

**THE INTERNATIONAL CLASSIFICATION OF
FUNCTIONING, DISABILITY AND HEALTH IN ADULTS
VISITING THE HIV OUTPATIENT CLINIC AT HELEN
JOSEPH MEMORIAL HOSPITAL**

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**A research report submitted to the Faculty of Health Sciences,
University of the Witwatersrand, Johannesburg, in partial
fulfilment of the requirements for the degree of Master of
Science in Physiotherapy**

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DECLARATION

I, Melissa Van As, declare that this research report is my own work. It is being submitted for the degree of Master of Science in Physiotherapy in the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other University.

Signature:



..... 14th day of November..., 2007

ABSTRACT

An estimated 18.8% of South Africans between 15-49 years of age were living with Human Immunodeficiency Virus (HIV) at the end of 2005 (UNAIDS, 2006). The introduction of anti-retroviral therapy has led to increased longevity, increased Cluster of Differentiation four counts and often-improved clinical well-being of people living with HIV and Acquired Immune Deficiency Syndrome (AIDS) (O'Brien, Nixon, Tynan and Glazier, 2004). Research on the physical impairments, activity limitations and participation restrictions of persons living with HIV/AIDS is limited and these aspects have profound effects on the health-related quality of life and functional abilities of those with the disease (Rusch, Nixon, Schilder, Braistain, Chan and Hogg, 2004).

This study aimed to develop a profile of the level of functioning, disability and health of an urban cohort of 45 South African HIV positive individuals attending an outpatient clinic at the Helen Joseph Memorial Hospital, Gauteng, South Africa. The International Classification of Functioning, Disability and Health Checklist as well as goniometry, dynamometry and Manual Muscle Testing were used to identify physical impairments, activity limitations, participation restrictions and influencing environmental factors.

The International Classification of Functioning, Disability and Health is a standardized tool used to classify functioning and disability in the face of the consequences of disease. The International Classification of Functioning, Disability and Health is structured to describe body functions and structure, functional activities and associated personal and environmental factors (World Health Organisation, 2003). Further research of the physical

impairments, activity limitations and participation restrictions experienced by persons living with HIV/AIDS will assist in the formulation of improved rehabilitation protocols, health care interventions as well as vocational and legislative policies (Worthington, Myers, O'Brien, Nixon and Cockerill, 2005; O'Dell, Hubert, Lubbeck and O'Driscoll, 1998; All, Fried, Roberto K, Shaw and Richter, 1997).

The results showed that there is a high prevalence of mild to moderate physical impairments, activity limitations and participation restrictions among the cohort and that environmental factors influence level of ability. The results supported the findings of international studies that physical impairments are linked with activity limitations and participation restrictions.

This study identifies the importance of assessing and addressing the functioning and disabilities of people living with HIV/AIDS, in addition to clinical markers, as it affects the physical, psychological and social functioning of this population and subsequently their total health-related quality of life.

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LIST OF ABBREVIATIONS

AIDS	-	Acquired Immune Deficiency Syndrome
ARV/s	-	Anti-Retroviral drugs
CD4	-	Cluster of Differentiation Four
CDC	-	Centre for Disease Control and Prevention
DNA	-	Deoxyribonucleic Acid
ICIDH	-	International Classification of Impairments, Disabilities and Handicaps
HAART	-	Highly Active Anti-retroviral Therapy
HIV	-	Human Immune Deficiency Virus
HSRC	-	Human Sciences Research Council
ICF	-	The International Classification of Functioning, Disability and Health
NNRTI	-	Non-Nucleoside Reverse Transcriptase Inhibitor
NRTIs	-	Nucleoside Analogue Reverse Transcriptase Inhibitors
PLWHA	-	People Living with HIV/AIDS
RNA	-	Ribonucleic Acid
SANHS	-	South African National HIV Survey
TB	-	Mycobacterium tuberculosis
WHO	-	World Health Organisation

LIST OF DEFINITION OF TERMS

Term	Definition
ARV-naïve (adj)	Used to describe persons who have not had any experience with the use of anti-retroviral treatments (Vajpayee et al., 2005; Idigbe et al., 2005; Call et al., 2000).
ARV-experienced (adj)	Used to describe persons who are taking/ have taken anti-retroviral treatment (Call et al., 2000; Low-Beer et al., 2000).
Disability (noun)	Disability is describes as the outcome of impaired interaction between individuals and the environment (Davis, 2006) or “any restriction or lack of ability to perform an activity within the range considered normal for a human being” (Nixon and Cott, 2000).
Functioning (noun)	A term encompassing the positive aspects of the ICF including body functions, structures, activities and participation (Davis, 2006).
Rehabilitation (noun)	A dynamic, multidimensional process which includes all prevention, treatment interventions and services which address physical impairments, activity limitations and participation restrictions for any individual (Worthington et al., 2005). The WHO (2002) define rehabilitation as “a process aimed at enabling persons with disabilities to reach and maintain optimal functional levels” or, in the light of the ICF, as a coordinated process that enhances “activity” and “participation” (Disler et al., 2002).
Quality of life (noun)	A dynamic, multidimensional concept which may be influenced by one’s environment and personal goals and expectations. Pertinent dimensions include physical and mental functioning, social interaction, family and friends (Davis, 2006).

Health-related quality of life (noun)	The ability to perform activities of daily living, such as walking and working, and well-being or lack thereof due to health. It covers broad dimensions of physical and mental health (Cunningham et al., 2005) Health-related quality of life describes health state with respect to aspects such as physical, emotional, cognitive and social functioning as well as mobility, selfcare, pain/discomfort and patient perception of health and well-being (Hughes et al., 2004; Webb & Norton., 2004).
Disciplinary (adj)	Of or for a discipline, which is described as training that produces a particular skill or a branch of learning or instruction (Davis, 2006).
Multidisciplinary (adj)	Efforts towards patient goals arise from a number of different disciplines (Davis, 2006).
Transdisciplinary (adj)	Across disciplines; blurring of goals- one person ensures that individual patients' needs are met (Davis, 2006).
Interdisciplinary (adj)	Between or among disciplines; joint/shared responsibility and group action in working towards agreed individual-centred goals (Davis, 2006).

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Chapter 1

Introduction

There are 38.6 million people living with Human Immune Deficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) in the world and 24.5 million of those are living in Sub-Saharan Africa (UNAIDS, 2006). Statistics from The South African National HIV Survey (SANHS), 2005, highlight the severity of the problem, especially in urban informal areas of residence with prevalence at 17.6%. The alarming numbers introduce challenges that stress the economy and productivity of the country (South African Business Coalition on HIV & AIDS, 2003) and thus attention with regards to HIV assessment, education, prevention and care is needed to combat such challenges (UNAIDS, 2004).

HIV/AIDS is considered in some societies to be a chronic disease as anti-retroviral drugs (ARVs) oppose the deleterious effects that HIV poses on the immune system, subsequently people living with HIV/AIDS (PLWHA) have higher Cluster of Differentiation four (CD4) counts and therefore live longer lives (O'Brien et al., 2004; Zonta, de Almeida, de Carvalho and Werneck., 2003). HIV has distinct multifaceted physiological, emotional and societal features at any stage of the disease and therefore there is always a threat of losing functional capacity and developing complications that affect functioning and health-related quality of life (Worthington et al., 2005; O'Dell et al., 1998). In addition, ARVs present new side-effects and limitations to function which must be considered amongst PLWHA (Rusch et al., 2004). Health care professionals need to look beyond common health indicators such as clinical symptoms, CD4 counts, morbidity and mortality and attempt to obtain a holistic picture of patients' functional profile (Üstün, Chatterji, Bickenbach, Konstantjsek and Schneider, 2004).

Health-related quality of life includes the ability to perform activities of daily living as well as aspects of physical and mental wellbeing. A multitude of factors at individual and societal level have been shown to impact upon health-related quality of life e.g. pain, physical impairments, psychological status, access to health care, ARVs and social support systems, socioeconomic status, coping strategies, and spiritual wellbeing (Cunningham, Crystal, Bozette and Hays, 2005; Vidrine, Arnick, Gritz and Arduino,

2003). Assessment of environmental and personal factors is important because a large proportion of PLWHA have mental, psychomotor and neuromusculoskeletal dysfunctions as well as activity limitations and participation restrictions. Environmental factors affecting function include employment, accommodation, transport, communication services, societal perceptions and attitudes, public services and legislation/policies. These factors may have a profound effect on HIV/AIDS related issues for PLWHA (Hwang and Nochajski, 2003). If the multifaceted needs of PLWHA are assessed and strategically addressed in an interdisciplinary manner, the issues of physical- and work-functioning have the potential to improve. Many tools have been used to assess the functional status and health-related quality of life of PLWHA and a great deal of which are based upon a framework similar to that of the International Classification of Functioning, Disability and Health (ICF) (Rusch et al., 2004; Vidrine et al., 2003).

The International Classification of Functioning, Disability and Health adopts a biopsychosocial approach for measuring physical and mental impairments, activity limitations, and participation restrictions as well as associated environmental and personal factors across types of disease as well as national and cultural boundaries (Hwang and Nochajski, 2003). The aim of the tool is to provide a unified, standard language and framework for the description of health and health-related states. The ICF checklist has been endorsed by the World Health Assembly for international use. It has also been translated into Zulu, Xhosa (Jelsma, Brauer, Hahn, Snoek and Sykes, 2006) and Sesotho (Myezwa, 2005) and is thus useful within the South African context.

Current management of HIV/AIDS focuses largely on the prevention of HIV-related infections and the administration of ARVs (Zonta et al., 2003). Patients' functional abilities and needs may not have been given much attention until recently. There has been insufficient research on the holistic, interdisciplinary long-term management for PLWHA. Research on the challenges faced by PLWHA, using the ICF checklist, may assist in the development of a conceptual rehabilitation framework which should include the definition and scope of rehabilitation, aspects of life to be included and professionals and providers to be involved (Worthington et al., 2005).

Worthington et al. (2005) describes rehabilitation as a dynamic, multidimensional process which includes all prevention, treatment interventions and services which address physical impairments, activity limitations and participation restrictions for any individual. Rehabilitation strategies should aim to improve, stabilise and optimise a person's functional, social, psychological and vocational wellbeing, health-related quality of life and prevent further limitations (Worthington et al., 2005; O'Dell et al., 1998). Rehabilitation must have services which emphasise promotion, prevention, curative, restorative and supportive aspects of Health care (Zonta, de Almeida, de Carvalho, Werneck, 2005). Health professionals are in a position to have a significant impact on maximising function through rehabilitation interventions for PLWHA. The use of appropriate assessment tools would be beneficial in assisting the rehabilitation process (Worthington et al., 2005). It is the responsibility of health care professionals to ensure that multidisciplinary services are available, acknowledged and utilized by PLWHA.

The ICF is expected to become the accepted framework in the assessment and description of functioning in rehabilitation (Stucki, Cieza, Ewert, Kostanjsek, Chatterji and Üstün, 2002). The versatility of the tool across national and cultural boundaries makes it suitable for use in the South African context. There is a need to ensure that the framework formulated operates from the perspective of PLWHA and considers all factors that may cause physical impairments, activity limitations and/or participation restrictions. One needs to develop a profile of the difficulties experienced by PLWHA in order to assist the designing of rehabilitation protocols and rehabilitation worker programmes.

There is a misconception that rehabilitation providers have little to offer for PLWHA, but rehabilitation is a field that is well equipped to address the multisystemic HIV/AIDS-related co-morbidities and to have a positive impact on the lives of PLWHA (Worthington et al., 2005). Developing a profile of the level of function and disability of a cohort of PLWHA in South Africa (using the ICF) may be helpful to influence health care professionals, especially those in the field of rehabilitation, to take it upon themselves to ensure that they acquire adequate and appropriate knowledge, intervention skills and open-minds to treat people living with such an unpredictable and challenging disease (Glenn, Garcia, Li and Moore, 1998; All et al., 1997).

Problem Statement

The level of functioning, disability and health of South African HIV positive outpatients is unknown.

Aim of the Study

This study aims to develop a profile of the level of functioning, disability and health of an urban cohort of South African HIV positive outpatients. The objectives of the study include:

Objective 1.

To determine the level of functioning, disability and health of a sample of adult HIV positive outpatients at the HIV clinic at Helen Joseph Hospital by ascertaining:

- a) Activity limitations
- b) Physical impairments
- c) Participation problems
- d) Environmental factors

Objective 2.

To determine the relationships between the level of functioning, disability and health and key variables that become evident from the data analysis.

Significance of the Study

The study contributes to the body of literature on the level of functioning and disability of PLWHA in South Africa. This is important as HIV/AIDS affects the physical, psychological and social functioning of this population and subsequently their total health-related quality of life.

The results of this study are of use as they identify main areas of impairments, activity limitations and participation restrictions and their associations in a South African HIV positive outpatient cohort. Such information emphasises the need for awareness and holistic assessment of problems and impending disabilities in order to inform the appropriate management which embraces prevention, primary care and rehabilitation of PLWHA. This study may also assist future research exploring appropriate and beneficial rehabilitation interventions to improve the lives of HIV-positive people in South Africa.

Chapter 2

Literature Review

This literature review examines current information regarding HIV, as a condition and as an epidemic. It describes the ICF and its suitability for use with HIV/AIDS and looks at research on functioning and disability and health-related quality of life. The review includes information regarding ARVs and their affect on aspects of function as well as recent developments in rehabilitation for PLWHA.

An electronic search was done using Pubmed, MDCConsult, Cochrane Database, Google Scholar, electronic bulletin boards and journals and World Wide Web sites. References were also gathered through a hand-search using journals in the University of the Witwatersrand Health Sciences Library. Journals searched included AIDS, AIDS Care, Journal of Rehabilitation, Quality of Life Research, Medical Care, Physiotherapy, South African Journal of Physiotherapy, Disability and Rehabilitation, Archives of Physical Medicine and Rehabilitation.

The search was limited to articles in English and those published after 1990. Four well-known articles that were published before 1990 were used. Keywords used included: International Classification of Functioning, Disability and Health, HIV, AIDS, physiotherapy, rehabilitation, health-related quality of life, HIV/AIDS statistics, antiretroviral therapy, activity limitations, physical impairments, Participation problems.

2.1. HIV within the Context of South Africa

It is important to acknowledge the prevalence of HIV/AIDS in South Africa as well as the rationale for the high prevalence and current government policies in place as all these factors contribute to the level of impairment and their interaction with the environment among individuals infected with HIV and their management (Human Sciences Research Council (HSRC), 2005).

There are 38.6 million HIV-infected people in the World and approximately 63% of those infected are Southern Africans (UNAIDS, 2006). There are varying reports on HIV statistics within South Africa; The South African National HIV Survey, 2005, reported the HIV prevalence amongst those between the ages of 15 and 49 to be 16.2% whilst UNAIDS (2006) reports the prevalence amongst this age group to be 18.8% (UNAIDS, 2006). The SANHS (2005) showed that 6.3% of females and 2.4% of males between the ages of 15 and 49 were HIV positive and that 13.3% of the females over the age of two years and 8.2% of the males were HIV positive in 2005 (HSRC, 2005)

The South African Department of Health Study (2006) estimated that in 2006, 29.1% of pregnant South African women were HIV positive. The highest HIV infection rates by province occur in Kwa-Zulu Natal (39.1%) Mpumalanga (32.1%), Free State (31.1%) followed by Gauteng (30.8%) (South African Department of Health Study, 2006). According to area of residence, the highest prevalence if HIV occurs in urban, informal locations (17,6%) (HSRC, 2005).

Projections from the Actuarial Society of South Africa (2005) report national HIV/AIDS prevalence at 11.3% in 2005 and estimate that there will be a gradual increase of approximately half a million new infections per year resulting in a prevalence of 11.8% by 2010.

Although the studies and projections portray different results, the outcomes show that the prevalence of infection is very high and far greater amongst females than males. There are multifaceted factors that have been explored in an attempt to explain the high HIV prevalence in South Africa:

Lau and Muula (2004) and the HSRC (2005) highlight the key factors contributing to the high prevalence of HIV in Sub-Saharan Africa which include a complex interplay between historical, political, socioeconomic and cultural reasons. Urbanisation, population relocation, social inequality and poor infrastructure facilitates the mobility of South Africans and thus the spread of HIV (Quinn, 1994). Inadequate services like sanitation and basic

medical care including the provision of ARVs, as well as poor nutritional status has lead to the proliferation of HIV (Department of Health, 2007). Africa has generally been slow to acknowledge the impact of HIV and traditionally HIV treatment and prevention programs have not been prioritised (Lau and Muula, 2004). From a cultural perspective, multiple partnerships and complex sexual networks are common and accepted and in addition, early sexual debut, low condom use and the subordinate position of women has been reported to contribute to a high HIV prevalence (Department of Health, 2007; Lau and Muula, 2004).

Poor knowledge, perceptions and lack of awareness of the contributing factors, ramifications and treatments with regards to HIV has resulted in minimal behavioural change amongst South Africans (HSRC, 2005). The stigma, discrimination and secrecy attached to HIV/AIDS create barriers to effective HIV treatment (Department of Health, 2007). Important risk environments include poverty, high density informal housing settlements and exposure to substances (HSRC,2005).

Poverty has been highlighted as a driver of HIV infections as it affects access to nutrition, education, medical services and hence less priority placed on healthcare and HIV prevention which results in undue exposure to HIV (HSRC, 2005). The poverty-HIV/AIDS relationship is complex as poverty exacerbates HIV infection and HIV/AIDS plays an important role in exacerbating poverty amongst HIV/AIDS-affected populations (Tladi, 2006; Lau and Muula, 2004; Drimie, 2002). Poverty at individual, household and community levels results in a lack of basic resources, education, marketable skills and information regarding HIV infection and risky sexual behaviours (Department of Health, 2007; Tladi, 2006). Conversely poverty alleviation is hampered by HIV/AIDS as the condition causes absenteeism and the inability of PLWHA to work causes loss of income for PLWHA. Medical expenses, loss of schooling and funeral expenses can lead to chronic impoverishment (Tladi, 2006).

In addition to poverty, HIV/AIDS poses profound social, economic, cultural and educational impacts upon those affected by the condition (Ruiz Perez, Rodríguez Baño, Lopez Ruiz , del Arco Jimenez, Causse Prados and Pasquau Liño, 2005; Barnett,

Whiteside and Desmond, 2001). HIV/AIDS affects the most productive people and potentially productive youth of a community (Louwenson and Whiteside, 2001). A decrease in productivity results in all sectors due to illness and absenteeism of skilled workers due to personal illness and funeral attendance (Coombe, 2000). High staff turnover due to the death of skilled labourers and training of new staff adds to the costs for industries (Drimie, 2002). The main sectors experiencing the economic impacts of HIV and AIDS in Southern Africa are the mining, agricultural and transportation sectors due to a large number of mobile workers (Drimie, 2002). It is estimated that the South African economy will be 22% less in 2010 than it potentially could be without the influence of HIV/AIDS (Drimie, 2002). Reduced productivity and poor economic growth increases poverty making individuals and communities more vulnerable to the HIV/AIDS epidemic (Louwenson and Whiteside, 2001)

HIV has serious educational impacts as it affects educators and scholars. Educator comprise the largest occupational group in South Africa and up to 12% are reported to be HIV positive (Coombe, 2000). Loss of qualified educators due to illness, death or mobility will reduce the effectiveness of schooling and the development of new skilled individuals (Carr-Hill, Katabaro, Katahoire and Oulai, 2002). The effects of HIV may result in fewer enrolments at education institutions due to childhood HIV/AIDS-related illnesses and deaths. Children may also be removed from schools to run households, care for family members or to substitute reduced household incomes (Drimie, 2002). The financial strain caused by HIV may result in the majority of household income going to healthcare costs rather than to education (Coombe, 2000).

