. An investigation of factors associated with the health and well-being of HIV-infected or HIV-affected older people in rural South Africa. *BMC Public Health*, 12(259), pp. 1-14.
- O'Brien, K. and Nixon, S., 2004. Evidence-Based Management of an Individual Living with HIV. *Physiotherapy Canada*, 62(3), pp. 202-205.
- O'Brien, K., Nixon, S., Glazier, R. and Tynan, A.M., 2009a. Progressive resistive exercise interventions for adults living with HIV/AIDS (Review). *The Cochrane Library*. Available at: <<http://www.thecochranelibrary.com>> [Accessed 08 November 2012].
- O'Brien, K., Davis, A.M., Strike, C., Young, N.L. and Boyoumi, A.M., 2009b. Putting episodic disability into context: a qualitative study exploring factors that influence disability experienced by adults living with HIV/AIDS. *Journal of the International AIDS Society* 2009, 12 (30), pp. 1-11.
- O'Brien, K., Nixon, S., Tynan, A.M. and Glazier, R., 2010. Aerobic exercise interventions for adults living with HIV/AIDS (Review). *The Cochrane Library*. Available at: <<http://www.thecochranelibrary.com>> [Accessed 08 November 2012].
- O'Brien, K., Wilkins, A., Zack, E. and Solomon, P., 2011. Developing clinical practice guidelines in HIV rehabilitation: process recommendations and guiding principles. *AIDS Education and Prevention*, 23(5), pp. 457–468.
- Oxford English Dictionary, 2012. "Disability". Available at: <<http://www.oed.com/>> [Accessed 15 November 2012].

- Ogden, J., Esim, S. and Grown, C., 2006. Expanding the care continuum for HIV/AIDS: bringing carers into focus. *Health Policy Plan*, 21 (5), pp. 333-342.
- Parker, R. and Aggleton, P., 2003. HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action. *Social Science and Medicine*, 57, pp. 13-24.
- Parry, M.F., Stewart, J., Wright, P. and McLeod, G.X., 2004. Collaborative management of HIV infection in the community: an effort to improve the quality of HIV care. *AIDS Care*, 16(6), pp. 690-699.
- Pons, T. and Shipton, E.A., 2011. Multilevel lumbar fusion and postoperative physiotherapy rehabilitation in a patient with persistent pain. *Physiotherapy Theory & Practice*, 27(3), pp. 238-245.
- Pope, D.S., Atkins, S., DeLuca, A.N., Hausler, H., Hoosain, E., Celentano, D.D. and Chaisson, R.E., 2010. South African TB nurses' experiences of provider-initiated HIV counseling and testing in the Eastern Cape Province: a qualitative study. *AIDS Care*, 22(2), pp. 238-245.
- Pryor, J.A. and Prasad, A., 2002. *Physiotherapy for respiratory and cardiac problems: adults and paediatrics*. 3rd ed, Edinburgh: Churchill Livingstone.
- Rohleder, P., Braathen, S.H., Swartz, L. and Eide, A.H., 2009. HIV/AIDS and disability in Southern Africa: a review of relevant literature. *Disability and Rehabilitation*, 31(1), pp. 51–59.
- Rusch, M., Nixon, S., Schilder, A., Braitstein P., Chan, K. and Hogg, R.S., 2004. Prevalence of activity limitation among persons living with HIV/AIDS in British Columbia. *Canadian Journal of Public Health*, 95(6), pp. 437-440.
- Sarantakos, S., 2005. *Social research*. 3rd ed. Basingstoke: Palgrave Macmillan.
- Silverman, D., 2000. *Doing qualitative research: A practical handbook*. London: Sage.

South African National AIDS Council (SANAC), 2011. National Strategic Plan on HIV, STIs and TB 2012-2016. Available at:<
<http://www.doh.gov.za/docs/stratdocs/2012/NSPfull.pdf>> [Accessed 13 November 2012].

Strauss, A. and Corbin, J., 1998. *Basics of qualitative research: Techniques and procedures for developing grounded theory*. London: Sage.

Taylor, N.F., Dodd, K.J., Shields, N. and Bruder, A., 2007. Therapeutic exercise in physiotherapy practice is beneficial: a summary of systematic reviews 2002–2005. *Australian Journal of Physiotherapy*, 53, pp. 7–16.