The social and cultural impacts of HIV/AIDS are influenced by poverty and must not be disregarded (Drimie, 2002). HIV contributes to a large proportion of the orphanhood among 2-18 year old South Africans (14.4%) (SANHS, 2005). In addition, child-headed households are run by 2.6% of 12-18 year olds (SANHS, 2005). The high number of orphans and childrun households results in a breakdown of family networks which impacts upon human and social development (Drimie, 2002). HIV particularly impacts upon women as their cultural responsibilities as caregivers are strained in the face of HIV/AIDS. The heightened workload in addition to poverty may even force women to engage in

sexual transactions as a source of income (Drimie, 2002; Carr-Hill et al., 2002). The HIV epidemic touches the lives of most South Africans, especially the socially and financially disadvantaged, and exacerbates social, economic and cultural inequalities amongst HIV/AIDS –affected households (Drimie, 2002). Significant efforts by multisectoral national entities are needed to help lighten the burden of HIV/AIDS in South Africa (Natrass, 2006).

In response to the effects and impacts of HIV/AIDS, several governmental and non-governmental organisations aim to increase outreach programs, health care worker training and prevention campaigns to the ease impact of HIV/AIDS (Department of Health, 2007). Government efforts currently in place include voluntary counselling and testing, emphasis on community involvement, health education, prevention of mother-to-child transmission, adopting safe-sex practices and provision of ARVs (Department of Health, 2007; HSRC, 2005). The HIV and AIDS and Sexually Transmitted Infections Strategic Plan for South Africa 2007-2011 (Department of Health, 2007) has highlighted four priority areas for addressing HIV/AIDS in South Africa. These are presented in table 2.1. Rehabilitation workers such as physiotherapists should take cognisance of priority areas and intervention aims and assist in assessing and resolving the problems pertinent to their local clientele (Disler, Cameron and Wilson, 2002; Nixon and Cott, 2000).

Table 2.1. The Four Priority Areas- The HIV and AIDS and Sexually Transmitted Infections Strategic Plan for South Africa 2007-2011

Key Priority Area	Intervention Aims
Prevention	○ Reduce vulnerability to infection and the impact of HIV/AIDS ○ Reduce transmission of HIV
Treatment, care and support	○ Increase voluntary counselling and testing ○ Enable PLWHA to live healthy and productive lives ○ Address special needs of women and children
Human and legal rights	○ Improve human rights with education, society mobilisation and empowerment of HIV positive people ○ Identify and remove legal, policy and cultural barriers to effective HIV prevention, treatment and support ○ Focus on human rights of those with disabilities and women
Monitoring, research and surveillance	○ Monitor, evaluate and develop HIV/AIDS frameworks and prevention technologies

Highly Active Anti-retroviral Therapy (HAART) provision in South Africa began in mid-2004 with the official rollout beginning in March of 2005 (Nattrass, 2006). At the end of 2005, 193 579 people were receiving HAART which is less than 30% of the planned total.

Despite the fact that South Africa accounts for one quarter of all people in sub-Saharan Africa receiving HAART, the coverage has been described as poor compared to other countries and government-set targets (Nattrass, 2006; UNAIDS, 2006). Data from the Actuarial Society of South Africa (2005) shows that 124 000 people were receiving ARVs by mid 2005 and this is projected to rise to 791 000 by 2010 (Nattrass, 2006).

The poor provision figures have largely been attributed to poor allocation and usage of the health budget and the lack of human resources, especially nurses, who battle to cope with AIDS-sick cases as well as HAART rollout functions (Nattrass, 2006). The Department of Health will need to address the straining human resource situation to scale up the rollout programme in order to supply those in need with HAART and meet target figures (Department of Health, 2007; Nattrass, 2006).

There are many factors contributing to the prevalence of HIV in South Africa and research has exposed the huge social, economic, educational and governmental burdens that accompany the virus (Coombe, 2000). Accompanying these burdens, comes a raised level of disability physically, mentally and functionally in areas with high HIV infection rates (UNAIDS, 2004). These physical, mental and functional problems have been studied in HIV positive individuals with and without the use antiretrovirals (Cunningham et al., 2005; Rusch et al., 2004; Low-Beer, Wood, Yip, Montaner, O'Shaughnessy and Hogg, 2000; O'Dell, Crawford, Bohi and Bonner, 1991). These problems will be discussed in the section on HAART and Functioning, Disability and Health-related Quality of Life.

In order to appreciate how these disabilities develop, an understanding of the pathophysiology of HIV and its effect on the body is necessary. This is in addition to understanding that a person may be HIV positive, not manifest disabilities but experience functional difficulties due to the arrangement of the environment. This is in line with the biopsychosocial model.

2.2. Replication of HIV and the Impact on the Immune system

HIV is a ribonucleic acid (RNA) retrovirus composed of a cylindrical core which encloses two molecules of the viral RNA genome (Sierra, Kupfer and Kaiser, 2005). The core is surrounded by a lipid envelope as the virion buds from an infected cell (Fauci, 1988). The components required for HIV replication are incorporated in the viral unit. These components include the virus encoded enzymes protease, reverse transcriptase, integrase, accessory proteins such as Vpu, Vif, Vpr and Nef, and cellular factors (Sierra et al., 2005; Fauci, 1988). The life cycle of HIV begins as the retrovirus binds to the cellular receptor, CD4, of the host cell and the viral lipid envelope fuses with the cellular membrane of the host and the viral core is released in to the cytoplasm of the host cell (Sierra et al., 2005). Viral RNA is transcribed to viral Deoxyribonucleic Acid (DNA) by reverse transcriptase within the cytoplasm and the complete provirus is incorporated into the DNA of the host by the integrase within the nucleus (Freed, 2001). Transcription of viral DNA by cellular RNA polymerase produces new viral particles. Full-length RNA molecules, which are exported from the nucleus of the infected cell by accessory proteins, provide new viral genomic RNAs and templates for the production of more core proteins and viral enzymes (Sierra et al., 2005; Fauci, 1988). Spliced mRNA units produce new envelope and accessory proteins so further replication of virions can occur. After replication, the new virions assemble at the plasma membrane and are released from the host cell (budding) after which retrovirus maturation occurs (Sierra et al., 2005; Barré-Sinoussi, 1996).

HIV infection causes profound immune system decline due to selective incapacitation of the helper T-lymphocytes (also known as T-cells). The speculated cytopathic mechanisms by which T-cells are destroyed include active replication and accumulation of the viral DNA within host cells, terminal differentiation of the infected cell and increased permeability of the host cell by the accessory proteins (Sierra et al., 2005; Fauci, 1988).

T-lymphocytes are the primary cells involved directly and indirectly in conducting the immune functions of the body. Debilitation of this subset of cells, which have the CD4 receptor for the virus, results in a global immune deficiency (Sierra et al., 2005; Fauci,

1988). The HI Virus also infects monocytes, which are responsible for antigen exposure to T-cells, thus the ability to destroy parasites is reduced (Smith, 1993). HIV also infects particular cells of the central nervous system which result in neurological complications and cognitive dysfunction (Smith, 1993). HIV infection thus causes immunosuppression, neoplasms and neuropsychiatric abnormalities, the onset of opportunistic infections and ultimately the diagnosis of AIDS depending on the quantity of CD4 + cells in the blood (Mars, 2004.). HIV infects many systems of the body and manifests at cellular, organ and system levels ultimately resulting in ill-health and poor functioning. A discussion on the disease staging and pathophysiology of HIV related to various body systems will follow (Mars, 2004; Evans and Scadden, 2000).

2.3. Disease Staging

Disease staging is important in order to classify patients according to clinical markers, presentation and physical performance. Staging allows surveillance of an HIV-infected population or individuals, especially after the initiation of ARVs (Vajpayee, Kaushik, Sreenivas, Wig and Seth, 2005). The World Health Organisation (WHO) Clinical Disease Staging System for HIV Infection and Diseases in Adults and Adolescents (WHO, 2005) describes four stages of HIV/AIDS, according to clinical presentation (WHO, 2005; Morgan, Mahe, Mayanja, Whitworth and Kilmarx, 2002). This staging system is presented in table 2.2.

Table 2.2. The WHO Clinical Disease Staging System

WHO Clinical Stage	Clinical signs
Primary HIV Infection	○ Asymptomatic ○ Acute retroviral syndrome
Clinical Stage 1	○ Asymptomatic ○ Persistent generalised lymphadenopathy
Clinical Stage 2	○ Moderate, unexplained weight loss ○ Recurrent respiratory tract infections ○ Herpes zoster ○ Recurrent oral ulcerations ○ Papular pruritic eruptions ○ Seborrhoeic dermatitis ○ Fungal finger nail infections
Clinical Stage 3	○ Unexplained chronic diarrhoea for longer than one month ○ Unexplained persistent fever

	- Severe weight loss - Oral candidiasis and/or oral hairy leukoplakia - Pulmonary Tuberculosis - Severe presumed bacterial infections - Acute necrotising ulcerative stomatitis, gingivitis or periodontitis
Clinical Stage 4	- HIV wasting syndrome - Pneumocystis pneumonia - Recurrent severe or radiological bacterial pneumonia - Chronic herpes simplex infection - Oesophageal candidiasis - Extrapulmonary Tuberculosis - Kaposi's sarcoma - Central nervous system toxoplasmosis - HIV encephalopathy - Extrapulmonary cryptococcosis including meningitis - Cytomegalovirus infection - Any disseminated mycosis - Recurrent non-typhoidal salmonella septicæmia - Lymphomas and invasive cervical carcinoma - Visceral leishmaniasis

(Adapted from WHO, 2005 and Morgan et al., 2001)

Mars (2004) describes the Centre for Disease Control and Prevention (CDC) coding which is similar to the WHO classification but combines clinical data and the number of CD4+ T lymphocytes for HIV infection classification. This classification system is shown in Table 2.3. (Valpajee et al., 2005; Mars, 2004; CDC, 1999)

Table 2.3. Centre for Disease Control and Prevention Classification

CDC Stage	Clinical Signs	Number of CD4+ T Lymphocytes (cells/ μ l)
A	- Asymptomatic - Persistent generalised lymphadenopathy	A1 >500 A2 200-499 A3 <200
B	- Early symptomatic pre-AIDS - Fever and/or diarrhoea lasting >one month - Oropharyngeal and vulvovaginal candidiasis - Herpes zoster	B1 >500 B2 200-499 B3 <200
C	- Mycobacterium tuberculosis - Pneumocystis Carinii pneumonia - Candidiasis of bronchi, trachea or lungs - Extrapulmonary cryptococcosis - HIV-related encephalopathies - Cytomegalovirus infection - Kaposi's sarcoma - HIV wasting syndrome	C1 >500 C2 200-499 C3 <200

(Adapted from Vaipajee et al., 2005; Mars 2004; CDC, 1999)

The acute AIDS related complex is associated with the early stages of HIV/AIDS

classification i.e. stage 1 and 2 according to WHO and stage A and B of the CDC coding system. Early presentation is characterised by fatigue, fever, lymphadenopathy, weight loss and diarrhoea without opportunistic infections or malignancies (Mars, 2004). Later stages of the disease i.e. stage 3 and 4 (WHO) and stage C (CDC) may be characterised by further decline of the CD4+T cell count after acute infections and the ensuing onset of opportunistic infections (e.g. oral candidiasis, Pneumocystis Carinii Pneumonia, Cytomegalovirus, Mycobacterium tuberculosis (TB), and cerebral toxoplasmosis as well as malignancies e.g. Kaposi's Sarcoma, Non-Hodgkin's Lymphoma and central nervous system lymphomas which have a profound impact upon function (Moylett and Shearer, 2002). Common late-stage neurological illnesses are debilitating and include toxoplasmosis, progressive multifocal leukoencephalopathy, HIV-associated dementia and cryptococcal meningitis. As the HIV infection progresses patients may be categorised into AIDS-related stages according to clinical manifestations and diagnosed conditions (WHO, 2005). Patients will be diagnosed with AIDS if they present with an AIDS defining illness such as malignancies or opportunistic infections or if their CD4 count is below 200 cells/ μ l (Mars, 2004).

It has been established that HIV affects the body on a cellular level and that clinical signs can result in every system of the body. A deeper understanding of the pathophysiology of HIV on the many systems of the body is vital to appreciate the underlying causes of HIV-related impairment and disability.

2.4. Pathophysiology of HIV and the effect on Major Body Systems

The main transmission routes of HIV are well known; sexual transmission, blood/blood product transmission and mother-to-child transmission (Schmid, Buve, Mugenyi, Garnett, Hayes, Williams et al., 2004; CDC, 1999). Once the virus enters the body, a primary infection of viral replication and CD4 molecule degradation occurs, thereafter the disease enters a latent phase (Mars, 2004). This largely asymptomatic phase is characterised by low extracellular presence of the virus and a small amount of infected CD4 molecules. The virus continues to multiply in the macrophages, dendritic cells and some of the CD4 cells

(Sierra et al., 2005; Mars, 2004). Continued destruction of CD4+ T lymphocytes, important units for humoral and cell-mediated immune response, results in dysregulation of immune functions and the body's defence system is rendered inadequate and is unable to prevent the chronic nature of the HIV1 infection and the onset of opportunistic infections (Sierra et al., 2005; Evans and Scadden, 2000). As the immune system declines, bacterial and viral infections (as outlined in Disease Staging) as well as intracellular organisms have adverse effects on multiple structures and systems and hence result in poor body functioning and reduced participation in activities (Moylett and Shearer, 2002).

The causes of most HIV-related manifestations are through the direct and indirect impacts of the HI Virus, viral gene products, HAART and infections. The following sections elaborate on the effects of HIV on adults at a systemic level. The body systems found in the literature to manifest physically and the literature on how they are affected was reviewed.

2.4.1. Haematological and Lymphoid Systems

The impact of HIV on the haematolymphoid system hinders haemopoiesis within the bone marrow (Moylett and Shearer, 2002). Virus-associated proteins affect the cell membranes of haematopoietic progenitor cells and thus cause haematological abnormalities such as anaemia, neutropaenia, cytopaenia, lymphopaenia and thrombocytopaenia which influence the circulatory integrity of all systems of the body (Davis and Zauli, 1995). Haematological measurements are clinical markers which contribute to signs and symptoms and physical and participatory dysfunction (Evans and Scadden, 2000).

2.4.2. Respiratory and Cardiac Systems

Wallace, Hansen, Lavange, Glassroth, Browdy, Rosen et al., 1997, examined the incidence of respiratory disorders in a multicenter HIV positive cohort. The most frequently reported disorders were upper respiratory tract infections with lower respiratory tract infections such as acute bronchitis, bacterial pneumonia and Pneumocystis Carinii pneumonia increasing with CD4 count decline (Wallace et al., 1997). Decreased physiological functioning of the pulmonary system due to conditions like pulmonary

disorders and HIV-related pulmonary hypertension can cause a reduction in pulmonary diffusion capacity and aerobic capacity which result in poor work capacity (Mars, 2004). Diaz, King, Pacht, Wewers, Gadek, Neal et al. (1999) investigated a group of HIV positive individuals with a reduced pulmonary diffusion capacity to further explain the physiological impact of HIV infection on pulmonary function. Reduced pulmonary diffusion capacity was reported to be related to the capillary blood volume component of gas exchange and represents the onset of early emphysema (Diaz et al., 1999). Cardiac conditions common in HIV include cardiomyopathies, endocarditis, coronary vasculopathy, pericardial effusion and metastases. Most cardiac complications have infectious, non-infectious and neoplastic etiologies and often present in advanced AIDS with ventricular insufficiency (Yunis and Stone, 1998). Haematological complications of the disease due to suppression of bone marrow, in combination with HIV-related cardiorespiratory problems, result in poor oxygen delivery to muscles and hence poor physical function (Mars, 2004).

2.4.3. Musculoskeletal System

HIV/AIDS-related musculoskeletal conditions include those of infectious and non-infectious nature (Tehranezhad, Ter-Oganesyan and Steinbach 2004). Infectious conditions which spread haematogenously include abscesses, cellulites, pyomyositis, septic bursitis, septic arthritis, osteomyelitis and bacillary angiomatosis as well as many mycobacterial infections. Simpson and Bender, 1988, examined the HIV-associated myopathies in 11 individuals at various stages of the condition and found the characteristic proximal muscle weakness to be due to muscle inflammation and muscle fibre necrosis. Non-infectious conditions include rheumatic disorders and neoplasms. These conditions affect the large muscle groups, bones, joint and tendons and may present with fever, cramp-like pain, arthralgia and joint swelling which hinder comfortable mobility and affect functioning (Levinson and O'Connell, 1991). Musculoskeletal TB is common and TB of the spine (Pott's disease) involves the vertebral column and can cause neurological complications, paraparesis, spinal cord compression and even paraplegia (Tehranezhad et al., 2004). Loss of muscle mass, as well as illness-associated deconditioning results in skeletal muscle atrophy, weakness and fatigue (Mars, 2004; Nixon and Cott, 2000). Soft tissue healing and fracture union are reported to be suppressed by malnutrition, anaemia and altered inflammatory responses as a result of HIV infection. Immunosuppression also

renders HIV positive people with musculoskeletal injuries more vulnerable to infections (Ryan, 2007; Harrison, Lewis, Lavy, 2004).

2.4.4. Gastrointestinal System

HIV impacts upon the gastrointestinal system which negatively affects nutritional status and energy levels (Nixon and Cott, 2000). Inadequate supply of nutrition due to limited availability and variety of food, nausea, oral and gastro-intestinal infections and malabsorption deplete energy supply and lead to decreased physical activity (Smith, 1993; O'Dell et al., 1991). In advanced AIDS muscle mass is lost and used as a source of amino acids for gluconeogenesis and protein synthesis in an effort to inadequate nutrition. This loss of lean body mass results in significant weight-loss, loss of strength and results in a reduction in mobility (Mars, 2004).

2.4.5. Nervous System

Neuronal functioning is hampered by the direct and indirect influence of HIV through cellular infection and the opportunistic infections (Kolson, Lavi and González-Scarano, 1998). Infection of neuronal cells, including macrophages, microglial cells and astrocytes, inhibition of neuroleukin (a neurotrophic factor for spinal and sensory nerves) and the generation of neurotoxins by infected cells negatively affect the functioning of neural tissue and are involved in causing HIV dementia (Kolson et al., 1998; Enting Hoetelmans, Lange, Burger, Beijnen and Portegies, 1998; Fauci, 1988). Direct HIV involvement of the central nervous systems causes considerable disability as infections and neoplasms affect the brain, spinal cord and meninges resulting in cognitive impairment and focal neurological disorders (Levinson and O'Connell, 1991). Toxoplasmosis, encephalopathies, cryptococcal meningitis and peripheral neuropathy are common neurological complications which cause pain, fever and affect neural functions (Moylert and Shearer, 2002; O'Dell, Levinson and Riggs, 1996). Peripheral neuropathies result in chronic, distal, symmetrical sensory dysfunction which can inhibit mobility (WHO, 2005; Levinson and O'Connell, 1991). Neurological degenerative conditions are common in AIDS and may result in cognitive impairment, loss of concentration and memory, motor and sensory deficits, behavioural changes and depression all of which influence a

person's capacity to carry out activities (Sierra et al., 2005; Moylett and Shearer, 2002; Levinson and O'Connell, 1991; Bell, 1998).

Psychological problems develop due to reduced energy levels, weakness and reduced morale due to the unfavourable visual presentation of HIV/AIDS related conditions (Mars, 2004). HIV poses a risk for psychological stressors which in combination with the multisystemic effects of the HIV infection, result in significant mental and physical problems, activity limitations and participation restrictions which affect functioning within the household and society (HSRC, 2005; Mars, 2004; Webb and Norton, 2004; Vidrine et al., 2003).

Current management to curtail the multisystemic and functional deficits caused by HIV/AIDS involves a complex regime of highly active antiretroviral drugs. Information on how HAART works to combat HIV at cellular and immunological levels as well as the side-effects posed by the potent medications is needed to appreciate the affects of HAART on function which will be discussed in this review.

2.5. Highly Active Anti-retroviral Therapy

This section describes the current HAART regimes in use. This section also explores the effects of HAART on the physiological and clinical manifestations of HIV/AIDS. In addition, the adverse side-effects introduced by HAART which impact upon function and rehabilitation are explored.

In 2003, the South African government made the decision to provide antiretroviral treatment to PLWHA in accordance with the Operational Plan for Comprehensive Care in the HIV/AIDS struggle and the rollout of HAART commenced in April of 2004 (AIDS Foundation South Africa, 2005). Studies conducted in South Africa and other parts of the world report increased CD4 counts and improved longevity in PLWHA who are on HAART but, due to the recent initiation of national HAART provision, conclusive studies on the long-term effects of HAART in South Africa are limited (Akileswaran, Lurie, Flanagan and Mayer, 2005; Badji, Bekker, Orrell, Pitt, Cilliers and Wood, 2004; Low-Beer et al., 2000; Patella, Delaney, Moorman, Loveless, Fuhrer, Satten et al., 1998).

A combination of two nucleoside analogue reverse transcriptase inhibitors (NRTIs) and a potent non-nucleoside reverse transcriptase inhibitor (NNRTI) or protease inhibitor is considered as highly active antiretroviral therapy (HAART) (Idigbe, Adewole, Eisen, Kanki, Odunukwe, Onwujekwe et al. 2005). Current Department of Health HAART regimens in South Africa include combinations of at least three drugs which usually consist of two NRTIs plus either a protease inhibitor or a NNRTI as shown in table 2.4. (Sierra et al., 2005; Department of Health, 2004).

Table 2.4. Recommended Antiretroviral regimens

Drug type	Drug Name	Abbreviated name
NRTI	Zidovudine	AZT
	Stavudine	ddI
	Lamivudine	3TC
NNRTI	Nevirapine Efavirenz	NVP EFV
Protease Inhibitor	Ritonavir Lopinavir	RTV LPV

(Sierra et al., 2005; Department of Health, 2004)

The purpose of NRTIs and NNRTIs is to inhibit the reverse transcriptase process of HIV viral replication. NRTIs incorporate nucleosides into the viral DNA chain which produces 'false' viral DNA during transcription of viral RNA. NNRTIs competitively block reverse transcriptase which suppresses HIV RNA replication. PIs oppose the envelope 'packaging' and budding of new viral proteins (Mars, 2004). HAART works by disturbing the HIV viral cycle which, after approximately six months of treatment, causes an increase in CD4+ T cell counts and a decrease in plasma viraemia to undetectable levels (Di Mascio, Sereti, Matthews, Natarajan, Adelsberger et al., 2006; Sierra et al., 2005).

Long-term use is hampered by drug-resistance, side effects, pharmacokinetic interactions and patients' personal choice (Sierra et al., 2005). All ARV regimens require strict patient adherence and a life-long responsibility. In order to ensure a high level of adherence, treatment preparedness support via health care professionals is needed (AIDS Foundation South Africa, 2005).

Management with HAART has increased the survival and improves the quality of life of HIV positive individuals but toxicity and adverse effects can interfere with the effectiveness of the treatment (Hofman and Nelson, 2006). Common side-effects include lipodystrophies, hyperlipidaemia, metabolic disorders, local and systemic inflammatory reactions and toxicities which affect the liver, kidneys, bones, skin and muscle tissue (Hofman and Nelson, 2006).

The side effects caused by HAART are multisystemic. The common side effects and the associated symptoms and impairments that affect function have been extracted from the literature and are presented in Table 2.5. (Montessori, Press, Harris, Akagi and Montaner, 2004; Schiller, 2004; Mars, 2004; Sccevola, Di Matteo, Lanzarini, Uberti, Sccevola, Bernini et al., 2003; Stanton, 1993; Lang, 1993).

Table 2.5. Some Side Effects of HAART and associated Symptoms, Impairments and Functional Limitations

Side Effects	Related treatment regimen/drug	Symptoms, impairments and functional limitations
Lipodystrophies e.g. dyslipidaemia and insulin resistance	Protease inhibitors, stavudine	Premature cardiovascular disease (especially with concomitant vascular inflammation)
Lactic Acidosis	NRTIs	Malaise, nausea, vomiting, fatigue, tachypnoea
Gastrointestinal Problems	HAART	Bloating, nausea, diarrhoea, weight loss
Anaemia	Zidovudine	Fatigue, headaches, lack of energy
Hypersensitivity reaction	Nevirapine	Rash, low grade fever, discomfort and cosmetic concerns
Neurological Disorders e.g. peripheral neuropathies	HAART, stavudine	Sleep disturbances, pins and needles, dull pain, numbness, problems with activities of daily living
Bone Conditions e.g. osteonecrosis, osteopenia, osteoporosis	HAART	Reduced bone strength, pain and decreased mobility
Toxicity of the liver and heart	HAART	Liver failure, cardiac dysrhythmias, death

Allied medical professionals such as physiotherapists should be aware of side-effects of HAART like pain, peripheral neuropathies and lipodystrophies which reduce mobility, as

they have an important role in improving the function and well-being of PLWHA with proactive rehabilitation interventions like exercise, manual and electrotherapy modalities and goal-based activities (Mars, 2004; Sccevola et al., 2003; Stanton, 1993; Lang, 1993). The effect of rehabilitation on HAART-related side-effects will be elaborated in section 2.8. HAART and Function.

The current classification systems for HIV/AIDS focus on disease markers and do not pay attention to the functional limitations experienced by PLWHA (WHO, 2005; Nixon and Cott, 2000). There exists a need to identify suitable, comprehensive assessment tools which include the evaluation of function and participation of PLWHA within their own living environment (UNAIDS, 2004; Hwang and Nochajski, 2003). Section 2.6. provides information on The International Classification of Functioning, Disability and Health which has been found to be useful in the assessment of functioning of PLWHA (Hwang and Nochajski, 2003).

2.6. The International Classification of Functioning, Disability and Health

The International Classification of Functioning, Disability and Health (ICF) was developed by the WHO and endorsed by the World Health Assembly for international use after revision of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), published in 1980 (WHO ICF website, 2005). The aim of the ICF is to provide a unified, standard language and framework for the description of health and health-related states (WHO, 2001). This aspect of the tool aims to promote communication between health care professionals, other sectors and people living with disabilities. It uses a methodical coding system to describe the various dimensions of disability across countries and cultures, enabling universal use of the tool (Hwang and Nochajski, 2003).

The long and short versions of the extensive original ICF were developed for the needs of users depending on the level of detail required. The short version of the ICF classifies data at two levels of detail whilst the long version classifies data at four levels of detail which can be combined into a higher level classification system which includes all the domains at the second level (WHO ICF website, 2005). The long version is designed for

use by professionals in specialised areas of health care whilst the short version is for use in cohort studies, surveys and service evaluations (Hwang and Nochajski, 2003). It is advised that these versions be used in conjunction with the ICF Checklist Version 2.1A which is designed for practical use by clinicians and health or social care professionals (WHO, 2003).

The ICF Checklist, published in 2001, was developed as a sequel to the ICDH 2. The ICDH was revised by experts and the most relevant domains were identified to form the ICDH 2 Checklist. This classification was used in international field tests focusing on reliability, utility and feasibility and the final ICF Checklist was produced on the basis of the chosen classification items and test data. The test-retest reliability showed high kappa values ranging from 0.7 to 1.0 for the ICDH 2 Checklist dimensions (Üstün et al., 2003; WHO, 2002; Nixon and Cott, 2000).

Functioning and disability are viewed as a dynamic relationship between the condition and the environmental, personal and contextual factors of the individual as shown in Figure 2.1. One aim of the ICF Checklist is to assess this relationship (Cieza, Geyh, Chatterji, Kostanjsek, Üstün and Stucki, 2006; WHO ICF website, 2005).

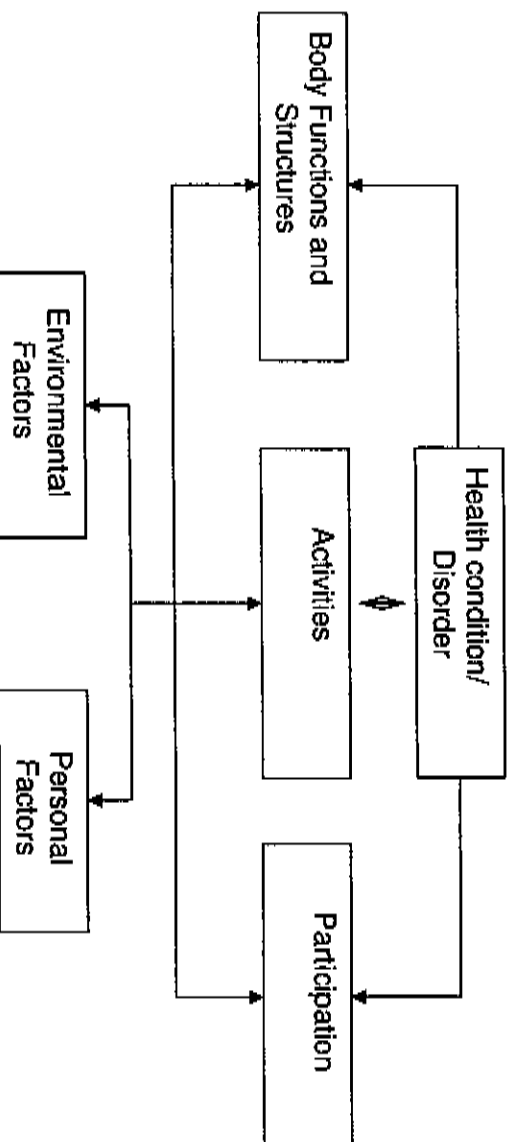


Figure 2.1. The Interaction between Health, Disability and Function.

Source: Cieza, Geyh, Chatterji, Kostanjsek, Üstün and Stucki, 2006; WHO ICF website, 2005.

Human Functioning in the ICF is defined as operating at three levels:

- Level 1 – at the level of the body and the body part
- Level 2 – the whole person
- Level 3 – the whole person in the social context

The components of functioning; body functions and structures, activities and participation, are illustrated to show their relation to the health condition as well as to contextual factors (Cieza et al., 2006). The negative aspects of the interaction between the person and environmental and personal factors are described as disabilities. 'Functioning' corresponds to the positive aspects of this relationship. Disability is thus a broad term for impairments, activity limitations and participation restrictions as described by the ICF (Cieza et al., 2006; Davis, 2006). Nixon and Cott (2000) describe disability as any restriction or lack of ability to perform an activity within the range considered normal for a human being.

2.6.1. Definition of ICF Items

In order to fully understand the scope of the ICF Checklist as a tool, one must be aware of the definitions of physical impairments, activity limitations and participation restrictions. According to the WHO (2002), physical impairments are defined as "problems in body function or structure as a significant deviation or loss"; Activity limitations are defined as "difficulties an individual may have in executing activities" and participation restrictions are defined as "problems an individual may experience in involvement in life situations". Body structures represent the anatomy of the body whilst body functions are physiological, psychological or cognitive functions of the body. Problems in body functions often correlate with deviations in body structure. In addition, body functions and structures are associated with activities and participation. The ICF checklist can thus be used to assess conditions at body, individual and societal levels (Hwang and Nochajski, 2003).

It must be noted that the relationships between physical impairments, activity limitations participation restrictions and environmental factors are fluid, may act in a bidirectional manner and don't necessarily follow expected one-to-one relationships e.g. one may have physical impairments without resulting capacity limitations or one may have performance

problems and capacity limitations without presenting with physical impairments. It is thus important to assess each component independently and thereafter explore associations between the dimensions of functioning and disability to gain a detailed perspective in to the full health experience (WHO ICF website, 2005; Hwang and Nochajski, 2003).

2.6.2. Structure of the ICF and the ICF Checklist

The ICF Checklist classifies data into two parts; functioning and disability, and contextual factors. 'Functioning' (body functions and structures) and 'Disability' (impairments) embrace the components of human functioning and include activity limitations and participation restrictions (Hwang and Nochajski, 2003). Contextual factors include elements such as environmental and personal factors. The components are divided into domains; for instance body function includes eight domains e.g. mental functions, sensory functions and pain, voice and speech functions. Each domain may be further divided into categories; for instance sensory functions and pain contains categories such as seeing, hearing, vestibular functions and pain. The categories contain the units of the ICF coding system and assist in identifying individual client-based problems within each domain (Jelsma et al., 2006; Hwang and Nochajski, 2003).

The ICF coding system uses 'qualifiers' which indicate the level of health or severity of the problem assessed in each domain (Arthanat, Nochajski and Stone, 2004). These qualifiers are used in each component to indicate the severity of disability on a scale from zero to four where zero denotes 'no problem' and four denotes a 'complete problem' (Arthanat et al., 2004).

The ICF Checklist is an abbreviated, practical list of ICF codes which measures health-related function with the use of qualifiers that are entered into the ICF coding system (Jelsma et al., 2006). The ICF Checklist measures three main dimensions of health states; impairments, activity and participation, contextual and environmental factors (Jelsma et al., 2006). The Checklist comprises 152 codes including 38 body function codes, 20 body structure codes, 57 activity and participation codes and 37 environmental codes which categorize data at the first and second level of classification (WHO, 2002). The first level

identifies a problem that causes activity and participation restrictions and the second level indicates the extent of the problem (Rowland, 2000).

The ICF Checklist components of activities and participations, are evaluated with the use of capacity and performance qualifiers. These qualifiers enable separation and description of an individual's innate 'capacity' to perform the actions within the ICF domains and the 'performance' within the environmental context of the individual. A limitation, which occurs at an individual level when a person encounters an inability to perform a task without considering external factors such as family assistance or mobility aids, is called a capacity limitation. Participation restrictions are shortcomings a person may experience at a societal level where external factors such as facilitators or barriers to participation are considered (Hwang and Nochajski, 2003).

Physical functioning involves the purposeful use of body functions in physical, social and attitudinal contexts (Enderby and Kew, 1995). The ICF Checklist emphasises the assessment of personal and environmental factors which may influence a person's health condition and captures the broad nature of potential therapeutic effort (Enderby and Kew, 1995). The results obtained from ICF assessments may reflect different natures of impact of services on different vulnerable population groups (Enderby and Kew, 1995). Personal and environmental factors may also alter the outcomes of interventions and hence are very important in the development of service policies (WHO, 2003).

The strengths and weaknesses of the ICF have been identified during its development and use (Jelsma et al., 2006; Üstün et al., 2003; Stucki et al., 2002) The strengths include its versatility across disorders, cultures, age groups and genders and its translation into at least 13 languages (Hwang and Nochajski, 2003). It can also be used by many sectors (not only health) as a statistical, research, clinical and social policy tool (Hwang and Nochajski, 2003). The most reported weakness of the ICF regards its substantial length which makes both assessment with the use of the ICF as well as its coding very time-consuming (Jelsma et al. 2006; Stucki et al., 2000). Researchers have found that not all domains of the ICF are useful for specific conditions and the ICF tool is not available in all languages at this stage (Jelsma et al., 2006).

The factors assessed by the ICF have often been compared to those affecting health-quality of life as they reflect the 'consequences of disease' (ICF homepage, 2006; Ruiz-Perez et al., 2005). Some of the components of the ICF are also assessed in health-related quality of life tools such as the Medical Outcomes Survey-HIV, Medical Outcomes Survey-Short Form, EuroQoL-5D and HIV Cost and Services Utilization Study (Health-Related Quality of Life measure (Powers, Marden, McConnell, Leidy, Campbell, Soeken et al., 2006; Cunningham et al., 2005; Hughes, Jelsma, Maclean, Darder, Tinise, 2004; Low-Beer et al., 2000; O'Dell et al., 1998). This connection is highlighted further by Lau and Muula (2004).

Lau and Muula, 2003, call attention to a connection between the ICF components and components of health-related quality of life. It was found that 36 quality of life components can be classified using the ICF classification at a functional, structural, activity, participation, environmental and personal level as shown in table 2.6. ICF categories and Components of Quality of Life (Davis, 2006).

Table 2.6. ICF categories and Components of Quality of Life (Davis, 2006)

Body function and structures	Activities and Participation	Environmental factors	Personal Factors
Limb function	Activity Participation	Working Capacity	Happiness
Bowel and bladder function	Activities of daily living	Formal social support	Dependence on medication/treatment
Vision and hearing	Dependence on medication/treatment	Social integration	Self concept: body image and self-worth
Language ability	Personal relationships	Physical safety and security	Coping
Cognition	Sexuality	Housing	Spirituality
Pain and Discomfort	Informal social support	Finance	Life satisfaction
Energy and fatigue	Opportunities for new information and skills	Transport	Sense of control
Sleep and Rest	Sense of acceptance	Physical environment	Negative feelings
		Leisure	

The similarity between quality of life assessments and the ICF becomes evident when searching for literature on functioning and disability as many health-related quality of life

tools assess impairments of physical and mental functioning as well as domains like social and role functioning, fatigue, energy, pain and selfcare (Cunningham et al., 2005; Low-Beer et al., 2000; O'Dell et al., 1998). ICF Core sets are being developed to more accurately assess the functioning for different conditions e.g. breast cancer, depression, arthritis, diabetes mellitus and ischaemic heart disease (Cieza, Ewert, Üstün, Chatterji, Kostanjsek and Stucki, 2004). The additional items of condition-specific ICF core sets allow a more detailed picture of particular conditions. These core sets may be used for assessment, for matching appropriate interventions within health states as well as for rehabilitation and outcome evaluation (Stucki et al., 2002).

Üstün, Chatterji and Kostanjsek (2004) promotes the ICF Checklist as a suitable outcome measure as the tool enables data collection across conditions and interventions. No literature could be found indicating the existence of a core set for use with PLWHA so the ICF Checklist can be considered for the assessment of clinical presentations as well as situational aspects of PLWHA. The ICF Checklist Version 2.1A incorporates aspects of physical and mental impairments, activity limitations and participation restrictions as well as environmental and contextual factors to allow comprehensive assessment of PLWHA (Hwang and Nochajski, 2003).

2.6.3. The Application of the ICF Checklist on People Living with HIV/AIDS

The chronic nature of HIV/AIDS is accompanied by a multitude of disabling conditions. Hwang and Nochajski (2003) offer an overview of the use of the ICF coding system and its application to AIDS; The ICF allows detailed scrutiny of HIV/AIDS-related matters such as clinical manifestations, mobility and limitations in activities of daily living, employment issues, related social services and policies and societal attitudes (Hwang and Nochajski, 2003). The tool may help to highlight the nature and magnitude of health and societal issues experienced by PLWHA (Hwang and Nochajski, 2003).

There are many assessment tools that take patient-based measures for HIV/AIDS into account, for example, the HIV Health Assessment Questionnaire (O'Dell et al., 1998), the EuroQol-5D (Hughes et al., 2004), The Work Role Functioning Questionnaire, the Medical Outcomes Survey-Short Form-36 (Braisstein, Montessori, Chan, Montaner, Schechter,

O'Shaughnessy et al., 2005; Call, Klapow, Stewart, Westfall, Mallinger, DeMasi et al., 2000), the Medical Outcomes Survey-HIV (Ruiz Perez et al., 2005; Badia, Podzamczek, Casado, López-Lavid, Garcia, Spanish MOS-HIV Validation Group, 2000) and the HIV Cost and Services Utilization Study Health-Related Quality of Life measure (Cunningham et al., 2005). Domains such as health perceptions, pain, physical and social role functioning, mental/cognitive function, health distress, quality of life and sexual functioning are covered. The categories included in the above-mentioned tools often overlap but all encompass the concepts of impairments, activity limitations and participation restrictions. The ICF Checklist goes one step further by adding the assessment of personal and environmental factors which may impact significantly upon the lives of PLWHA. The ICF Checklist integrates variables that cover factors affecting health-related quality of life, which is a pertinent area of assessment for PLWHA (Hughes et al., 2004).