Tehranzadeh, J., Ter-Oganesyan, R. and Steinbach, L.S., 2004. Musculoskeletal disorders associated with HIV infection and AIDS. *Skeletal Radiology*, 33, pp. 249-259.

Trochim, W.M.K., 2001. *The research methods knowledge base*. 2nd ed. Cincinnati: Atomic Dog Publishing.

United Nations, 2008. Convention on the rights of persons with disabilities. Available at: <<http://www.un.org/disabilities/default.asp?id=150>> [Accessed 14 November 2012].

UNAIDS, 2010. Report on the global AIDS epidemic. Available at: <http://www.unaids.org/globalreport/Global_report.htm> [Accessed 14 November 2012].

University of KwaZulu-Natal (UKZN), 2012. College of Health Sciences handbook, 2012. Available at:< <http://www.ukzn.ac.za/docs/handbooks-chs/syllabi.pdf?sfvrsn=4>> [Accessed 24 November, 2012].

Ustun, T.B., Chatterji, S., Konstanjek, N., Rehm, J. Kennedy, C., Epping-Jordan, J., Saxena, S., von Korff, M. and Pull, M., 2010. Developing the World Health Organization Disability Assessment Schedule 2.0. *Bulletin of the World Health Organisation*, 88, pp. 815–823.

Van As, M., Myezwa, H., Stewart, A., Maleka, D. and Musenge, E., 2009. The International Classification of Function Disability and Health (ICF) in adults visiting the HIV outpatient clinic at a regional hospital in Johannesburg, South Africa. *Aids Care*, 21(1), pp. 50-58.

Visser, M.J., Makin, J.D. and Lehobye, K., 2006. Stigmatizing attitudes of the community towards people living with HIV/AIDS. *Journal of Community and Applied Social Psychology*, 16, pp. 42–58.

World Health Organization (WHO), 2001. International Classification of Functioning Disability and Health. Available at: <<http://www.who.int/classifications/icf/en/index.html>> [Accessed 07 November 2012].

World Health Organization (WHO), 2002. ICF: towards a common language for functioning, disability and health. Available at: <<http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf>> [Accessed 07 November 2012].

World Health Organisation (WHO), 2003. ICF checklist: version 2.1a, clinician form. Available at: <<http://www.who.int/classifications/icf/training/icfchecklist.pdf>> [Accessed 08 November 2011].

World Health Organisation (WHO), 2010. WHO Disability Assessment Schedule 2.0. Available at: < <http://www.who.int/classifications/icf/whodasii/en/index.html>> [Accessed 14 November 2012].

World Health Organisation (WHO), 2011. World report on disability. Available at: <http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf> [Accessed 17 November 2012].

Worthington, C., Myers, T., O'Brien, K., Nixon, S. and Cockerill, R., 2005. Rehabilitation in HIV/AIDS: development of an expanded conceptual framework. *Aids Patient Care STDs*, 19 (4), pp. 258-271.

Note: Harvard referencing system used

Appendices

Appendix 1: WHODAS 2.0 - 36-item, interviewer-administered



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

This questionnaire contains the interviewer-administered 36-item version of WHODAS 2.0.

Instructions to the interviewer are written in bold and italics – do not read these aloud.

Text for the respondent to hear is written in

standard print in blue.

Read this text aloud.

Section 1 Face sheet

Complete Items F1–F5 before starting each interview

F1	Respondent identity number			
F2	Interviewer identity number			
F3	Assessment time point (1, 2, etc.)			
F4	Interview date			
		day	month	year
F5	Living situation at time of interview (circle only one)	Independent in community		1
		Assisted living		2
		Hospitalized		3



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Section 2 Demographic and background information

This interview has been developed by the World Health Organization (WHO) to better understand the difficulties people may have due to their health conditions. The information that you provide in this interview is confidential and will be used only for research. The interview will take 15–20 minutes to complete.

For respondents from the general population (not the clinical population) say:

Even if you are healthy and have no difficulties, I need to ask all of the questions so that the survey is complete.

I will start with some background questions.