Jelsma et al. (2006) conducted a pilot study using the ICF Checklist to determine the suitability of using the checklist to assess the functioning of HIV positive people in a township near Cape Town. This study was the first to be conducted using the ICF Checklist in South Africa. The study was conducted on a small sample of twelve ARV-naïve subjects and it was concluded that this was not representative of a larger population or those currently on ARVs. Despite these limitations, the study demonstrated that the ICF Checklist is a useful framework to assess functioning in a poorly resourced community (Jelsma et al., 2006). The tool's emphasis on environmental factors is especially relevant in the assessment of well-being. The ICF Checklist proved to have limitations as it is time-consuming, the questionnaire had to be translated into Xhosa and some codes were not relevant or poorly understood (Jelsma et al., 2006). Such factors indicate a need for the use of specific core sets of the short version of the ICF as well as the need for adequate training in order to ensure the tool is comprehensive when applied to participants. Cieza et al. (2004) highlighted a need for the ICF Checklist to be tested in different countries, subsets of patients, condition characteristics and healthcare settings. The tool's validity and reliability will be able to be established with more frequent use (Jelsma et al., 2006).

Research has shown that the ICF Checklist and other tools assist in establishing the impairments and activity limitations which result in compromised functional independence

of PLWHA, and thus help in assessing health-related quality of life of HIV positive populations (Zonta et al., 2003).

2.7. Functioning, Disability and Health-Related Quality of Life

In this section impairments, activity limitations, participation restrictions, environmental factors and health-related quality of life for PLWHA are explored. The relationships between impairments, activity limitations and participation restrictions as well as external factors experienced by PLWHA are also described. This section probes the literature to examine the magnitude and interrelated presence of impairments, activity limitations and participation restrictions for PLWHA. The literature review will focus on the aspects of health and functioning in parts. In section 2.7.1. Impairments of body structure and function will be discussed. Section 2.7.2. will discuss activity limitations and participation restrictions and section 2.7.3 will cover environmental and personal factors. Health-related quality of life is affected at the level of impairments, activity limitations, participation restrictions and environmental factors and will thus be discussed throughout each subsection.

HIV is a complex multisystem infection which affects many systems including neuromusculoskeletal, neurological and cardiorespiratory systems and therefore there is a threat of losing functional capacity and developing complications that affect functioning and wellbeing (Nixon and Cott, 2000 O'Dell et al., 1996). It is important to look beyond the clinical markers of a disease and acknowledge the physical, emotional, social and functional aspects as well as the environmental and personal factors that may influence an individual with HIV (O'Dell et al., 1998).

Physical impairments, activity limitations and participation restrictions (components of health and functioning) are intricately linked to independence and quality of life for PLWHA (Davis, 2006; Zonta et al., 2003). It is important to explore the literature to ascertain the current findings with regards to functional limitations and their effect on the HIV positive population in order to determine gaps in the research and pinpoint possible intervention changes that can be implemented. Studies reviewed include mostly cross-sectional and population-based studies which provide an overview of variables evaluated to describe the

level of functioning of PLWHA (Rusch et al., 2004; Zonta et al., 2003; Crystal et al., 2000; O'Dell et al., 1998). Some studies focused on measuring impairments, others activity limitations and participation restriction and others touched on environmental factors in relation to health-related quality of life. The studies have been reviewed and have been placed in the most appropriate section within the ICF format.

2.7.1. Impairments of Body Structure and Function

Impairments of body structure and function influence health-related quality of life issues for PLWHA (Webb and Norton, 2004). Health-related quality of life includes physical and emotional impairments and physical, social and cognitive functioning as well as mobility and selfcare. It has been found that the number of impairments experienced is associated with health-related quality of life, regardless of CD4 count (Webb and Norton, 2004). Regularly reported areas of impairment include internal, mental, sensory, neural and muscular impairments and pain as found by HIV-related reviews (O'Dell et al., 1996; Levinson and O'Connell, 1991). Issues of importance to PLWHA include fatigue, pain, diarrhoea, nausea and vomiting, sleep problems, depression, sexual dysfunction and body image changes (Nixon and Cott, 2000; Lang, 1993). Anaemia is the most common haematological abnormality in HIV positive patients (Evans and Scadden, 2000) and results in fatigue and reduced health-related quality of life. Fatigue has also been attributed to malabsorption, infection, nutritional deficiencies and psychological sources (Nixon and Cott, 2000). Nausea and vomiting may be due to the side-effects of drugs. Sleep problems may be caused by a multitude of factors such as depression/anxiety, fever, diarrhoea, cough or night sweats. Weakness is another factor that has been found by research to be a pertinent problem for PLWHA and may have neurological, nutritional and infectious aetiologies (Jelsma et al., 2006; Zonta et al., 2003; Nixon and Cott, 2000; Lang, 1993). An overview of the use of the ICF framework with AIDS by Hwang and Nochajski (2003) pointed out that neuromusculoskeletal and movement-related dysfunctions and neurological problems are important areas of functional impairment for PLWHA. Central and peripheral neuropathies bring about mental disorders, psychomotor slowness physical impairments and functional loss and are important areas for rehabilitation.

Clinical markers and impairments are linked to aspects of function as investigated by Call et al., (2000). Results of Call's cross-sectional study showed a significant ($p < 0.05$) negative association between viral load and physical functioning scores, body pain, general health, emotional functioning and vitality which in turn, influences health-related quality of life. There was no significant association found between viral load and mental components or social functioning. ARVs (especially with the concomitant use of protease inhibitors) reduce the viral load and thus have the capacity to increase health-related quality of life (Call et al., 2000). It must be noted that this study was conducted using a small, non-representative sample of mainly white, homosexual males of whom only 60% were on ARVs so the results cannot be generalised to a population that includes non-whites, heterosexuals and females. A similar cross-sectional study by Kohli et al. (2005) found an association between CD4 count and health-related quality of life for HIV positive patients at various stages of the disease. Those with lower CD4 counts experienced greater impairments in the areas of physical health, cognitive functions, sleep, activities of daily living, sexual and social activities as well as pain when compared to those with higher CD4 counts. Call et al. (2000) and Kohli et al. (2005) used Medical Outcomes Study questionnaires that were answered in different languages and countries, yet both found associations between clinical markers such as CD4 count, functional aspects like physical and emotional functioning and pain, and ultimately health-related quality of life. Previously there was a greater focus on biological markers of HIV but attention is gradually being turned towards patient-based domains related to aspects of health-related quality of life, adherence and patient satisfaction. There exists a relationship between traditional measures of disease state and patient-focused measures but one should include outcomes which aim to increase both quality and length of life for PLWHA.

Ruiz Perez et al. (2005) conducted a cross-sectional study on 320 patients (who had started ARVs) in Spain. The results indicated that those with increased support, decreased mental illness, no difficulties with medication, increased CD4 counts and decreased viral loads also had increased health-related quality of life scores. The results not only indicated that AIDS infection is associated with decreased physical and mental health-related quality of life but also with psychological morbidity. Cleary et al. (1993) conducted a cross-sectional study on 198 subjects which assessed health-related quality

of life in persons with AIDS by analysing life satisfaction, general health perceptions, physical function, emotional well-being, fatigue, disability, pain, symptoms and illness severity. Results revealed that the physical symptom score and level of fatigue were the best predictors of overall perceived health status, which has an impact on functioning and provides a direction for the development of interventions. Ruiz Perez et al. (2005) and Cleary et al. (1993) emphasize the linked effect of physical and mental impairments upon health-related quality of life indicating that neither aspect should be assessed in isolation. The mental and emotional status of PLWHA must never be disregarded as psychological well-being and perceived health status are strong correlates of life satisfaction (Cunningham et al., 2005; Cleary et al., 1993). It should also be noted that physical and mental impairments hinder important daily activities and social roles which influence functioning and health (Crystal et al., 2000; Nixon and Cott, 2000; O'Connell and Levinson, 1991).

HIV-related impairments may occur in the early stages of the disease and do not always correlate with the clinical disease progression. One needs to assess all components of function from symptomatology to impairments to activity, participation restrictions and environmental influences (Webb and Norton, 2004; O'Dell, 1998).

2.7.2. Activity Limitations and Participation Restrictions

Many studies have explored the functioning and disability of PLWHA with regards to various components of activity limitations and participation restrictions.

Rusch et al. (2004) used a tool based on the ICF framework to assess the level of physical and mental impairments, activity limitations and participation restrictions in a cohort of PLWHA. The results of the National Population Health Survey in British Colombia and found that the ARV-naïve cohort of 762 HIV positive people reported increased rates of activity limitations than the general population even with high CD4 counts. Common participation restrictions included sexual role, hobby, sport and leisure, financial independence and social role. Poor social functioning was related to decreased mental function and activity limitations (household chores and moderate to vigorous activities). This population based survey however acknowledged under-representation of females,

intravenous drug-users and those without homes. Hughes et al. (2004) reported similar findings from a cross-sectional study of 123 late stage (WHO stage 3 or 4), ARV-naïve HIV positive South Africans. Results from the use of the EuroQol-5D health-related quality of life assessment tool show that the cohort experienced limitations in mental and physical components of health-related quality of life. A significant decrease in health-related quality of life was noted for those in stage 3 and 4 in the impairment and activity domains of mobility, activities of daily living, pain, depression, vitality and sleep. As part of its limitations, the study recognized an overrepresentation of females comprising 65% of the sample. Rusch et al. (2004) and Hughes et al. (2004) report similar findings with regards to the functioning of PLWHA. It must be noted that both studies relied on self-reporting in different languages and that the cohorts included ARV-naïve people so the results cannot be generalised to ARV-experienced individuals. The study results highlight the need for multidisciplinary interventions which assist PLWHA to overcome limitations in order to impact upon their daily participatory activities like activities of daily living and employment.

Twamley et al., 2006, conducted a cross-sectional study comparing the work-related abilities of 27 schizophrenic unemployed people, 27 HIV positive unemployed people and 27 HIV positive employed individuals. The results demonstrated that unemployed subjects experienced lower maximal lifetime job functioning regardless of diagnosis. The schizophrenic and HIV positive individuals may both experience limitations in the domains of learning, executive functioning, information processing and motor abilities. HIV infection may be associated with neurological, psychological and functional impairments that can affect work status (O'Dell et al., 1996). Research by Hwang and Nochajski (2003), O'Dell et al. (1996) and Twamley et al. (2006) indicates that neurocognitive impairments are common amongst PLWHA and that such impairments can negatively influence participation with regards to work ability and employment.

Research by Zonta et al. (2003), O'Dell et al. (1998) and Grimes & Cole (1996) shows that an intricate connection exists between problems at functional, activity and participatory level. Zonta et al. (2003) assessed the functional status of 74 HIV positive patients in Brazil using a cross-sectional observational study. The results demonstrated that 91% of the subjects had a degree of functional impairment and the most pertinent impairments

were weakness and neurological involvement. Despite the fact that the mean CD4 count of the group was low at 91 cells per μ l and 51% had an AIDS-defining illness, 79% were described as independent and only 7% were deemed dependent. Limitations in activities of daily living were found to be associated with decreased CD4 count, increased viral load, decreased muscle strength and unemployment. Similar, but somewhat contradictory results were obtained from a cross-sectional observational study by O'Dell et al. (1998) in California on 531 pre-AIDS subjects. A self-administered questionnaire showed that less than 10% of the HIV positive subjects experienced a degree of perceived limitation. The study also showed that less than 2% of the subjects experienced severe disability in any category. Most of the deficits occurred in instrumental activities of daily living (including reach, grip and chores). The results of the two articles indicates that pre-AIDS subjects may experience fewer activity limitations and participation restrictions than those with AIDS-defining illnesses and that most of the limitations experienced have minor effects on the independence of the subjects.

Limitations, whether at body, activity or participation level, influence the independent functioning of PLWHA. A cross sectional study by Grimes and Cole (1996) reiterates the concept that more advanced HIV disease may result in increased dependency and conversely that greater involvement (independence) in areas like selfcare, personal, family and social roles improves perceived well-being and thus positively influences health-related quality of life. The information from patient assessment suggests that by teaching enabling skills to PLWHA who are largely dependent due to progressive disease may enhance health-related quality of life by improving involvement in one's own health management (Grimes and Cole, 1996; Lang, 1993; Stanton, 1993).

Crystal et al. (2000) conducted a nationally representative cross-sectional survey of 2836 HIV positive participants in the USA. The data, in agreement with the reviews by Hwang and Nochajski (2003), O'Dell et al (1996) and Levinson and O'Connell (1991), captures the impact that functional impairments have on social roles and major life areas. Evidence shows that PLWHA have the greatest limitations in the areas of complex roles such as employment, domestic life and schooling as well as individual energy-demanding physical tasks such as climbing stairs, walking distances greater than one block, instrumental

activities of daily living and selfcare (Rusch et al., 2004; Crystal et al., 2000; O'Dell et al., 1996). These difficulties are often associated with an individual's severity of symptoms, global health status, perceived pain and fatigue (Cunningham et al., 2005; Crystal et al., 2000). Crystal et al. (2000) found that decreased activity limitations were associated with the administration of protease inhibitors (ritonavir and indinavir) showing further the change in functional status with advancements in treatment patterns. It should be noted that the results by Crystal et al. (2000) were based on self-reports of individuals attending an HIV care institution, and do not apply to those who are not aware of their HIV status or those not attending a care facility. Crystal et al. (2000) and Hwang and Nochajski (2003) show a need for research into functional assessment and disability screening in HIV in order to address symptoms and maximise function with interventions that focus on employment, home management skills and mobility.

2.7.3. Environmental and Personal Factors

External factors such as sociodemographic variables, environmental factors, societal attitudes and available services and policies also influence physical, psychological and social functioning and the exploration thereof is important (Ruiz Perez et al., 2005; Hwang and Nochajski, 2003). Functional status and health-related quality of life in an HIV positive population in Texas was investigated by Vidine et al. in 2003 using a cross-sectional survey. Their findings showed significant associations between physical and mental component scores and sociodemographic variables. Racial/ethnic minorities and those of a lower socioeconomic status had significantly poorer physical functioning and work-role functioning with a reduced health-related quality of life (Vidine et al., 2003). The study used a small sample for the analysis of several outcomes resulting in limited statistical power. Braistein et al. (2005) also found, through a self-administered questionnaire, that those with a co-infection of Hepatitis C experience an increased level of depression and fatigue as well as reduced health-related quality of life, but such problems were strongly associated with sociodemographic and socioeconomic factors such as poverty, employment, housing status and gender. One must consider that the cohort under examination was on ARVs and the results may be different for those who are ARV-naïve. When assessing functioning and disability, the impact of sociodemographic and socioeconomic influences that may add to the burden of disease should be considered

(Ruiz Perez et al., 2005). The studies also imply that potential interventions may be non-biological and include improving social skills, exercise, vitamin treatment and coping skills as well as aids to upgrade socioeconomic status (Nixon and Cott, 2000; Stanton, 1993).

Contextual information at individual, family, community and health-care levels is important in the assessment of function (Hwang and Nochajski, 2003). Olley et al. (2004) used a cross-sectional study to investigate the predictors of depression in recently diagnosed HIV positive patients in South Africa. Factors that were found to predict depression include gender, disability and marked negative life events e.g. unemployment, poverty, decreased financial support. Most of the cohort under investigation (98,7%) was ARV-naïve at the time of the experiment, thus the results may differ for those on ARVs. Kohli et al.(2005) found that HIV positive women have poorer role performance, social functioning and mental health than HIV positive men and thus have a lower health-related quality of life. Similar studies found that situational factors affect psychological and thus disability status (Ruiz Perez et al., 2005; Chou and holzemer, 2004). Social support was found to have a profound affect upon functioning by positively influencing functions such as selfcare (Chou & Holzemer, 2004).

Jelsma et al. (2006) incorporated the assessment of physical impairments, activity limitations, participation restrictions and environmental factors (according to the ICF framework) to form a profile of the functional abilities in a small South African pilot study. Results showed that the main problem areas for PLWHA in the cohort included emotional functioning, energy and drive functions, sensitivity to sound and relationships with community members. Movement related function was compromised in the area of joint mobility and muscle power and hence tasks such as lifting and carrying heavy objects were hindered. Health-related quality of life was documented to be compromised with regards to mobility, pain, anxiety, depression and ability to maintain usual activities. When assessing relationships, people in authority, immediate family and health care professionals were found to be facilitators of function whilst acquaintances, peers, colleagues, neighbours and community members were barriers to function. Jelsma et al. (2006) emphasize the importance of holistic assessment of physical impairments, activity limitations, participation restrictions and environmental factors to create a detailed profile

functioning, disability and health of PLWHA (Arthanat et al., 2004; Hwang and Nochajski, 2000).

The literature review has thus revealed a high prevalence of impairments, activity limitations and participation restrictions among PLWHA (Rusch et al., 2004; Hwang and Nochajski, 2003; Zonta et al., 2003). There exist associations between impairments, activity limitations and participation restrictions where differences are largely influenced by contextual factors which must be taken into account (Olley et al., 2004; Vidrine et al., 2003). Assessment of these components of functioning and health are of importance as they affect health-related quality of life. The evaluation of health-related quality of life can improve quality of care by assessing and optimising treatment and may result in increasing patient adherence, improving communication between patients and clinicians and documenting changes in patients' conditions (Webb and Norton, 2004). Studies demonstrate that it is imperative to understand the effect of ARVs at a physiological and functional level in order to develop a profile of the disability associated with HIV/AIDS with concurrent use of ARVs (Cunningham et al., 2005; British Colombia Persons with AIDS Society, 2004). However, there appears to be a lack of evidence for PLWHA who are asymptomatic and for those on HAART.

2.8. Highly Active Anti-Retroviral Therapy and Function

This section explores the effects of ARVs focused on morbidity at a systemic and functional level and their impact upon exercise and rehabilitation.

HAART gives hope by decreasing mortality and morbidity therefore issues relating to function and health-related quality of life are becoming more and more pertinent with increased longevity (British Colombia Persons with AIDS Society, 2004). Many articles (Worthington et al., 2005; Rusch et al., 2004; Hwang & Nochajski 2003) have stressed the need for further research into impairments, activity limitations and participation restrictions. This can be attributed to the chronicity of HIV since the introduction of antiretroviral therapies such as HAART (Worthington et al., 2005; Rusch et al., 2004; Hwang & Nochajski 2003; Nixon and Cott, 2000).

Idigbe et al. (2005) conducted a prospective observational study on 50 ARV-naïve Nigerian HIV positive subjects in stage 2 and 3 of HIV infection on initiation of a common HIV treatment regimen of nevirapine, stavudine and lamivudine. Measurements over 48 weeks of treatment showed a drop in viral load, an increase in CD4 count, opportunistic infections had reduced and average body mass increased by 4.8kg. Of the cohort, 36% (n=72) experienced minor, transient side-effects from the treatment. Although other studies (Kohli et al., 2005; Zonta et al., 2005; Vidrine et al., 2003; Call et al., 2000) report that CD4 count is not an accurate predictor of function, loss of mass and deconditioning has been reported to negatively affect physical functioning (Mars, 2004; O'Dell, 1993). Similarly, Palella et al. (1998) studied the use of various HIV treatment regimens on morbidity and mortality rates of 1255 HIV outpatients and reiterated the positive effects of intensive antiretroviral therapies. The cross-sectional observational study shows that combination antiretroviral therapy reduces mortality rate and opportunistic infections regardless of sex, race, age and risk factors. The article concluded that the use of intensive ARV combinations (including protease inhibitors) have the best results with regards to mortality and opportunistic infection reduction. However, the study pointed out that those receiving protease inhibitors were on private medical aid which introduces the socioeconomic factors that could possibly have an influence on morbidity. Studies show that antiretroviral treatments affect mortality and morbidity and enhance the immune system and have been shown to be closely associated with physical and social functioning (Idigbe et al., 2005; Cunningham et al., 2005; Low-Beer et al., 2000; Palella et al., 1998).

In a prospective cohort study by Cunningham et al. (2005), those on HAART experienced decreased mortality as well as higher physical functioning than those not on HAART. According to a cross-sectional study by Low-Beer et al. (2000) of 179 HIV positive British Colombians, the use of protease inhibitors as an addition to the ARV regimen has the potential to improve health-related quality of life especially with regards to physical, social and role functioning and health perceptions. Both studies had no indication of patient adherence or control groups with which to compare the results. The studies indicate that ARVs have a positive effect upon health-related quality of life and subsequently the level of functioning especially in areas such as physical and social functioning and health perceptions (Low-Beer et al., 2000).

In addition to ARV's decreasing morbidity and aspects of functioning, the type of regimen may also have an impact upon areas of physical and mental function (Powers et al., 2006). A prospective survey of 40 adult HIV positive patients indicated that continuous HAART may be more beneficial than intermittent HAART as the intermittent HAART group revealed reduced mental health scores over time. Individuals receiving continuous HAART receive HAART with no interruption while intermittent HAART as an example with intervals of one month off therapy followed by two months on therapy (Neumann et al., 1999). The study also emphasises the life-long commitment to HAART as it is paramount for clinical efficacy and improved physical and mental functioning. Health professionals need to take cognisance of the type of ARV regimens in use and the possible associated side-effects. Regular assessment of mental health, physical health and symptom distress may be warranted (Powers et al., 2006).

It is important to consider the limitations on exercise potential due to HIV and its treatment. Mars (2004) reviewed the literature and found that the manifestations of HIV, the side-effects of HAART as well as secondary infections result in limitations on exercise. Although HAART has been documented to reduce viral loads and increase CD4 counts, HAART-induced pathologies such as lipodystrophies, increased risk of ischaemic heart disease and stroke, glucose intolerance, diabetes and lactic acidosis have an effect on a person's ability to exercise and function at a participatory level. Lipodystrophies also create cosmetic concerns which hamper social functioning (Montessori et al., 2004). HIV and HAART are associated with mitochondrial dysfunction which results in reduced working capacity and VO_2 max (VO_2 max is the maximum amount of oxygen in millilitres that one can use in one minute per kilogram of body weight; McArdle, Katch and Katch, 2001). HAART, especially when including protease inhibitors, is associated with increased posterior wall and septum thickness of the heart, atherosclerosis, osteopenia and exercise-limiting myopathies which are risks when it comes to exercise prescription. Despite the vast array of possible conditions that can affect PLWHA, research has shown that the potential benefits to exercise outweigh the risks for exercise. Exercise should therefore not be excluded from those with the HI-virus but prescribed with the risks in mind at all times (Mars, 2004; O'Brien et al., 2004; Scevola et al., 2003).

An understanding of the impacts of HAART upon the client must not be disregarded by health professions as they have a profound effect on daily function (Webb and Norton, 2004). HAART-related side effects such as nausea, anxiety, confusion, vision changes, anorexia and insomnia must not be disregarded in the assessment and rehabilitation of PLWHA. Rehabilitation must include interventions to oppose these side effects effectively as well as to address the changes on lifestyle and activities created by HAART. There is a need for a biopsychosocial approach to rehabilitation of the 'HAART society' (Worthington et al., 2005).

2.9. Rehabilitation for People Living with HIV/AIDS

There exists a challenge not only to provide appropriate evaluative frameworks, but also suitable multidisciplinary health services for PLWHA within a resource-poor country (Nixon and Cott, 2000). The roles of rehabilitation must be redefined using the needs identified from the target group (Hughes et al., 2004; Nixon and Cott, 2000; O'Dell et al., 1991).

Due to the chronicity of HIV, long-term management has become important and health roles change at different stages of the disease (Nixon and Cott, 2000). There are many definitions of rehabilitation within the literature. "Rehabilitation" is broadly described as an active, dynamic, continuing process covering physical, social and psychological aspects. This rehabilitation process involves improving an individual's health status and quality of life by curtailing the consequences of disease (Davis, 2006). Rehabilitation is a comprehensive practice used in a variety of life-domains, in order to stabilise and optimise function and prevent deterioration (Worthington et al., 2005). The outcome of rehabilitation services in the HIV context is not proven but has the potential to impact upon many life domains as it is client-centred, goal-orientated and designed to address body impairments, activity limitations and participation restrictions (O'Dell et al., 1991). Further research on the life domains affected by HIV/AIDS will enable the development of an improved multidimensional rehabilitation framework (Worthington et al., 2005; O'Dell et al., 1991)

Weakness is a primary disabling complaint experienced by HIV positive people, yet there is minimal evidence of referral for physical rehabilitation (Zonta et al., 2003; O'Dell, 1993). It has been pointed out by Zonta et al. (2003), that most HIV-related referrals to

rehabilitation services are due to pulmonary complications or acute conditions. Little emphasis is placed on physical activity and exercise in the light of complaints of weakness and difficulty in performing or sustaining physical activities. Although only mild to moderate disability was reported, the results showed the need for nutrition, light resistive exercise, moderate aerobic exercise and physical activity. O'Dell (1993) on the other hand reviewed the rehabilitation consultation records of 30 HIV positive inpatients and showed that 80% of the cohort was referred to physical therapy for interventions aimed at deconditioning, fatigue and painful neuropathies. There is some data to support exercise as an intervention to improve health-related quality of life, perceived health status, weight maintenance, pain and muscle tone (O'Brien et al., 2004; WHO, 2004; Lang, 1993; O'Dell et al., 1991) Health care professionals have a central role in augmenting these lifestyle changes. The results of the studies (Zonta et al., 2003 and O'Dell, 1993) however cannot be generalised to a large population as they did not include the effect of ARVs and the cohort consisted primarily of homosexual, white men. People of different, genders, sexual orientations and races have different socioeconomic, cultural and environmental backgrounds. These differences influence access to resources such as nutrition, education and health services and have been reported to impact upon the impairments and social restrictions experienced by PLWHA (Tiadi 2006; Barnett et al., 2001).

A systematic review by O'Brien et al. (2004) examined the effectiveness and safety of aerobic exercise on PLWHA. A review of 10 randomised controlled trials showed a small statistically insignificant yet clinically significant change in CD4 count, viral load and VO2 Max. There was some improvement noted in anxiety, depression, general health, mood, life satisfaction and health-related quality of life. It was stated that the findings are limited to those who continued to exercise and received adequate follow-up. Unfortunately studies used small sample sizes, had high drop-out rates and only two of the studies included those on ARVs. More research, using larger population-representative samples, on interventions for PLWHA will aid rehabilitation prescription, improve HIV management and evaluate outcomes.

Sccevola et al. (2003) investigated the effect of exercise and strength training on cardiovascular status for HIV positive patients on HAART. HAART is reported to decrease morbidity and mortality yet the treatment has also been known to introduce changes in

metabolic profiles, body shape and fat distribution which renders those taking them more prone to coronary heart disease which compromises function (Mars, 2004; Montessori et al., 2004; Schiller, 2004). Exercise has been shown to decrease atrophy of muscle and bone, reduce joint stiffness, aid cardiovascular conditioning, reduce anorexia, improve gastrointestinal mobility and alleviate insomnia and depression. The study concluded that a combination of aerobic and anaerobic conditioning for those on HAART may be beneficial for the cardiovascular, metabolic and muscular systems and can aid in improving muscle endurance and body composition in HIV positive patients. Exercise, in combination with pharmacological interventions (anti-hyperlipidaemia drugs), dietary guidance and supplementation, may also decrease side-effects and treatment requirements as well as correct nutritional imbalances (Schiller, 2004; Scevola et al., 2003).

There is ample evidence which implies that exercise for those with HIV is beneficial yet exercise is often discouraged in people with viruses such as HIV due to the risk of developing myocarditis (Mars, 2004). Although HIV and HAART affects the pulmonary, cardiovascular, skeletal and endocrine systems, resulting in limitations to exercise, exercise may improve work capacity, aerobic threshold and aerobic capacity, change lipid profiles, improve strength as well as improve psychological limitations experienced by PLWHA. Exercise should be prescribed subsequent to exercise testing for those with severe hypercholesterolemia, central fat accumulation and pulmonary pathologies, as exercise has the potential to alleviate some of the effects of HIV and its treatment if conducted in a monitored, responsible fashion (Mars, 2004; Nixon and Cott, 2000). In addition to monitoring before and during exercise programs, research advocates addressing the aetiological factors that cause weight loss, lethargy and fatigue with nutritional, endocrine and psychological interventions as a step towards improving energy levels, morale and function (O'Dell et al., 1996; O'Dell et al., 1991).

O'Dell et al. (1996) discuss appropriate rehabilitation interventions for common HIV-related complications. The initiation of simple exercises like supervised walking, upper limb exercises and breathing techniques can be useful for pulmonary complications like pneumonias (O'Dell et al., 1996). Low intensity exercise and progressive resistance exercise can improve function in HIV-associated cardiac disease, pain and

rheumatological manifestations (O'Dell et al., 1996). Therapeutic modalities such as ice, heat, vibration, massage and electrotherapy have been documented to assist with painful neuropathies (O'Dell et al., 1996; Stanton, 1993). Deficits in endurance and fatigue can limit rehabilitation and energy-saving techniques and dietary advice are useful to augment maximum independence with activities of daily living and self-care (Stanton, 1993).

Fields and Selwyn (2003) describe a myriad of physical, mental and medical complaints in a cohort of end-stage HIV positive black men at a nursing home in New England. Physical function, ambulation and the need for assistive devices were paramount areas of difficulty. The results cannot be generalised to non-blacks, women or those who are asymptomatic as the cohort constituted only black, end-stage males. The results found are consistent with studies by Zonia et al. (2003), Crystal et al. (2000) and O'Connell and Levinson (1991) who revealed high numbers of physical impairments, activity limitations and participation restrictions. The authors concluded that there is a need for occupational therapy, physiotherapy and recreational therapy to carry out client-specific interventions to deal with cognitive, physical and emotional impairments (Nixon and Cott, 2000). In addition to multidisciplinary institution-based interventions, home modifications, assistive devices and home programs may be necessary to facilitate independent function within the environment of PLWHA (O'Dell et al., 1996; Stanton, 1993; O'Dell et al., 1993; O'Connell and Levinson, 1991).

It is clear that allied health professionals have a significant role to play in the management of PLWHA (O'Connell and Levinson, 1991). Rehabilitation must be conducted between and across disciplines (interdisciplinary and transdisciplinary) in order to appropriately address the multifactorial disabilities and role restrictions experience by PLWHA (Worthington et al., 2005; Levinson and O'Connell, 1991) Health care professionals need to work holistically to assess patients and prescribe exercises and lifestyle changes in an optimal and safe manner (Nixon and Cott, 2000). All forms of interventions that enable PLWHA to cope better within their daily lives should be considered and carried out in accordance with assessment of the problems pertinent to the populations concerned (Lang, 1993).

2.10. Conclusions

The HIV pandemic in South Africa and worldwide creates a continuing need for attention to this population (UNAIDS, 2004). The HI virus affects many systems of the body resulting in structural, functional and participatory dysfunctions which limit functional independence and decrease capacity for selfcare, mobility and work productivity; and this introduces economical and social ramifications (Nixon and Cott, 2000; O'Dell et al., 1998). HAART augments the chronic quality of the disease and introduces new manifestations and side effects that limit activities of daily living and social and economic functioning (Mars, 2004).

A variety of tools have been used in the evaluation of various dimensions of disablement of PLWHA and many resemble the framework used by the ICF (Ruiz Perez et al., 2005; Fusch et al., 2004; Vidrine et al., 2003). The ICF is an internationally endorsed assessment tool which is considered comprehensive and useful in the appraisal of PLWHA across populations (Hwang and Nochajski, 2003). The literature review indicates high numbers of interrelated physical impairments, activity limitations and participation restrictions among all HIV positive cohorts studied as well as the strong influence of contextual and environmental factors upon functioning at an individual and societal level (Rusch et al., 2004; Hwang and Nochajski, 2003; Zonta et al., 2003; Nixon and Cott, 2000).

The chronicity of HIV/AIDS is associated with physical and mental disability at any stage of the disease and with varying treatment regimens. Evidence demonstrates that rehabilitative efforts have the capacity to deal with some of the difficulties faced by PLWHA (Worthington et al., 2005; Nixon and Cott, 2000; O'Dell et al., 1996). Quantitative studies on the physical, psychological and social challenges of PLWHA and their effect on function and disability are limited and vital for the development of interventions which may optimise the value and worth of the extended lives of those living with HIV (Rusch et al., 2004).

Chapter 3

Methodology

3.1. Location of Study

This study was conducted at the Thembu Lethu ARV Roll-out Clinic at Helen Joseph Hospital, Gauteng. The clinic has a patient base of approximately 6000 HIV positive people who are consulted on an outpatient basis for diagnoses, medication and follow-up appointments. The superintendent of the Helen Joseph hospital granted permission for commencement of the study on the 5th of May, 2006.

3.2. Study Design

A cross-sectional, descriptive study design was used. A cross-sectional approach is the simplest variety of descriptive or observational epidemiology that is conducted on a sample of society (Abrahamson & Abrahamson, 2000). The study is descriptive as it describes the impairments, activity limitations and participation restrictions found amongst a cohort of PLWHA as well as the influence of contextual and environmental factors on function, disability and health. The results of the study were gathered with the use of both qualitative and quantitative data collection. Quantitative measures such as haemoglobin, CD4 counts, dynamometry and goniometry were used. Most of the data was collected at the time of the interview whilst the most recent retrospective information was obtained from the participants' medical records. Qualitative data was collected through self report from the participants and recorded quantitatively using the ICF Checklist guidelines.

3.3. Sample Selection

Subjects were selected from the outpatients attending the Thembu Lethu HIV Clinic at Helen Joseph hospital using consecutive recruitment.

3.3.1. Inclusion Criteria: Subjects were:

- HIV positive adults
- Between the ages of 18 and 49
- Attending the clinic as an outpatient (HSRC, 2005)

3.3.2. Exclusion Criteria: Patients were excluded if:

- Subjects did not fit the inclusion criteria
- Subjects were institutionalised/hospitalised
- Subjects were unable to answer questions (due to severe speech problems or dementia unless accompanied by a caregiver) or had disabilities unrelated to HIV.
- Subjects had pre-existing conditions unrelated to HIV that could lead to physical impairments, activity limitations or participation restrictions

3.4 Sample Size

- The sample size included 45 patients.
- A sample of convenience was determined by reviewing similar cross-sectional studies which investigated the manifestation of disability, function and impairments among PLWHA (O'Dell, 1993 – 30 patients, O'Dell et al., 1991- 37 patients; Powers et al., 2006-46 patients; O'Connell and Levinson, 1991- 51 patients; Zonta et al., 2003- 74 patients) In consultation with a statistician, it was decided that a midpoint figure of 45 participants would be sufficient for this research report and to gain an understanding of the presentation of impairments, activity limitations and participation restrictions in a cohort of outpatients living with HIV/AIDS (Russell and Gregory, 2003).
- The study uses the ICF Checklist which requires the collection of data of 125 variables which adds to the depth of the study.

3.5 Ethical Clearance

Ethical clearance was granted by the Human Research Ethics Committee (Medical) of the University of Johannesburg prior to data collection. (Clearance Certificate no. M060311). This is a sub-study which was conducted under a larger study entitled "Mainstreaming HIV

into Physiotherapy Education and Practice for which ethical clearance has been granted (Clearance Certificate no. M050206)

The following steps were taken to ensure ethical integrity:

- A letter and a copy of the research proposal were given to the superintendent of Helen Joseph Hospital and the coordinators of the HIV clinic. With permission from the hospital and clinic staff to proceed with the study, it was conducted over 3 weeks in June, 2006.
- The patients were initially approached by a member of the clinical team with whom the patient had established rapport before the investigator was introduced. At this stage, an information sheet/full explanations was supplied to the patients attending the clinic.
- Written consent was obtained before the study commenced.
- All documentation was available in English and Zulu or explained in full in a suitable language to ensure full understanding of the content and requirements of the study.
- The study took place in a private, research-conducive environment. Participants were assured that anonymity and confidentiality of all information would be maintained at all times during and after data collection and analysis. No names were recorded on the questionnaires themselves. Instead, each participant was given a number which was recorded on the ICF questionnaire and only the investigator had access to the list linking the names to the numbers. After the study was completed and the data were analysed all questionnaires were destroyed.
- The participants were compensated for their bus fare if a further appointment was needed to complete the assessment.

- If it was found that the patient was in need of rehabilitation, the investigator informed the patient and the clinic team and referred appropriately to the hospital's outpatient allied health departments.

3.6. Measurement Tools

The ICF Checklist Version 2.1a (Appendix 1) is the primary tool that was used in this study to assess physical impairments, activity levels and participation problems of the participants.

Validity and reliability of the ICF:

- The ICF Checklist was produced on the basis of the field tests conducted on the ICDH2 Checklist. These tests focusing on reliability, utility and feasibility showed high kappa values (0.7-1.0) for the ICDH 2 Checklist dimensions to be used in the ICF Checklist (Üstün et al., 2003; WHO, 2002)
- The framework of the ICF was developed, published and revised by the WHO (2001) and endorsed by the Fifty-Fourth World Health Assembly, 2001, after extensive use in 65 countries, across genders, age groups, cultures and health conditions (Weigl, Cieza, Kostanjsek, Kirschneck and Stucki, 2006; WHO, 2001).
- Research has reported the ICF to be a reliable tool in the assessment of health, social and environmental challenges faced by PLWHA (Jelsma et al., 2006; Hwang and Nockajski, 2003)
- Okochi, Utsunomiya and Takahashi (2005) examined the test-retest reliability of the tool which was shown to be low but improved with evaluator experience.
- A pilot study was conducted to determine the efficient use of the ICF checklist in this study.
- Crosswalking- The concept involves using the results of objective measures e.g. Haemoglobin or measurement of joint range of movement to rate the variables in the ICF (ICF homepage, accessed 2006; personal communication with ICF expert).

Muscle Strength Measurements

Muscle strength was determined with the use of a standard hand-held dynamometer and Manual muscle testing (Hislop and Montgomery, 1995). A Wagner Force Dial™ FDK/FDN Series Push Pull Force Gage was used for the dynamometry. The instrument is calibrated with certified test weights. Kilmer, McCrory, Wright, Rosko, Kim and Aitkens (1997) evaluated the test-retest reliability of hand-held dynamometry in measuring muscle strength in individuals with neuropathic weakness. Results showed hand-held dynamometry to be a reliable method of measuring muscle strength in persons with neuropathic pain and useful for other conditions in a clinical setting. Bohannon (1987) examined the test-retest reliability of hand-held dynamometry during a single session of strength assessment. The results showed that hand-held dynamometry can be a reliable strength assessment technique when used by a single tester. Merini, Mazzone, Solari and Morandi (2002) also showed excellent test-retest reliability results for hand-held dynamometry in spinal muscular atrophy and stated that it is a reliable measure of limb muscle strength, especially for longitudinal studies and clinical trials.

Range of Motion Measurements

Range of motion was determined with the use of a large, perspex 360° universal goniometer. Gajdosik and Bohannon (1987) examined the reliability and validity of goniometry related studies and their results encourage the use of goniometry as a reliable, objective measure of range of motion. In addition results of a study by Rothstein et al. (1983) showed that intratester reliability for flexion and extension of the knee and the elbow joints was high ($r = .91$ to $.99$). Intertester reliability was also high ($r = .88$ to $.97$) for these measurements except for measurements of knee extension ($r = .63$ to $.70$). Dynamometry, manual muscle testing and goniometry were used to rate the domain of neuromuscular and movement related functions; muscle power and joint mobility. Bohannon (1997) in a study testing for goniometry reference values used a convenience sample of 106 men and 125 women volunteers. Each muscle group was tested twice with an Ametek digital hand-held dynamometer (Bohannon RW, 1997).

Assessment of Muscle Tone and Involuntary Movements

Muscle tone and involuntary movements were assessed during the assessment of range of motion and muscle strength. Muscle tone was assessed using the modified Ashworth

Scale and is graded according to the amount of resistance to passive movement (Carr and Shepherd, 2002). Involuntary movements were assessed visually during the objective assessment as well as by asking the patient during the ICF Checklist interview.