A1	Record sex as observed	Female	1
		Male	2
A2	How old are you now?	_____ years	
A3	How many years in all did you spend <u>studying in school, college or university?</u>	_____ years	
A4	What is your <u>current marital status?</u> (Select the single best option)	Never married	1
		Currently married	2
		Separated	3
		Divorced	4
		Widowed	5
		Cohabiting	6
A5	Which describes your <u>main work status best?</u> (Select the single best option)	Paid work	1
		Self-employed, such as own your business or farming	2
		Non-paid work, such as volunteer or charity	3
		Student	4
		Keeping house/ homemaker	5
		Retired	6
		Unemployed (health reasons)	7
		Unemployed (other reasons)	8
		Other (specify) _____	9



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Section 3 Preamble

Say to respondent:

The interview is about difficulties people have because of health conditions.

Hand flashcard #1 to respondent and say:

By health condition I mean diseases or illnesses, or other health problems that may be short or long lasting; injuries; mental or emotional problems; and problems with alcohol or drugs.

Remember to keep all of your health problems in mind as you answer the questions. When I ask you about difficulties in doing an activity think about ...

Point to flashcard #1 and explain that "difficulty with an activity" means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity.

Say to respondent:

When answering, I'd like you to think back over the past 30 days. I would also like you to answer these questions thinking about how much difficulty you have had, on average, over the past 30 days, while doing the activity as you usually do it.

Hand flashcard #2 to respondent and say:

Use this scale when responding.

Read the scale aloud:

None, mild, moderate, severe, extreme or cannot do.

Ensure that the respondent can easily see flashcards #1 and #2 throughout the interview



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Section 4 Domain reviews

Domain 1 Cognition

I am now going to ask some questions about: understanding and communicating.

Show flashcards #1 and #2 to respondent

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D1.1	Concentrating on doing something for ten minutes?	1	2	3	4	5
D1.2	Remembering to do important things?	1	2	3	4	5
D1.3	Analysing and finding solutions to problems in day-to-day life?	1	2	3	4	5
D1.4	Learning a new task, for example, learning how to get to a new place?	1	2	3	4	5
D1.5	Generally understanding what people say?	1	2	3	4	5
D1.6	Starting and maintaining a conversation?	1	2	3	4	5

Domain 2 Mobility

I am now going to ask you about difficulties in getting around

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D2.1	Standing for long periods such as 30 minutes?	1	2	3	4	5
D2.2	Standing up from sitting down?	1	2	3	4	5
D2.3	Moving around inside your home?	1	2	3	4	5
D2.4	Getting out of your home?	1	2	3	4	5
D2.5	Walking a long distance such as a kilometre [or equivalent]?	1	2	3	4	5



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Domain 3 Self-care

I am now going to ask you about difficulties in taking care of yourself.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D3.1	<u>Washing your whole body?</u>	1	2	3	4	5
D3.2	<u>Getting dressed?</u>	1	2	3	4	5
D3.3	<u>Eating?</u>	1	2	3	4	5
D3.4	<u>Staying by yourself for a few days?</u>	1	2	3	4	5

Domain 4 Getting along with people

I am now going to ask you about difficulties in getting along with people. Please remember that I am asking only about difficulties that are due to health problems. By this I mean diseases or illnesses, injuries, mental or emotional problems and problems with alcohol or drugs.

Show flashcards #1 and #2

In the past 30 days, how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D4.1	<u>Dealing with people you do not know?</u>	1	2	3	4	5
D4.2	<u>Maintaining a friendship?</u>	1	2	3	4	5
D4.3	<u>Getting along with people who are close to you?</u>	1	2	3	4	5
D4.4	<u>Making new friends?</u>	1	2	3	4	5
D4.5	<u>Sexual activities?</u>	1	2	3	4	5



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Domain 5 Life activities

5(1) Household activities

I am now going to ask you about activities involved in maintaining your household, and in caring for the people who you live with or are close to. These activities include cooking, cleaning, shopping, caring for others and caring for your belongings.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days, how much difficulty did you have in:	None	Mild	Moderate	Severe	Extreme or cannot do
D5.1 Taking care of your <u>household responsibilities</u> ?	1	2	3	4	5
D5.2 Doing your most important household tasks <u>well</u> ?	1	2	3	4	5
D5.3 Getting all the household work <u>done</u> that you needed to do?	1	2	3	4	5
D5.4 Getting your household work done as <u>quickly</u> as needed?	1	2	3	4	5

If any of the responses to D5.2–D5.5 are rated greater than none (coded as “1”), ask:

D5.01	In the past 30 days, on how many days did you reduce or completely miss <u>household work</u> because of your health condition?	Record number of days _____
-------	---	-----------------------------

If respondent works (paid, non-paid, self-employed) or goes to school, complete questions D5.5–D5.10 on the next page. Otherwise, skip to D6.1 on the following page.