3.7. Procedure

Training in the use of the ICF Checklist:

Extensive training in the use, application and analysis of the ICF Checklist was provided to the researcher to ensure that the checklist was completed in a standard manner for each participant. Training included:

- Attending sessions with an experienced researcher in the use of the ICF Checklist where the framework and use of the ICF was explained. The researcher conducted shadow scoring while attending the training sessions.
- Observing the use of the ICF Checklist by an experienced researcher during assessments with patients.
- A pilot study using 5 subjects was conducted to eliminate any problems and ensure efficient use of the ICF checklist. It was found from the pilot study that the sufficient time must be allocated to completion of the ICF Checklist as it is time-consuming (approximately 45min per assessment) and many of the concepts of the checklist take time to explain to the patients. Concepts that were found difficult were:
 - Perceptual functions
 - Community, social and civic life
 - Products and technology
 - Services, systems and policies.

Data Collection:

- The investigator met with the clinical management team of the HIV clinic at the Helen Joseph Hospital on agreed appointment dates and times for data collection.

- A member of the clinical management team approached each patient (by consecutive recruitment), explained the aims, objectives and ethical issues of the study and obtained initial consent from the patient.
- Once permission was granted, the investigator explained the study in detail to the patient. A translator assisted with explanations when needed. Information pamphlet covering the outline and requirements of the study was given to each patient and all questions or concerns were addressed.
- The patients were given an opportunity to make an informed decision about taking part in the research.
- Those who agreed to participate were asked to sign a written consent form prior to commencement of the data collection.

Participant Assessment:

- The participants were assessed in a private room within the HIV clinic. The assessment of the musculoskeletal system and movement related functions took place on a plinth within the room where participants dignity was maintained throughout the assessment.
- Each participant was assured privacy and was assessed once using the ICF Checklist.
- All available information was used to complete the checklist i.e. written records, primary respondent, other informants (nurses and doctors at the clinic and family members accompanying the respondents during the assessment) and direct observation (WHO ICF Checklist guidelines). In addition:
 - Questions formed from the MINI Mental Test were used to standardise the questioning technique for the section on Mental Functions. The questions were used to test recall and orientation to cover parts of the mental function section e.g. orientation, consciousness and higher level cognitive functions.
 - Dynamometry, Manual muscle testing and goniometry were undertaken to determine muscle strength and range of movement and to provide objective information to be used in crosswalking the information gathered in the domain neuromuscular and movement related functions. All the measurements and

assessments were done by the same researcher. An overview of each participant's joint range and muscle strength was developed by gathering goniometry, dynamometry and Manual Muscle strength data of flexion and extension at the shoulder, elbow, wrist, hip, knee and ankle joint.

Procedure for assessment with the ICF Checklist

The WHO ICF Checklist guidelines were followed for completion of the checklist.

Systematic completion of the Clinician Form was carried out including:

- A. Demographic information
- Part 1a: Impairments of Body functions
- Part1b: Impairments of Body Structures- qualifiers denoting the severity of the problems were used.
- Part 2: Activity Limitations and Participation restriction- covered with the use of capacity and performance qualifiers.
- Part 3: Environmental factors- qualifiers were used to rate the barriers and facilitators within the participants' environment.
- Part 4: Personal information and brief health information. Personal factors were assessed qualitatively during the interview. Information gathered included the type of housing, number of rooms, number of individuals living in the house, water and electricity supply, access to shops and church and possession of television and radio.
- Additional probing within Parts 1, 2 and 3 provided additional information which may be used in the description of the function, disability and health of the participant.

Procedure for goniometry (Clarkson and Gilewich, 1989)

To assess range of joint motion, the universal goniometer is placed lateral to the joint and the axis of the goniometer is placed over the axis of movement of the joint to be measured. The stationary arm of the goniometer is held parallel to the longitudinal axis of the fixed proximal joint segment. The moveable arm lies parallel to the longitudinal axis of

the moving distal joint segment and is moved around the fulcrum of the joint being measured.

Procedure for dynamometry and Manual muscle testing (Hislop and Montgomery, 1995; Clarkson and Gilewich, 1989)

The participant is positioned on the plinth to isolate the muscle group to be assessed in either a gravity- eliminated position or one where the patient works against gravity. The muscle is placed in full outer range and the assessor instructs the participants to move the limb at moderate pace throughout the entire available range. Manual resistance/ placement of the dynamometer is applied at a 90° angle to the limb segment and is applied from the distal end of the limb to be tested. Table 3.1. shows the starting positions and distal dynamometry measurement points for Manual muscle testing and dynamometry. Only the starting positions for grade four and five of the Medical Research Council muscle grading scale have been described as all the participant could move in a gravity-assisted position.

Table 3.1. Starting Positions and Distal Dynamometry Measurement Points for Manual muscle testing and Dynamometry

Movement	Patient starting position for grade 4 and 5 (gravity-resisted positions)	Distal dynamometry placement
Shoulder Flexion	Short sitting, arms at sides, elbow slightly flexed, forearm pronated	Not tested
Shoulder Extension	Prone with arms at side and shoulder internally rotated	Not tested
Elbow Flexion	Short sitting with arms at sides and forearm in midposition between pronation and supination	Distal, ventral aspect of distal radio-ulnar joint
Elbow Extension	Prone, arm at 90° abduction and forearm flexed and hanging vertically over the side of the table	Not tested
Wrist Flexion	Short sitting with forearm supported on its dorsal surface on the table. Forearm slightly supinated with the wrist in the neutral position	Not tested
Wrist Extension	Short sitting with elbow and forearm supported on the table and forearm in full pronation	Distal dorsal surface of the metacarpals
Hip Flexion	Short sitting, thighs supported on the table, legs hanging over the edge. Arms at side for trunk stability	Distal thigh, proximal to knee joint

Hip Extension	Prone	Posterior thigh just above the knee
Knee Flexion	Prone	Posterior leg just above the ankle
Knee Extension	Short sitting, therapist's hand maintaining the femur in a horizontal position. Arms at side for trunk stability	Downward resistance applied at the distal tibia above the ankle
Ankle Plantarflexion	Prone with feet off the end of the table	Distal plantar aspect of the metatarsals
Ankle Dorsiflexion	Short sitting or supine	Distal dorsal aspect of the metatarsals

Muscle Testing Grading system – Medical Research Council grades (Carr and Shepherd, 2002)

- Grade 5 (Normal) - Holds end position of movement against maximal resistance
- Grade 4 (Good) - Holds end position against strong to moderate resistance
- Grade 3 (Fair) - Completes test range but tolerates no resistance other than gravity
- Grade 2 (Poor) - Completes the test range in a 'gravity-eliminated' position
- Grade 1 (Trace) - The muscles exhibit palpable or visual contractile activity
- Grade 0 (Zero) - No palpable or visual contractile activity of the muscles

Measurement of muscle strength and range of joint motion were also taken in a matched group (n=12) of age-matched and gender-matched HIV negative individuals from a similar socioeconomic background in order to compare the data of the HIV positive and HIV negative groups to ascertain if a statistical difference between the muscle strength and range of joint motion exists between the groups. These participants were approached from a convenience sample, consent was obtained and dynamometry was tested in the same positions as described in table 3.1. The information sheet and informed consent form used for the HIV positive study participants were supplied to the HIV negative individuals (Appendices 4.3. and 4.4.)

3.8. Data Analysis

Descriptive Statistics were used to analyse data. Frequencies were determined using categorical data and means. Standard deviations were determined from the continuous data. Chi-square Tests (p value < 0.05 and odds ratios) were used to determine whether

there are any relationships between certain categorical variables within the data set, e.g. within the domains and categories of the ICF. The Mann-Whitney test was used to determine the differences in muscle strength between the study group and the HIV negative group. In addition to univariate and bivariate analysis, multiple logistic regressions were used to determine if body impairments predict activity and participation limitations (including adjusting for demographic variables). The data was entered onto a computer using Epi-Info statistical package.

Chapter 4

Results

In chapter four the results of the study will be presented. A discussion of the results will follow in chapter five.

4.1 Univariate Analysis

The results of the univariate analysis assist in determining the level of ability of the sample by determining the physical impairments, activity limitations, participation restrictions and associated environmental factors (as indicated by objective 1.)

4.1.1. Demographics of the Study Cohort

Table 4.1 provides an outline of the demographic information of the study cohort

Table 4.1 Demographics of Study Cohort (n=45)

Variable	Attribute	Sample % (n)
Gender	Female	64.6 (29)
	Male	35.6 (16)
Age (years) range:21 -49	20-24	6.7 (3)
	25-29	17.8 (8)
	30-34	22.2 (10)
	35-39	37.8 (17)
	40-44	8.9 (4)
	45-49	6.7 (3)
Marital status	Never married	57.8 (26)
	Currently married	26.7 (12)
	Divorced	6.7 (3)
	Widowed	2.2 (1)
	Cohabiting	6.7 (3)
Occupation	Paid employment	35.6 (16)
	Student	2.2 (1)

	Unemployed (health reason)	33.3 (15)
	Unemployed (other reason)	24.4 (11)
	Self-employed	4.4 (2)
Years of Formal Education	0 -5	11.1 (5)
	5 - 10	28.9 (13)
	>10	60.0 (27)
On ARVs	Yes	73.3 (33)
	No	26.7 (12)
CD4 count (cells/ μ l)	>200	55.6 (25)
	<200	44.4 (20)

Most of the patients were between the ages of 25 and 39 years (77.8%; n=35) and the mean age of the cohort was 34.4 years. The range for years of formal education was 1 – 16 years with a mean value of 10 years (SD = $\pm$ 3.7). The majority of the cohort 60% (n=27) reported over 10 years of formal education.

Most of the cohort was receiving ARVs (73.3%; n=33). CD4 count (cells/ μ l) ranged from 5- 628 with a mean value of 192 (SD = $\pm$ 158.1). Fifty-six percent (n=25) had CD4 counts above 200 μ l and the remaining 44.4% (n=20) had CD4 counts below 200. Only 6.7% (n=3) of the cohort had CD4 counts above 500 cells/ μ l. Of those taking ARVs (n=33), 17 participants had CD4 counts below 200 cells/ μ l and 16 had CD4 counts above 200 cells/ μ l.

4.1.2. Impairments of Body functions

Tables 4.2 to 4.5 reflect the information gathered from the ICF Checklist. The WHO states that an ICF code without a qualifier does not have an inherent meaning when used for individuals or cases (Üstün et al., 2002). In this study, the qualifiers were used during data collection then the data was recoded into dichotomous variables to make data analysis feasible for a cohort of patients as opposed to the individual case. Those with mild, moderate and severe impairments were recoded to group/code 1 to represent a group with functional problems. Those with no problems in the domain were put into group/code 0 and are represented in the tables as such. Further analysis within the domains revealed

additional information and has been provided below each corresponding table. Table 4.2. summarises the impairments of body functions experienced by the cohort

Table 4.2. Impairments of Body Functions (n=45)

Domain	Persons experiencing No impairments (0)	Persons experiencing Impairments (1)
	% (n)	% (n)
Mental functions	31.1 (14)	68.9 (31)
Sensory functions and pain	28.9 (13)	71.1 (32)
Functions of the cardiovascular, haematological, immunological & respiratory systems	0 (0)	100 (45)
Functions of the digestive, metabolic & endocrine systems	55.6 (25)	44.4 (20)
Genitourinary & reproductive functions	68.9 (31)	31.1 (14)
Neuromusculoskeletal & movement related functions	73.3 (33)	26.7 (12)
Functions of the skin and related structures	68.9 (31)	31.1 (14)
Voice and speech functions	100 (45)	0 (0)

The most common areas of impairments of body function included mental functions, sensory functions and pain and functions of the cardiovascular, haematological, immunological & respiratory systems.

Mental functions:

Of those experiencing problems (n=31), 28 described their impairments as mild and moderate. The most problematic categories of mental function included:

- Energy and drive where 31.1% (n=14) experienced impairments. Further subjective probing revealed that many of the participants feel they have insufficient energy to sustain a full day of activities without regular rests.
- Sleep problems were experienced by 35.6% (n=16). Many participants reported that they wake up for unknown reasons without being able to fall asleep again.
- Emotional problems were experienced by 44.4% (n=20). Emotional impairments often related to disease disclosure and coming to terms with the diagnosis.

Sensory Functions and Pain:

Of the cohort 71.1% (n=32) experienced impairments in the domains of sensory function and pain. A large proportion of those with impairments (n=26) reported only mild to

moderate problems. The categories showing the highest levels of impairments within the domain of sensory function and pain included:

- Seeing (33.3%; n=15) and
- Pain (57.8%; n=26).

Functions of the cardiovascular, haematological, immunological & respiratory systems:

One hundred percent of the cohort experienced impairments in this domain;

- Impairments of blood pressure (usually hypertension) were experienced by 33.3% (n = 15) of the cohort (41%; n=12 of the females in the cohort and 18.8%; n=3 of the males).
- Respiratory problems were reported by 22.2% (n = 10) and most indicated mild to moderate impairments. Respiratory problems were largely attributed to TB (active TB, post-TB or current TB), shortness of breath and opportunistic chest infections.
- Ninety-six percent (n=43) had at least 1 haematological problem due to the effect of HIV and HAART on CD4 counts, mean cell volume, haemoglobin, platelets lymphocytes and leukocyte levels (Evans and Scadden, 2000).

Table 4.3 summarises the available haematological results of the cohort including the normal value ranges, ranges of the cohort, and means and standard deviations of the cohort with regards to CD4 count, mean cell volume, haemoglobin, white cell count and platelet levels.

Table 4.3. Haematological Results of the Cohort

Variable (n=45)	Normal Value	Range of cohort	Mean	SD
CD4 count (cells/ μ l) (n=45)	600 - 1200	5 - 628	192	$\pm$ 158.1
Mean cell volume (fl) (n=37)	76-100	72-114.4	94.16	$\pm$ 9.52
Haemoglobin (g/dl)	11.5-16.5 (female)	3.3 - 14.2	11.1	$\pm$ 3.12
(n=40; 26 female, 14male)	13-18 (male)	9.9 - 17.1	12.5	$\pm$ 2.12
White Cell Count ($\times 10^9$ /l) (n=41)	4.0 - 11.0	0.8 - 22.9	5.29	$\pm$ 4.06
Platelets ($\times 10^9$ /l) (n=32)	150-350	152 - 801	318.5	$\pm$ 118.5

Functions of the digestive, metabolic and endocrine systems:

Forty-four percent (n=20) experienced problems in this category with domains of digestion, defecation and weight maintenance proving to be the common areas for impairments. Constipation and diarrhoea were commonly reported problems of defecation. Reduced weight was commonly reported to be a problem with regards to weight maintenance issues.

Genitourinary and Reproductive functions:

Thirty-one percent (n=14) experienced problems in the domain of genitourinary and reproductive functions with most problems appearing in the category of sexual function at 28.9% (n=13). Reports of sexual dysfunction included reduced libido and genital infections like vaginal candidiasis.

Functions of the skin and related structures:

31.1% (n =14) experienced mild and moderate impairments of the skin. The most common skin problem reported was the rash caused at the initiation of HAART.

Neuromusculoskeletal and movement-related functions:

Twenty-seven percent (n=12) reported neuromuscular and movement-related impairments and the dominant category in which people experienced mild problems was muscle power (26.7%; n=12). There were no reported problems in the categories of muscle tone, joint mobility and involuntary movements indicating that the primary neuromuscular problem for the cohort was muscle power and weakness. The goniometry results of the cohort indicated no limitations in joint mobility with all patients falling within the normal ranges of movement. Dynamometry and Manual muscle testing revealed mild deficits in muscle strength as all patients (n=45) recorded manual muscle strengths of grade four and five as shown in (Table 4.4.) and dynamometry showing poorer muscle strength than a group of HIV negative individuals (Table 4.5.).

Results for Joint Range

All participants of the HIV positive study group and the HIV- group exhibited active range of motion within the normal limits (Clarkson and Gilewich, 1989).

Results for Manual muscle testing

All participants in the HIV – group (n=12) had normal muscle strength (grade five). The study participants (n=45) had either grade four or five muscle strength as shown in Table 4.4.

Table 4.4. Manual muscle testing Results of the Study Group (n=45)

Movement	Participants with grade 4 muscle strength	Participants with grade 5 muscle strength
Shoulder Flexion	13	32
Shoulder Extension	12	33
Elbow Flexion	11	34
Elbow Extension	11	34
Wrist Flexion	13	32
Wrist Extension	14	31
Hip Flexion	13	32
Hip Extension	15	30
Knee Flexion	12	33
Knee Extension	12	33
Ankle plantarflexion	12	33
Ankle Dorsiflexion	14	31

Table 4.5. summarises the dynamometry results for the study group and the HIV- group that was matched for age and gender.

Table 4.5. Dynamometry Results of the Study Group and the HIV- Group matched for gender and age

Variable	Dynamometry of HIV + study group (Newtons) (n=45)			Dynamometry of HIV – group (Newtons) (n=12)			Mann-Whitney Tests	
	Range	Mean	SD	Range	Mean	SD	Z- Value	p-value
Elbow flexion	3.0-7.6	4.7	±1.05	5.6-9.6	7.2	±1.1.8	-4.756	<0.001
Wrist extension	2.2-6.2	3.5	±5.78	4.6-8.0	5.9	±1.06	-4.773	<0.001
Hip flexion	3.2-8.2	5.1	±1.12	5.8-10.2	7.8	±1.15	-4.814	<0.001
Hip Extension	3.6-7.0	5.1	±0.81	5.8-8.0	6.7	±0.85	-4.317	<0.001
Knee Flexion	3.2-8.2	5.5	±1.34	5.4-8.8	7.0	±1.00	-3.336	<0.001
Knee Extension	3.4-12.2	6.1	±1.71	6.4-12.0	8.4	±1.59	-3.864	<0.001
Ankle Dorsiflexion	0.2-7.0	4.3	±1.22	5.0-8.2	6.6	±1.08	-4.482	<0.001
Ankle Plantarflexion	2.8-7.8	5.2	±1.13	4.8-9.4	7.5	±1.32	-4.444	<0.001

Statistical testing comparing the dynamometry measurements of the study group and the HIV-group confirmed that the two groups were appropriately age-matched and gender-matched and that the strength measurements of the study group were significantly lower than those of the HIV negative group ($p<0.001$ for all the muscle group tested). The dynamometry and Manual muscle testing results indicated that the study group had poorer muscle strength than a group of HIV negative individuals.

4.1.3. Impairments of Body Structure

Table 4.6. summarises the impairments of body structure of the study cohort. It must be noted that impairments of body structure were assessed using verbal communication, visual observation and medical records. Medical records provided information from doctors' consultations, x-rays and haematology and sputum tests. Magnetic Resonance Imagery scans, Computed Tomography scans, ultrasound scans, Electromyography measurements and microscopic measures were not available for the evaluation of body structure. Some impairments of body structure may have been missed due to the unavailability of certain diagnostic tests.

Table 4.6. Impairments of body Structure (n=45)

Domain	Persons experiencing no impairments	Persons experiencing impairments
	% (n)	% (n)
Structure of the Nervous System	57.8 (26)	42.2 (19)
The eye, ear and related structures	80.0 (36)	20.0 (9)
Structure of the Cardiovascular, immunological & respiratory systems	75.6 (34)	24.4 (11)
Structures related to the digestive, metabolism & endocrine systems	82.2 (38)	17.8 (8)
Structures related to Genitourinary and reproductive system	86.7 (39)	13.3 (6)
Structures related to movement	75.6 (34)	24.4 (11)
Skin & related structures	68.9 (31)	31.1 (14)
Voice and speech functions	100 (45)	0 (0)

The highest prevalence of impairments of body structures included the nervous system (42.2%; n=19), the cardiovascular, immunological and respiratory systems (24.4%; n=11),

structures related to movement (24.4%; n=11) and skin & related structures (31.1%; n=14).