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

5(2) Work or school activities

Now I will ask some questions about your work or school activities.

Show flashcards #1 and #2

Because of your health condition, in the past 30 days how much difficulty did you have in:		None	Mild	Moderate	Severe	Extreme or cannot do
D5.5	Your day-to-day <u>work/school</u> ?	1	2	3	4	5
D5.6	Doing your most important work/school tasks <u>well</u> ?	1	2	3	4	5
D5.7	Getting all the work <u>done</u> that you need to do?	1	2	3	4	5
D5.8	Getting your work done as <u>quickly</u> as needed?	1	2	3	4	5
D5.9	Have you had to work at a <u>lower level</u> because of a health condition?				No	1
					Yes	2
D5.10	Did you <u>earn less money</u> as the result of a health condition?				No	1
					Yes	2

If any of D5.5–D5.8 are rated greater than none (coded as “1”), ask:

D5.02	In the past 30 days, on how many days did you <u>miss work for half a day or more</u> because of your health condition?	Record number of days
-------	---	-----------------------



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

Domain 6 Participation

Now, I am going to ask you about your participation in society and the impact of your health problems on you and your family. Some of these questions may involve problems that go beyond the past 30 days, however in answering, please focus on the past 30 days. Again, I remind you to answer these questions while thinking about health problems, physical, mental or emotional, alcohol or drug related.

Show flashcards #1 and #2

In the past 30 days:		None	Mild	Moderate	Severe	Extreme or cannot do
D6.1	How much of a problem did you have <u>joining in community activities</u> (for example, festivities, religious or other activities) in the same way as anyone else can?	1	2	3	4	5
D6.2	How much of a problem did you have because of <u>barriers or hindrances</u> in the world around you?	1	2	3	4	5
D6.3	How much of a problem did you have <u>living with dignity</u> because of the attitudes and actions of others?	1	2	3	4	5
D6.4	How much <u>time</u> did you spend on your health condition or its consequences?	1	2	3	4	5
D6.5	How much have you been <u>emotionally affected</u> by your health condition?	1	2	3	4	5
D6.6	How much has your health been a <u>drain</u> on the financial resources of you or your family?	1	2	3	4	5
D6.7	How much of a problem did your <u>family</u> have because of your health problems?	1	2	3	4	5
D6.8	How much of a problem did you have in doing things <u>by yourself</u> for <u>relaxation or pleasure</u> ?	1	2	3	4	5



WHODAS 2.0

WORLD HEALTH ORGANIZATION
DISABILITY ASSESSMENT SCHEDULE 2.0

36

Interview

H1	Overall, in the past 30 days, <u>how many days</u> were these difficulties present?	<i>Record number of days</i> ____
H2	In the past 30 days, for how many days were you <u>totally unable</u> to carry out your usual activities or work because of any health condition?	<i>Record number of days</i> ____
H3	In the past 30 days, not counting the days that you were totally unable, for how many days did you <u>cut back</u> or <u>reduce</u> your usual activities or work because of any health condition?	<i>Record number of days</i> ____

This concludes the interview. Thank you for participating.

Flashcard 1

Health conditions:

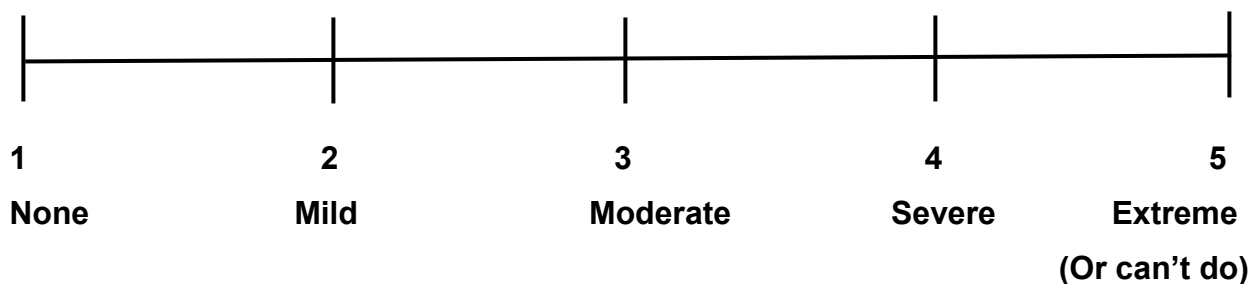
- Diseases, illnesses or other health problems
- Injuries
- Mental or emotional problems
- Problems with alcohol
- Problems with drugs

Having difficulty with an activity means:

- Increased effort
- Discomfort or pain
- Slowness
- Changes in the way you do the activity

(Think about the past 30 days only)

Flashcard 2



Appendix 2: Interview question schedule

My name is Saul Cobbing and I am a researcher and physiotherapist from the University of KwaZulu-Natal. I have already been through the informed consent form with you agreed to take part in this research. Thank you for agreeing to participate in this study. I am interested in hearing your account of living with HIV and disability and the experience you had receiving physiotherapy treatment at hospital. This interview will take about 30 minutes. If at any time during the interview you require a break, please let me know and we can start again when you are ready. Do you have any questions or concerns you would like me to address before we begin?

This interview will also be audio-recorded. I am going to be turning on the audio-recorder now. I will be writing down some notes during the interview as well. Are you ready for us to start? (If yes) I am now turning on the recorder and will start by noting our date and other details, after which I will start our discussion.

TURN ON AUDIO RECORDER

Question schedule:

1. When were you admitted to hospital?
2. Are you currently taking any medication? *[If the answer to the above is yes: what are they and how long have you been taking these medications?]*
3. Did you have any disability before finding out you were HIV positive? *[For each condition ask what year they first had the condition and what (if anything) caused the condition].*
4. Do you know why you were referred for physiotherapy at this hospital? *[If yes, prompt further as to what the problem was].*
5. Has the physiotherapy treatment helped with the problem you were referred for?
6. Has the physiotherapy treatment helped (or worsened) any impairments that your disability has caused. *[Prompt: for example pain, tingling, weakness, fatigue].*
7. Has the physiotherapy treatment helped (or worsened) any activities in your daily life. *[Prompt: for example walking, dressing, bathing, driving].*

8. Has the physiotherapy treatment helped (or worsened) your participation in your daily life. [*Prompt: for example as a parent, as a bread-winner, in your church*].
9. Did you have any difficulty getting to the physiotherapy department?
10. What did you enjoy most about your period of physiotherapy treatment?
11. What did you enjoy least about your physiotherapy treatment?
12. Is there anything you could suggest that could improve the physiotherapy service at this hospital?
13. Would you like to continue with physiotherapy treatment at this hospital or would you prefer to do your own treatment at home?
14. Is there anything else you would like to tell us about your period of treatment at this hospital?

I want to thank you again for taking time to describe your challenges and sharing your experiences with me. Your responses will help provide a better understanding of the challenges people living with HIV face, and how they are dealing with them. Your testimony will help us to provide relevant information to the physiotherapy department at this hospital and improve the understanding of the effects that rehabilitation has on people living with HIV and disability.

Appendix 3: Interview question schedule for research assistants (isiZulu)

Igama la mi _____ ngufuthi n gingumsizi womcwaningi ov ela eNyuvesi YaKwaZulu Natali. Sengifundile incwadi yesivumelwano futhi ngiyavuma ukuba kulolu cwaningo. Ngiyabonga ukuthi ube yingxenye yalolu cwaningo. Ngithanda ukwazi indlela yakho ng okuphila nesifo s e s andulela ngculaza (HIV) futhi nokukhubazeka k anye nolwazi mayelana n okuhlengwa k wi-physiotherapy es ibhedlela. I mibuzo i zothatha imizuzu ewu- 30. Uma udinga ikhefu ungazise, singaphinde siqale futhi uma usulungile. Ikhona eminye imibuzo onayo ongafuna ukucaciselwa kuyo ngaphambi kokuthi siqale?