- Within the domain of the nervous system, results revealed that 17.8% (n=8) had structural abnormalities of the brain and 31.1% (n=14) had problems with the spinal cord and peripheral nerves. Common complaints were of headaches and peripheral neuropathies.
- Respiratory problems dominated in the domain of the cardiovascular, immunological and respiratory systems as 24.4% (n=11) complained of structural problems of the respiratory system. TB and recurrent chest infections were commonly reported problems.
- Problems of movement-related structures were reported mostly in the categories of upper extremity (15%; n=7), shoulder region (11.1%; n=5) and lower extremity (11.1%; n=5). Muscle atrophy and weakness were commonly described by participants.

4.1.4. Activity Limitations and Participation Restrictions

Table 4.7. summarises the activity limitations and participation restrictions experienced by the participants at an individual level (Capacity qualifier - without assistance) and with assistance (Performance qualifier)

Table 4.7. Activity Limitations & Participation Restrictions (n=45)

Domain	Persons with Activity Limitations and Participation Restrictions: Performance Qualifier	Persons with Activity Limitations and Participation Restrictions: Capacity Qualifier
	% (n)	% (n)
Learning and applying knowledge	8.9 (4)	26.7 (12)
General tasks and demands	2.2 (1)	37.8 (17)
Mobility	2.2 (1)	40.0 (18)
Self Care	2.2 (1)	2.2 (1)
Domestic Life	0 (0)	6.7 (3)
Interpersonal Interactions & Relationships	4.4 (2)	55.6 (25)

Major Life Areas	26.7 (12)	57.8 (26)
Community, Social and Civic Life	0 (0)	6.7 (3)
Communication	0 (0)	0 (0)

Activity Limitations

Of the components of activity limitations, the most common domains of difficulty at an unassisted level (capacity qualifier) include major life areas, interpersonal interactions & relationships, mobility and general tasks & demands.

Major life areas

Fifty-eight percent (n=26) reported limitations in the domain of major life areas.

Categories where limitations were common include:

- Areas of education where 13.3% (n=6) experienced problems with school education and 28.8% (n=13) had difficulties with higher education. Many of the participants reported difficulties with higher education or experienced difficulty accessing education facilities.
- Remunerative employment where 55.6% (n=25) had problems and economic self-sufficiency where 46.7% (n=21) reported difficulties.

Interpersonal interactions & relationships

Fifty-six percent (n=25) experienced problems in the domain of interpersonal interactions and relationships. Results showed activity limitations in relating to strangers (17.8%; n=8), formal social relationships (17.8%; n=8), family relationships (20.0%; n=9) and intimate relationships (15.6%; n=7).

Mobility

Forty percent (n= 18) of the cohort reported mobility problems, especially in the categories of lifting and carrying (33.3%; n=15) and using transport (13.3%; n=6)

General tasks and demands:

Thirty-eight percent (n=17) of the cohort experienced problems in this domain and all of the complaints included mild difficulty in undertaking multiple tasks without assistance.

Participation Restrictions

There were low levels of participation restrictions (with assistance) for the cohort.

Learning and applying knowledge:

Domains of learning and applying knowledge remained problematic even with assistance where 8.9% (n=4) of the cohort reported difficulties.

Major life areas

Major life areas also remained problematic even with assistance as 26.7% (n=12) of the cohort described issues with major life areas.

- Eighteen percent (n=8) complained of restrictions in the category of remunerative employment at a participatory level.
- Results for economic self sufficiency also remained high at a participatory level where 20% (n=9) of the participant's described problems with regards to financially sustaining themselves and their immediate families.

4.1.5. Environmental and Personal Factors

Table 4.8. provides a summary of the environmental factors affecting the study cohort.

The severity of the impact of facilitators and barriers to function were assessed and recorded as; those with no barriers, those with no facilitators, those with mild to complete barriers and those with mild to complete facilitators.

Table 4.8. Environmental factors (n=45)

Domain	No Barriers	Barriers: mild to complete	No facilitators	Facilitators: mild to complete
	% (n)	% (n)	% (n)	% (n)
Products & technology	48.9 (22)	51.1 (23)	4.4 (2)	95.6 (43)
Natural environment and human made changes to the environment	46.2 (19)	57.8 (26)	68.9 (31)	31.1 (14)
Support & relationships	57.8 (26)	42.2 (19)	0 (0)	100 (45)
Attitudes	46.2 (19)	57.8 (26)	2.2 (1)	97.8 (44)
Services, systems & policies	26.7 (12)	73.3 (33)	4.4 (2)	95.6 (43)

Environmental Barriers

The most prominent barriers to function included services, systems and policies and attitudes.

Services, Systems and Policies

Seventy-three percent (n=33) experienced problems in this domain. The categories representing strong barriers to function included

- Labour and employment (53.3%; n=24) and
- Legal and housing services (both 31.1%; n=14)

Attitudes

Fifty-eight percent (n=26) of the cohort reported that negative attitudes are barriers to function. Categories of attitudes that were found to be greatest barriers to function included:

- Societal attitudes where 40% (n=18) of the cohort felt the attitude of society hinders their function.
- Societal norms, practices and ideologies were found by 28.9% (n=13) of the cohort to be strong barriers to function. There were regular comments by participants regarding negative stigma of HIV positive people which was reported to hamper function.

Environmental Facilitators

The strongest facilitators of function included support & relationships, and attitudes.

Support and Relationships

One hundred percent (n=45) of the cohort reported that support and relationships are facilitators of function. Ninety-six percent (n=43) of the cohort felt that the support and relationships with health- and health-related professionals proved to be strong facilitators of function.

Attitudes

Ninety-eight percent (n=44) of the cohort reported positive attitudes to be strong facilitators of function. Within the domain of attitudes, attitudes of health- and health-related professionals where described by 91.1% (n=41) and 93.3% (n=42) of the cohort as being strong facilitators of function.

Personal Factors

The participants lived in a variety of housing types from single-roomed shacks to three-roomed flats and concrete houses with six rooms. Each house accommodated one to eight individuals, mostly family members and partners. All the participants except two had water and electricity supply to their houses. All the participants (n=45) reported that the shops were easy to access by foot or taxi but many complained of the considerable distance to the HIV clinic and their places of worship which could only be accessed by taxi and bus. All the participants except three had television and radio within their houses.

4.2. Associations between Physical Impairments and Activity Limitations

Bivariate analysis was carried out in order to determine the relationships between the level of ability and key variables (Objective 2.). Cross tabulations were constructed in order to determine associations between components of physical impairment, activity limitations and participation restrictions as well as the influence of environmental factors:

Table 4.9. shows the significant results obtained from cross tabulating variables of physical impairments, activity limitations and participations restrictions as well as environmental factors. Mobility was the only domain of activity limitations and participation restrictions that was found to be significantly associated ($p<0.05$) with domains and categories of physical impairments. Table 4.9. shows all the significant associations between variables of physical impairments with mobility.

Table 4.9. Associations between Variables of Physical Impairments and Mobility

Variable	p-value (Fishers exact)
Sensory functions and pain	<0.05
Pain	<0.01
Neuromusculoskeletal and movement-related functions	<0.01
Muscle power	<0.01
Energy and drive functions	<0.0001

Limitations in mobility were shown to be significantly associated with numerous physical impairments. Problems in the domains of sensory functions and pain, and neuromusculoskeletal and movement related functions were shown to be associated with limitations in mobility.

Further cross tabulations of categories of physical impairments and mobility revealed that problems in the categories of pain (a category of sensory functions and pain), muscle power (a category of neuromusculoskeletal and movement related functions) and energy and drive functions (a category of mental functions) were significantly associated with mobility problems.

4.3. Regression analysis

Multiple logistic regressions were used to determine whether body impairments predict activity and participation limitations. The regressions incorporated adjusting for demographic variables including age, sex, marital status, CD4 count and whether or not the participants were taking ARVs.

A regression analysis was conducted and the domains of body impairments which predicted activity limitations and participation restrictions are shown in Table 4.10.

Table 4.10. Body Impairments shown to Predict Activity Limitations and Participation Restrictions

Predictor (Body impairments)	Activity Limitations, Participation Restrictions & Environmental Factors.	p Value	Odds ratio; 95% Confidence Interval
Sensory functions and Pain	Mobility	0.04	5.50 (1.05-28.87)
	Interpersonal Interactions and Relationships	0.002	14.05 (2.59-76.32)
	Attitudes (barriers)	0.02	4.95 (1.23- 19.97)
Functions of the Digestive, Metabolic and Endocrine systems	Mobility	0.02	4.75 (1.32- 17.11)
	Services, Systems and Policies (barriers)	0.04	6.00 (1.13- 31.74)
Neuromusculoskeletal and movement-related Functions	Learning and applying knowledge	0.04	4.50 (1.07-18.92)
	Mobility	0.007	8.00 (1.76-36.38)
	Interpersonal Interactions and Relationships	0.04	6.00 (1.13-31.73)

Logistic regression indicated that impairments of sensory functions and pain, functions of the digestive, metabolic and endocrine systems as well as neuromusculoskeletal and movement-related functions were the greatest predictors of activity limitations and participation restrictions.

Sensory Functions and Pain

The results indicated that impairments of sensory functions and pain were strong predictors of mobility ($p=0.04$), interpersonal interactions and relationships ($p=0.002$) and attitudes ($p=0.02$). The results indicate that if a participant has sensory dysfunction and/or pain, they are five times more likely to have problems in the areas of mobility and attitudes (barriers) and fourteen times more likely to have problems with interpersonal interactions and relationships than those without sensory dysfunction and pain.

Functions of the Digestive, Metabolic and Endocrine systems

Functions of the digestive, metabolic and endocrine systems strongly predict mobility ($p=0.02$) and services, systems and policies ($p=0.04$). Those with problems of the digestive, metabolic and endocrine systems are five times more likely to have mobility problems and six times more likely to experienced barriers with regards to services, systems and policies.

Neuromusculoskeletal and Movement-related Functions

Neuromusculoskeletal & movement-related functions proved to be strong predictors of learning and applying knowledge ($p=0.04$), mobility (0.007) and interpersonal interactions and relationships ($p=0.04$). Neuromusculoskeletal dysfunction resulted in one being five times more likely to have problems of learning and applying knowledge, eight times more likely to have mobility issues and six times more likely to have a limited capacity for interpersonal interactions and relationships.

After adjusting for variables such as age, sex, marital status, CD4 count and whether or not the participants were taking ARVs, it was evident that both sensory functions and pain as well as a decreased CD4 count ($p=0.03$), are predictors of barriers with regards to attitudes.

Conclusion

Univariate, bivariate and regression analyses showed the presence of the physical impairments, activity limitations and participation restrictions experienced by the study cohort as well as the association between the domains and the predictors of function and disability. The main physical problems included those related to mental functions, pain and the functions of the cardiovascular, haematological and immunological systems.

Weakness was another important physical problem reported by the cohort. Participation restrictions were generally low amongst the cohort whilst the domains: major life areas, interpersonal interactions, mobility and general tasks and demands presented high levels of activity limitations.

Mobility was the only domain found to be associated with physical impairments such as pain, neuromusculoskeletal problems and energy and drive problems. Logistic regressions showed the domains of physical impairments which predicted activity limitations and participation restrictions. Important domains included sensory function and pain, neuromusculoskeletal and movement-related functions, and functions of the digestive, metabolic and endocrine systems. A discussion of these key findings will follow in Chapter Five.

Chapter 5

Discussion

Chapter five will discuss the results obtained from the assessment of 45 HIV positive outpatients and compare them to those recorded in previous studies. This chapter will discuss the profile of the sample with regards to demographic data, activity limitations, participation restrictions and environmental factors and includes limitations of the study.

5.1. Impairments of Body Function

Mental functions

Mental functions proved to be a significant problem for the cohort as 68.9% ($n=31$) which were found to be problematic in the domain. The categories of mental functions function. Other research has found that mental/cognitive health has a profound impact upon PLWHA. Studies indicate that, within the domain of mental health, fatigue, depression and memory problems are of the most common complaints (Rusch et al., 2004; Hwang and Nochajski, 2003; Fields and Selwyn, 2003).

This study showed that aspects of mental impairments are related to limitations in activity as results revealed that energy and drive functions are strongly associated with mobility ($p<0.0001$). Rusch et al., 2004, found that 78.2% ($n=596$) of the cohort studied reported mental impairments (especially chronic fatigue) and that mental impairments are strongly associated with social role restrictions. Similarly, Call et al. (2000) found that vitality (feeling full of pep, having energy, and feeling tired and worn out) was strongly associated with disease state and physical components of health-related quality of life. Cleary et al. (1993) also found that fatigue is strong predictor of limitations in activities of daily living.

This study revealed that 44.4% (n=20) of the participants had emotional impairments. Many of the participants attributed the emotional impairments to pain, coming to terms with the diagnosis, disclosing to loved ones and to dealing with the stigma associated with HIV/AIDS. Hughes et al. (2004) also found that emotional function, with regards to anxiety and depression, was high in an HIV positive experimental group (33.4%; n=42).

Thirty-six percent (n=16) of the cohort described impairments related to sleep. The sleep disturbances were often related to insomnia, light sleep and inability to sleep due to emotional worries. High levels of sleep disturbances among PLWHA has also been described by Cleary et al. (1993), Kohli et al. (2005) and Webb and Norton (2004) as having a negative effect on health-related quality of life.

The research thus indicates that a lack of energy and initiative, emotional impairments and sleep disturbances are common among PLWHA and have adverse effects on a person's health-related quality of life and ability to function at an activity and social level. Worthington et al. (2005) and Hughes et al. (2004) indicate that rehabilitation of the psychological domain, via neuropsychiatric interventions, is imperative within the rehabilitation framework for PLWHA.

Sensory Functions and Pain

Researchers have used many HIV-appropriate health-related quality of life measures to express that sensory and pain issues are prevalent among PLWHA e.g. EuroQol-5D, Medical Outcomes Survey-HIV and Medical Outcomes Survey-Short Form-36. (Ruiz Perez et al., 2005; Braistein et al., 2005; Hughes et al., 2004; Call et al., 2000). Use of the ICF Checklist in this study also showed that sensory issues and pain are common amongst PLWHA.

Seventy-one percent (n=32) of the cohort under examination experienced impairments of sensory function and pain. In particular were impairments in seeing (33.3; n=15) and many complaints of pain (57.8%; n=26). Pain was most often attributed to peripheral neuropathies, especially in the lower limbs.

These results can be compared to those found by Rusch et al. (2004) where 71.9% (n=548) of a cohort of HIV positive British Columbians reported sensory impairments, especially pain where greater than half of the sample experienced pain and those with lower CD4 counts were more inclined to report moderate to severe pain. The results of this study demonstrated that mild and moderate pain was most regularly reported but that no association between pain and CD4 count exists. The difference in pain prevalence cannot be attributed to ARVs as 73.3% of the South African cohort and 64.5% (n=493) of the British Colombian cohort, across all CD4 count ranges, were taking ARVs. The relationship between CD4 count and pain may not be evident in this study, as opposed to the study by Rusch et al. (2004), due to the use of a small sample size.

Similarly, the South African study carried out by Hughes et al. (2004) reported that 69.1% (n=85) of the sample experienced pain and discomfort. Most of the sample reported 'some problems' as opposed to 'severe problems' yet the sample represented those in Stage 3 and 4 of the WHO Clinical Disease Staging System.

The significant association of the domain, sensory function and pain, against mobility ($p < 0.05$) links problems of body function to activity limitations and participation restrictions with regards to mobility. Logistic regression indicated that impairments of sensory functions and pain are strong predictors of mobility issues ($p = 0.04$). A further significant association between pain (a category of sensory function and pain) and mobility demonstrated that the presence of pain in particular can influence a person's mobility.

Other results from logistic regression suggest that impairments of sensory functions and pain are also predictors of problems with regards to interpersonal interactions and relationships ($p = 0.002$) and perceived barriers in the domain of attitudes ($p = 0.02$). These associations indicate that impairments of body functions not only influence activities and participation. This would also include the perceived influence of environmental factors like the attitudes of others. The wide confidence intervals found in the regression analysis may be due to the self-reported nature of the tool as well as the small sample size. The findings of this study are in agreement with studies relating pain to limitations in functional status and health-related quality of life. Hughes et al. (2004) and Webb and Norton (2005)

reported pain, especially pain associated with peripheral neuropathy, to be related to functional ability and thus have a profound bearing on health-related quality of life. Crystal et al. (2000) and Cleary et al. (1993) also found pain to be a significant predictor of physical and role limitations.

Research indicates that pain is a pertinent problem for PLWHA and it has marked unfavourable effects upon the function and health-related quality of life at impairment, activity, participation and contextual levels. Rehabilitation efforts directed at controlling pain, either by pharmacological or non-pharmacological means, may have the potential to adequately relieve PLWHA from pain in order to allow them have improved function (Hughes et al., 2004; Crystal et al., 2000).

Functions of the Cardiovascular, Haematological, Immunological and Respiratory Systems.

Impairments associated with the cardiovascular, haematological, immunological and respiratory systems were experienced by all of the participants of this study as shown in Table 4.2. Haematological impairments were experienced by 95.6% (n=43) where the greatest discrepancies from normal ranges occurred in CD4 count and haemoglobin. Low haemoglobin levels were found in nine of the females and eight of the males and of these individuals, four females and two males experienced problems with muscle power in addition to haemoglobinaemia. Evans and Scadden (2000) and Moylett and Shearer (2002) attribute anaemia to a decrease in erythropoiesis primarily caused by infections and therapeutic agents. Haemoglobinaemia hinders oxygen delivery to muscles, causing fatigue and thus negatively affecting physical performance (Webb and Norton, 2004).

All but one of the participants in this study had CD4 count below the normal range (600-1200 cells/ μ l). Reductions in CD4 count are reported to be due to the direct and indirect effects of HIV-1 on T-lymphocytes; HIV-specific cytotoxins cause T-cell lysis and as a result, there is weakening of the immune system and the onset of opportunistic infections ensues (Mars, 2004; Evans and Scadden, 2000). Many studies have implied that clinical markers are predictors of functionality. Both Ruiz Perez et al. (2005) and Kohli et al. (2005) found that an increase in CD4 count is associated with a better health-related

quality of life. Vidrine et al. (2003) found CD4 count to be a strong predictor of physical-, psychological- and work-related function. These findings were also found by Zonta et al. (2005) and O'Dell et al. (1998) who demonstrated associations between a decrease in CD4 count and disability. No such associations were found in the current study, possibly due to the small sample size and the self-report nature of the ICF, but CD4 count was found to be a predictor of perceived barriers in the domain of attitudes. According to Sierra et al. (2005), the main cause for AIDS-related disability is a decrease in CD4 count and research has also shown that disabilities relate to negative suppressive attitudes and social self-restriction (Inoue, Yamazaki, Seki, Wakabayashi and Kihara, 2004). These factors, as well as a fear of discrimination, may cause people to perceive the attitudes of components of the environment negatively and thus limit functioning.

Respiratory problems were reported by 22.2% (n=10) of the cohort where respiratory complaints where predominantly of chest pain, shortness of breath and recurrent chest infections. These results can be compared to research by Røge, Calbet, Møller, Ullum, Hendel, Gerstoft and Pederson (2002) which indicates that the pulmonary system is a common site for opportunistic infections as well as an HIV-related reduction in diffusion capacity which ultimately reduces the function of the lungs and hence the activity and exercise capacity of the individual.

Impairments in blood pressure (hypertension) were experienced by 41% (n=12) of the females and 18.8% (n=3) of the males in the cohort. The results of blood pressure problems are comparably higher than those reported by the South African Department of Health Study (2004) which reported a prevalence of 21.2% in females and 9.2% in males in the province of Gauteng. The increase in blood pressure amongst the cohort may be attributed to HIV-related cardiac abnormalities and HAART-associated hypercholesterolemia and atherosclerosis (Mars, 2006), however no results were available to confirm this in the study.