Lokhu kubuzwa kuzokuqoshwa ngesiqopha mazwi. Sengizosivula isiqophi mazwi sami manje. Ngizobe ngibhala phansi nami ngibe ngikubuza futhi. Usulungele ukuqala? Uma uvuma ngizokuvula isiqophamazwi ngibe ngibhala usuku neminye imininigwane, lapho ke sizoqala ukuxoxisana.

KHANYISA ISIQOPHA MAZWI

Uhlelo lokubuza:

1. Wangeniswa nini esibhedlela?
2. Kukhona i mithi namaphilisi ow adlayo? *[Uma um buzo w angaphezulu uthi yebo: Buza uhlobo futhi nesikhathi sokuwathatha].*
3. Kukhona uk ukhubazeka ob e nakho ng aphambi kokuthola u kuthi une-HIV? *[Kokubili buza uny aka ab athola ngawo uk ukhubazeka f uthi thola ukuthi kwakudalwe yini na].*
4. Uyazi ukuthi wedluliselwani kubahlengi bakwa-physiotherapy esibhedlela? *[Uma evuma, qhubeka ubuze ukuthi kwakwenziwa yini aze adluliselwe khona]*
5. I-Physiotherapy isizile na mayelana nenkinga owawudluliselwe yona lapha?
6. Isizile i-physiotherapy noma ikwenze kwanda ukulimala okudalwe ukukhubazeka kwakho? *[Ngokushesha nj e: I sibonelo ubuhl ungu, ukunsonsotha n oma ukuphelewa amandla noma ukukhathala]*

7. Ikusizile i-physiotherapy noma ikwenze kwanda ukwenza izinto ngokuziphilisa njalo? [Ngokushesha nje: Isibonelo ukuhamba, ukugqoka, ukugeza nokushayela]
8. Ikusizile i-physiotherapy noma ikwenze kwanda ukuzimbandakanya kwakho njalo empilweni yakho? [Ngokushesha nje: Isibonelo ukuba umzali, ukuba inhloko yekhaya noma enkonzweni]
9. Kukhona ubunzima oba nabo ukuze ufike esibhedlela kwisigaba se-physiotherapy?
10. Iyiphi into oyithokozele kakhulu ngesikhathi sakho uza ukuzokwelashwa lapha?
11. Iyiphi into oyithokozele kakhulu ngokwelashwa nge-physiotherapy?
12. Kukhona ongakusho ukuze kwenziwe izinto ngcono esibhedlela?
13. Ungathanda ukuqhubeka ngokwelashwa nge-physiotherapy esibhedlela?
14. Kukhona okunye ofisa ukusitshela khona mayelana nesikhathi sokwelashwa esibhedlela?

Ngithanda ukukubonga futhi ngokuthatha isikhathi sakho uzongichazela kabanzi ngesipiliyoni nezinselelo zakho. Izimpendulo zakho zizokusiza ukuqonda okungcono okuphathelele nezinselelo abantu abanesandulela ngculazi (i-HIV) abahlangabezana nazo, futhi bangaqondana nazo kanjani. Ukufakaza kwakho kuzosiza nathi ukuthi sibe neminingwane kwisigaba se-physiotherapy esibhedlela futhi kwenze ngcono ukuqonda inzuzo eba khona ekwelashweni ngokwe-physiotherapy kubantu abanesandulela ngculazi (i-HIV) nokukhubazeka.

Appendix 4: Study information sheet for participants

Dear Sir/Madam

Thank you for taking time to participate in this study. Your assistance is greatly appreciated. Please read this form thoroughly before consenting to participate in the study and feel free to ask me any questions that you may have.

PURPOSE OF STUDY

I am currently undertaking a master's degree, through the University of KwaZulu-Natal (UKZN). This study aims to understand the experiences of people living with the human immunodeficiency virus (PLHIV) and the disabling effects that this disease places upon them. It further aims to examine the effects that rehabilitation services provided by UKZN physiotherapy students has on the impairments, activities and participation of PLHIV and disability.

WHAT DOES THE STUDY INVOLVE?

You will be asked a number of specific questions by the researcher or research assistants in order to ascertain your current level of disability. You will then undergo a period of rehabilitation in an effort to improve your level of physical ability. Following this period you will be asked some questions related to your experiences during your period of rehabilitation. This interview will be recorded using an audio recorder.

DOES MY PARTICIPATION IN THE STUDY INVOLVE ANY PHYSICAL RISK?

No, it does not. If you agree to participate in the study, you will be asked a number of questions before and after the period of rehabilitation you receive at this hospital. The study will involve no physical testing.

WHO WILL RECEIVE THE RESULTS?

Your name and any other personal information will be kept confidential. Information from the study that may be presented or published will not identify you personally.

CAN I WITHDRAW FROM THE STUDY?

While your participation will be greatly appreciated, the study is entirely voluntary and you will be free to withdraw from it at any time. This will not influence your continued treatment by the Physiotherapy Department at this hospital.

Researcher: Saul Cobbing

Telephone (work): 031 2607817

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Research Supervisor: Jill Hanass-Hancock

Telephone (work): 031 2603125

e-mail: Hanasshj@ukzn.ac.za

Humanities and Social Sciences Research Ethics Committee

Telephone: 031 2603857/8350

e-mail: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za

Appendix 5: Study information Sheet for participants (isiZulu)

Sawubona Mnumzane/ Nkosazane

Ngiyabonga ukuthi uvume ukuba yingxenye yalolu cwaningo. Usizo lwakho lwamukelekile kakhulu. Ngicela ufunde leli fomu kahle ngaphambi kokuvuma ukusiza kulolu cwaningo futhi ukhululeke ukubuza uma kukhona ofisa ukukwazi.

INHLOSO YOCWANINGO

Ngisenza izifundo zami zobuchwepheshe (master's degree) esikhungweni esibizwa ngokuthi i-Nyuvesi of KwaZulu Natali (UKZN). Lesi sifundo inhloso yaso ukwazi izinkinga abantu abanesandulela ngculazi (PLHIV) abahlangabezana nazo futhi nokuthi ibakhubaza kanjani. Ngaphezu kwalokho, sibheka izinzuzo ngezindlela zokwelapha ezisetshenziswa abafundi abase-UKZN abenza i-physiotherapy lapho kuvela inzuzo ekukhubazekeni, ekusebenzeni nasekuhlanganyeleni uma une-HIV nokulimazeka.

SIPHATHELENE NANI LESI SIFUNDO?

Uzokubuzwa imibuzo emayelana nocwaningo, kuzobe kubuza umcwaningi noma abasizi bakhe ukuthola izinga lakho lokukhubazeka. Uzokuhlengwa amaviki amahlanu ukuze ube ngcono ekukhubazekeni kwakho ngokozenzela khona ngomzimba. Okulandela lawa maviki uzokubuzwa imibuzo ephathelene nemibono ekusizakaleni kwakho ngenkathi uhlangwa. Imibuzo izoqoshwa ngesiqopha mazwi “i-rekhoda”.

UKUBA KULOLU CWANINGO KUPHATHELENE NOBUNGOZI EMZIMBENI NA?

Cha, abukho ubungozi. Uma uvuma ukuba kulolu cwaningo, uzokubuzwa imibuzo ngaphambi kokuhlengwa nangemuva kokuhlengwa futhi ozobe ukuthola esibhedlela. Ucwanningo aluphathelene nokukuhlola ngokukuthinta emzimbeni.

UBANI OZOTHOLA IMIPHUMELA?

Igama nokunye okuphathelene nawe kuzonakekelwa ngokwethembeka. Imininingwane evela kulolu cwaningo ezokuqoshwa noma ibhalwe ngokuphelele ngeke iveze imininigwane yakho.

NGINGAPHUMA KULOLU CWANINGO?

Njengoba ukuzimbandakanya kwakho kuzokwamukelwa kakhulu, ucwaningo lungokuzinikela ngokuphelele futhi ungaphuma noma yisiphi isikhathi. Lokhu ngeke kuvimbele ukuhlengwa kwakho esibhedlela Physiotherapy Department.

Umcwaningi: Saul Cobbing

Ucingo (Emsebenzini): 031 2607817

E-mail: cobbing@ukzn.ac.za

Umhloli womcwaningi: Jill Hanass-Hancock

Ucingo (Emsebenzini): 031 2603125

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Humanities and Social Sciences Research Ethics Committee

Ucingo: 031 2603857/8350

e-mail: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za

Appendix 6: Study consent form in both English and isiZulu

I..... (full names of participant) hereby confirm that I understand the nature of the research project, and I consent to participating in this study.

I consent to my interview being audio recorded.

☐

I understand that I can withdraw from the project at any time, should I so desire.

Signature Participant

Date

.....

Ifomu Lemvume

Mina.....(amagama aphelele ophendulayo)
ngiyaqinisekisa ukuthi ngiqonda kahle okudingwa yilolucwaningo. Ngelokho-ke
ngiyavuma ukuzibandakanya kulolucwaningo.

☐

Ngiyavuma ukuba lemibuzo engibuzwa yona iqoshwe.

Ngiyaqonda futhi ukuthi ngingayikhipha lemvume kulolucwaningo nganoma isiphi
isikhathi uma ngithanda.

Kusayina Obuzwayo

Usuku

.....

Appendix 7: Study consent form for research assistants

I..... (full names of research assistant) hereby confirm that I understand the nature of the research project, and I consent to assisting in this study.

I understand that I can withdraw from the project at any time, should I so desire, and that this will in no way influence the assessment of my clinical block.

Signature Participant

Date

.....

Appendix 8: Letter of support from the study facility (note subproject 1)

30th May 2012

To Whom It May Concern

**Confirmation of Support From [REDACTED] for HEARD/UKZN Project
"Developing a Model of Care to Address the Disabling Effects of HIV in the Context of
Resource-Poor Settings taking KwaZulu-Natal as an Example"(a project of the READ
initiative)**

The abovementioned Umbrella Project that will take place at [REDACTED] Mariannhill, together with its associated Clinics and its Outreach Project, has been reviewed by the EXCO Team at the Hospital from an operational perspective and is fully supported by the Hospital.

[REDACTED] has engaged with HEARD on two previous or current projects one of them focusing on the disabling effects of HIV (Nathi Singabantu) and the other one on HIV-related depression (depression intervention pilot study). Based on these two studies the proposed project is in the interest of [REDACTED] and has our full support. We are aware that this project uses a community engagement methodology "Learning in Action Approach" (ILA) and that we will be engaging with HEARD and UKZN staff on several subprojects. At this point we would also like to express particularly our support for the proposed sub-projects:

- Subproject 1: Exploratory Study of Physiotherapy Rehabilitation in the context of disability and HIV in a semi-rural hospital in KZN
- Subproject 2: Retrospective study of disabling effects of HIV
- Subproject 3: Knowledge translation project
- Subproject 4: Capacity building project (CBW) Closing the Gap Training health Care workers on the interrelationship of disability and HIV
- Subproject 5: Development of a model of care in the physiotherapy approach to People living with HIV (PLHIV) in a semi-rural setting in KwaZulu-Natal, South Africa (Intervention Study - IS):

This approval for the Umbrella Project and the Sub-Projects listed above, is subject to approval by both UKZN Ethics Board and the "in-hospital" Ethics Committee of [REDACTED]. We are looking forward to our further cooperation with HEARD and UKZN.

Yours truly,



Dr. DP Ross MBBCh MBA (BSN)
Chief Executive Officer

[REDACTED] Hospital Trust

MP No. 0338397

PR No. 0140000097985

Please note: Hospital name blacked out for reasons of confidentiality

Appendix 9: UKZN ethical approval letter



5 September 2012

Mr Saul Cobbing 211558534
School of Health Sciences

Dear Mr Cobbing

Protocol reference number: HSS/0325/012M

Project title: Exploration study of physiotherapy rehabilitation in KwaZulu Natal in the context of HIV and disability.

Full approval notification

This letter serves to notify you that your application in connection with the above has now been granted full approval following your response to queries raised by the Humanities and Social Sciences Research Ethics Committee.

Any alteration/s to the approved research protocol i.e. Questionnaire/interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach/Methods must be reviewed and approved through an amendment /modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years

Best wishes for the successful completion of your research protocol

Yours faithfully

Professor Steven Collings (Chair)
Humanities & Social Sciences Research Ethics Committee

cc Co-PI Dr Jill Hanass-Hancock
cc Mrs Margaret Rhode
cc Academic leader Professor M Mars
cc School Admin. Ms Phirdile Kene