All participants in this study experienced impairments in the area of haematological, cardiac, immunological and respiratory problems and such abnormalities hamper the function of the body and can thus affect capacity for simple activities of daily living and

participation in complex role such as employment as 33% (n=15) of the cohort were unemployed for health reasons. Understanding clinical markers and their implications will assist the clinician in drawing a more accurate picture of the patients' present condition and eliminating contra-indications when implementing interventions.

Neuromusculoskeletal and Movement-related Functions

Of the cohort under investigation, 26.7% (n=12) experienced problems relating to the neuromusculoskeletal system and all the complaints lay within the category of muscle power. Results from the ICF Checklist, dynamometry and Manual muscle testing confirmed the high prevalence of mild muscle weakness. Statistical analysis of the dynamometry measurements showed that the HIV positive cohort was weaker than the age- and gender-matched HIV negative population ($p<0.001$). Neuromusculoskeletal aspects and their association with the functioning of PLWHA have been well-documented (Zonta et al., 2005; Vidrine et al., 2003). Similar to this study, Zonta et al. (2005) found muscle strength to be reduced in 52% (n=120) of a cohort examined and described the weakness to be largely related to muscle wasting, disabling neurological involvement, psychomotor slowness and fatigue. The findings are substantiated by the information that HIV-related myopathies and muscle atrophy cause deconditioning and thus decreased physical activity amongst PLWHA (Mars, 2004).

Regression analysis revealed neuromuscular dysfunction to be a strong predictor of activities such as learning and applying knowledge, mobility and interpersonal interactions and relationships. This implies that a person with poor neuromuscular function, usually muscle weakness and endurance, will have a reduced capacity to learn, be sufficiently mobile and interact with others on a social basis. Both O'Dell et al. (1998) and Zonta et al. (2003) emphasise the association between neuromusculoskeletal function, especially reduced muscle strength, and the limitations it places on daily activities, functional capacity and wellbeing.

It is evident that HIV introduces a high prevalence of multiple body impairments, and although they were reported to be mainly mild and moderate, their impact on capacity for daily activities and participation must not be disregarded in assessment and treatment. Knowledge of neuromusculoskeletal problems can also assist when developing exercise

programmes for patients as research shows that aerobic and progressive resisted exercise combinations can benefit PLWHA on a physical and psychological level (Mars, 2006; O'Brien et al., 2004; Scevola et al., 2003).

It must be noted that the assessment of impairments of body function (as well as body structure, activity and participation limitations, and environmental factors) was carried out without information regarding the time since infection or diagnosis, or duration of ARV treatment which may affect the prevalence of impairments. This information was not included in the medical records and ARV regimens were often changed and discontinued and restarted. O'Dell et al. (1998) used a longitudinal study and obtained information on time since infection and medical history. It was also highlighted that HIV presentation occurs in a continuum of overlapping clinical and functional manifestation as opposed to a disease course occurring in distinct stages. Similarly, Zonta et al. (2005) and Ruiz Perez et al. (2005) gathered information on time since HIV/AIDS diagnosis and advocate that longitudinal studies give strength to disability assessments. A recommendation for future studies, with or without the use of the ICF Checklist, may consider obtaining information pertaining to time since diagnosis or initiation of medication with the possible consideration of using a longitudinal study to explore the varied effects of HIV and HAART over time.

5.2. Impairments of Body Structure

The impairments of body functions are strongly related to the problems of body structure reported by the participants; the highest prevalence of impairments of body structures included the nervous system, the cardiovascular, immunological and respiratory systems, structures related to movement and skin & related structures as found in impairments of body function. It is however evident that the rates of impairments in body function greatly exceed the impairments of body structure which may indicate the presence of limitations of function without obvious evidence of structural problems or may reflect that more objective measures are needed to adequately assess structural abnormalities related to HIV and AIDS.

Minimal focus was placed on assessment of structural impairments due to the unavailability of sufficient objective measures. Impairments of body structure were

assessed using verbal communication, visual observation, medical records (including doctors' consultations, x-rays, haematology and sputum tests) and dynamometry. In most cases within this cohort, minimal structural investigations had been carried out at the time of the assessment due to the absence of severe obvious impairments found at follow-up consultations. The structural assessment was carried out with the functional impairments in mind, and this may have guided the evaluation to an extent.

5.3. Activity limitations and participation Restrictions

The most common domains of activity limitations at an unassisted level included learning and applying knowledge, general tasks and demands, mobility, interpersonal interactions & relationships and major life areas.

Major Life Areas

Education was a considerable problem for the cohort as 13.3% (n=6) and 28.8% (n=13) had difficulties with school education and higher education respectively. The subjects were educated in variety of contexts ranging from basic informal primary education to tertiary and university education. Many of the participants reported difficulties with accessing and financing education, either during youth or at present. Reduced access to facilities may not necessarily be related to the difficulties posed by HIV infection itself but may be related to national education concerns as the cohort had a far higher average education (ten years) than national estimates (6.1 years; UNESCO, 2004). There was no association between age and problems with school or higher education although the greatest report of problems in higher education occurred in the older age group of 35 to 39 years (13.3%; n=6). This may be due to this being the largest age group in this cohort or that education was less accessible for this age group during their youth.

Financing was found to be problematic as remunerative employment and economic self-sufficiency were evident problems at an activity level (46.7%; n=21 & 55.6%; n=25) and also at a participation level (17.8%; n=8 & 20%; n=9). Participants often described financial challenges in sustaining themselves and their immediate families with regards to food, housing, education and medication. A discussion by Vidrine et al. (2003) and Twamley et al. (2006) points out that PLWHA have a lower work-related functioning and

overall health-related quality of life than the non-infected population. It was also found that problems in work related functioning to be significantly related to fewer years of education. In this study, employment and economic self sufficiency was not related to years of formal education which may indicate that difficulties may arise due to challenges associated with the disease as well as socioeconomic influences.

Zonta et al. (2005) found a large number of infection-related job resignations (43%; n=52) and 44% of those were due to weakness which prevents job sustainability. Zonta et al. (2005) and O'Dell et al. (1998) found variables related to work to be associated with disability and reduced functional stability. Research implies that challenges in major life areas like remunerative employment, economic self-sufficiency and aspects of education are influenced by HIV-related factors of body impairment, especially muscle power, peripheral neuropathies and fatigue, as well as environmental deficits in education and vocational training (Murray, Sonnenberg, Nelson, Shearer, Bester, Begley and Glynn, 2005; Glenn et al., 2004). There were no significant relationships found between body impairments and major life areas in this study, however it is important to acknowledge that educational and work-related activities require physical and social functioning which implies that the functions of selfcare and mobility be intact (Zonta et al., 2005).

Mobility

Results of the study revealed that mobility is a prime activity affected by many body impairments related to HIV/AIDS. Mobility was found to be strongly associated with impairments in body functions such as sensory dysfunction ($p<0.05$), pain ($p=0.006$), neuromusculoskeletal problems ($p=0.006$), muscle power ($p=0.006$) and energy & drive functions ($p<0.0001$). Further analysis showed sensory functions and pain, functions of the digestive, metabolic and endocrine systems and neuromusculoskeletal functions to be predictors of mobility highlighting the fact that body impairments have significant effects on activities like mobility, which are prerequisites to participation in simple and complex roles within the normal environment.

These findings are supported by similar studies which report mobility, as part of physical functioning and health-related quality of life, to be an important problem amongst PLWHA

(Hughes et al., 2004; Webb and Norton, 2004). As mobility is an important part of physical function, it may impact upon aspects of participation in other activities such as self care, domestic life and access to services. Selfcare and domestic tasks were not demonstrated to be important areas of dysfunction in this study and they were not significantly affected by any areas of body impairments as implied by Zonta et al. (2005), O'Dell et al. (1998) and Rusch et al. (2004). Findings in this study may differ as the cohort attended the clinic for follow-up appointments at an outpatient basis and generally led fairly independent lives at a participatory level, requiring and receiving assistance from family members. Research highlights the fluctuating nature of HIV as it is accompanied by a variety of health- and functional manifestations at any stage of the disease. The multi-systemic manifestations influence an individual's capacity for independent function and need for assistance and must be assessed and addressed accordingly (Worthington, 2005; Rusch et al., 2004; Webb and Norton, 2004).

Interpersonal Interactions and Relationships

Issues with interpersonal interactions and relationships were experienced by a large percentage of the cohort (55.6%; n=25). Logistical regression showed that problems in this area may be predicted by sensory dysfunction and pain ($p=0.002$) as well as neuromusculoskeletal dysfunction ($p=0.04$). It is understandable that a person with pain and weakness, for example, may find carrying out meaningful social relationships, especially those that are formal and family-related, challenging. Although this study did not demonstrate any significant associations between mental impairments and activity and participation problems, research has demonstrated the combined effects that physical impairments, pain and psychological conditions have on social functioning and health-related quality of life (Kohli et al., 2005; Webb and Norton, 2004). Crystal et al. (2000) also found that pain and fatigue, as well as symptom intensity, are associated with role- and social limitations. Studies thus suggest that there is a need for psychosocial interventions as well as physical rehabilitation (Kohli et al., 2005; Hughes et al., 2004).

Many tools assess social functioning as an important aspect of function and health-related quality of life for PLWHA e.g. Medical Outcomes Survey-HIV, the Functional Assessment of HIV Infection and the HIV Cost and Services Utilization Study health-related quality of

life measure (Webb and Norton, 2004). Results from this study, using the ICF Checklist, and those from studies by Rusch et al. (2004) and Crystal et al. (2000), show that impairments and activity limitations are significantly associated with social role restrictions and that management of body impairments has the potential to improve physical- and thus social functioning.

General Tasks and Demands

A large percentage of the cohort experienced difficulties in this domain and, in particular, 37.8% (n=17) had mild difficulties in the category of carrying out multiple tasks without assistance. Of the seventeen participants who had problems undertaking multiple tasks, eight of those also experienced impairments in the area of energy and drive. Crystal et al. (2000) also found multiple tasks to be an issue especially those of a complex, energy-demanding nature. Inability to carry out multiple tasks on a daily basis may hamper role-functioning such as work, school, domestic and social roles. It is suggested that the difficulty in carrying out multiple or complex tasks may be related to associated mobility and energy deficits. Research has also proposed that interventions, for example exercise and dietary supplementation, have the potential to improve mobility and endurance which will assist in carrying out multiple, energy-demanding tasks (Mars, 2004; Sccevola et al., 2003). Although difficulty with multi-tasking for this cohort was not associated with mental functions, some research has found that mental functioning is related to social role restrictions which can include ability to carry out multiple tasks. The rehabilitation worker must take mental factors into account when assisting with role-functioning and task completion (Rusch et al., 2004).

Participation Restrictions

Participation restrictions were low amongst this cohort. The most striking domain which remained a problem, despite some assistance, was major life areas. Remunerative employment and economic self-sufficiency remained problematic as 17.8% (n=8) and 20% (n=9) experienced problems in these areas respectively which may emphasise the effect that socioeconomic factors and the compound influence of HIV have on PLWHA. Rusch et al. (2004) showed that poor participation in important daily roles is associated with increasing number of impairments. The low levels of participation restrictions (with

assistance) in this outpatient cohort may be attributed to sound social and familial support structures available. The potential benefits of efficient vocational and financial services, along with physical and psychosocial rehabilitation, should be considered when designing intervention protocols for PLWHA.

5.4. Environmental and Contextual Factors

Research has shown that assessment of PLWHA should include socioeconomic and sociodemographic information because environmental and contextual factors influence limitations at body, activity and participation levels (Olley et al., 2004; Vidrine et al., 2003; Hwang and Nochajski, 2003 and O'Dell et al., 1998). The cohort in this study revealed a variety of barriers and facilitators to function:

The most common barriers to function include problems with services, systems and policies and perceived negative attitudes. Dysfunctions of the digestive, metabolic and endocrine systems were shown to be predictors of barriers with regards to services, systems and policies ($p=0.04$) This result may indicate that those with problems of the digestive, metabolic and endocrine systems are unsatisfied with housing and health services as aspects like poor water supply, sanitation, nutrition and medical resources have been shown to cause digestive, metabolic and endocrine problems which hinder healthy functioning (Thorn and Forrest, 2006). Research thus indicates that societal conditions can create health disparities and that social policies have a critical role to play in HIV care (Poundstone, Strathdee and Celentano, 2004).

Among this cohort, employment and labour services proved once again to be a problem as implied in the section on major life areas (5.3.) which further demonstrates that environmental factors can impact upon impairments, activity limitations and participation restrictions. Bratstein et al. (2005) reported that health-related quality of life is strongly associated to socioeconomic issues and suggested a need for non-biological interventions like occupational and monetary counselling and assistance.

The diagnosis of HIV is a stressful life event which may evoke negative psychological and behavioural changes such as depression and anxiety (Murray et al., 2005; Olley et al., 2004). Logistic regression revealed that the perception of negative attitudes is predicted

by sensory dysfunction and pain ($p=0.04$). This result suggests that those with pain and/or sensory problems are likely to perceive the attitudes of the entities within the environment to be negative and thus impair optimal function. Research also shows that impairments like pain are related to depression which, in addition to stigma, may lead to the perception of environmental negativity (Olley et al., 2004). Given these problems, a clinician must understand networks within the community in order to refer patients appropriately.

Strong facilitators of function included support and relationships and perceived positive attitudes. All the participants ($n=45$) reported that positive family support and relationships are important facilitators of function and 97.8% ($n=44$) reported positive attitudes to be facilitatory. In the categories of participation, especially general tasks and demands, mobility, selfcare, domestic life and community, social and civic life, there were minimal problems experienced and this may be due to the facilitatory influence of positive attitudes and support as well as good relationships with those who assist with the functioning of those living with HIV/AIDS. Rusch et al. (2004) and Kohli et al. (2005) relate psychosocial function to activity level, which indicates that if PLWHA experience positive attitudes and receive support from their surrounding environment, they may cope better with daily activities and fulfilment of roles. Positive attitudes were strong facilitators of function for the cohort, especially attitudes from family, friends, personal care providers and healthcare professionals. Ruiz Perez et al. (2005) and Chou and Holzhemer (2004) found that better physical and mental health, and health-related quality of life was influenced by the acquisition social support, as well as the other psychological and environmental factors, thus by addressing such influential factors, we may hope to enhance the health-related quality of life of PLWHA.

5.5. Participant Profile

Gender

According to the HSRC (2005), of those infected with HIV, 61.9% are female and 38.1% are male. Females and males were represented similarly in this study (64.6% female: 35.6% male).

Age

The highest prevalence of HIV in South Africa occurs in those between 20 and 39 years of age (SANHS, 2005). The age range of the cohort (21-49 years) is comparable to that reported by the national survey. The pattern of age-related HIV prevalence among the cohort is similar to national statistics where infection rate (according to age) increases from 20 years with a steady rise between 25 and 35 years of age, then decreases from 35 years onwards. However, this cohort is different as the highest numbers of PLWHA were in the 35-39 year age range. This may be attributed to the fact that a large proportion of the cohort were taking ARVs and are thus living longer lives as research shows that ARVs are associated with a reduction in morbidity and mortality (Palella et al., 1998).

Occupation

An analysis of the cohort showed that 19 participants (42.4%) were employed or studying and 26 (57.7%) were unemployed (for health- or other reasons). These results are much higher than the statistics provided by the Statistics South Africa Labour Force Survey (2005) which reported the unemployment rate in Gauteng to be 22.8% in 2005. The levels of unemployment among this cohort may relate to the educational and socioeconomic status as well as the associated health-related limitations caused by HIV.

Years of Formal Education

The average number of years of formal education for the cohort was ten years. This was surprisingly high considering that South African education statistics show that the average years of schooling among adults is 6.1 years (UNESCO, 2004). The subjects were educated in variety of contexts from basic primary education to colleges and tertiary education. The higher level of education could be due to this population possibly having been educated in an urban and more developed area of Gauteng where education is more accessible than in rural areas (Department of Education, 2005; Nelson Mandela foundation, 2005). In addition, those rural people who are fortunate to be educated may move to urban areas for financial and employment reasons. Clinicians must take factors such as gender, age, occupation and education into consideration when assessing and addressing problems faced by PLWHA in order to maximise their health-related quality of life through appropriate interventions and referrals.

ARVs

A large percentage (73.3%; n=33) of the cohort was receiving ARVs at the time of the assessments. According to the AIDS Foundation South Africa (2005), 29000 people are taking ARVs throughout the country which is less than 5% of South Africa's HIV/AIDS prevalence of 6.29 million (South African Department of Health Study, 2004). The large percentage of the cohort receiving ARVs may be due to their attendance at the Themba Lethu Clinic at Helen Joseph hospital which is the flagship of National ARV rollout sites (Centre for HIV/ AIDS Networking, 2006). Many of those who were not taking ARVs were being trained and counselled to start treatment, others did not qualify for ARV treatment as their CD4 counts exceeded 200 cells/ μ l (national guidelines), and some did not wish to start treatment due to fears of side effects. Clinicians must take note of patients' ARV-history as research shows that ARVs have a profound impact on improvement of morbidity, mortality and health-related quality of life for PLWHA (Powers et al., 2006; Idigbe et al., 2005; Pallela et al., 1998)

CD4 Count

The CD4 counts of the cohort ranged from 5-628cells/ μ l (SD = 158.1). All ranges of the CD4+ T-lymphocyte classification were represented by the cohort but none of those with a CD4 count below 200cells/ μ l could be classified as having the presence of a major complication such as an opportunistic infection or malignancy as indicated by the late stage CDC HIV Infection Classification. Only three (6.7%) participants had CD4 counts above 500 cells/ μ l yet the entire cohort was ambulatory and fairly independent with mild to moderate limitations with regards to body function, activity and participation. These results may indicate that CD4 count may not be a predictor of activity level for this cohort whereas other studies found CD4 counts to be a predictor of function. (Kohli et al., 2005; Zonta et al., 2005; Vidine et al., 2003; Call et al., 2000).

5.6. Limitations of the study

The results of this study are of value as they identify important areas of physical impairments, activity limitations and participation restriction in a South African cohort. They also indicate the need for holistic assessment and management of level of activity in order

to positively affect the health-related quality of life of PLWHA. However, the limitations of the study are:

- I. Small Sample size: Although the researcher took guidance from similar studies, a larger sample size could be considered in the future however this the research report had limited funding and sought to build an initial profile of an out patient cohort.
- II. Lack of availability of adequate objective measures and information for assessment of body structure e.g. X-rays, magnetic resonance imagery scans, computed tomography, ultrasound scans, electromyography measurements and microscopic measures.
- III. Lack of information regarding the time since infection or diagnosis, or duration of ARV treatment.

5.7. Recommendations for Further Research

- The use of a larger sample size in future studies may strengthen the results obtained in this study. Larger studies would be needed to be more representative of the HIV population.
- Information regarding the time since HIV/AIDS diagnosis and initiation of ARVs/HAART can be useful if available. Such information can assist in further classifying function in relation to these factors.
- Controversy exists with regards to whether CD4 count is a good predictor of function or not. A larger sample would be useful to assess the functional situation, in a South African population, according to CD4 ranges. Future research should stratify the sample according to those on ARVs or not or according to CD4 count ranges to gain a deeper understanding into the function and disabilities of these categories of the HIV/AIDS population.
- The sensitivity of the outcome measures of the ICF Checklist could be strengthened by using other validated outcome measures of function such as the functional independence measure and Barthel Index and the Rankin Scale to assist in scoring the categories of the ICF Checklist (Zonta et al., 2003; Sulter, Steen & De Keyser, 1999; O'Dell et al., 1991).

- This study looked at an urban population of different socioeconomic circumstances. To be truly representative of a South African population, research should be conducted in a rural and a well-resourced area.

5.8. Conclusion

It is evident from this discussion that body impairments, activity limitations and participation restrictions are clearly affected in PLWHA and that level of ability is influenced by environmental factors. This study along with similar studies (O'Dell et al., 1998; Cleary et al., 1993) emphasises the need to assess discrete and diffuse measures of functioning due to the broad impact of the disease. A detailed picture of the factors which influence the level of ability of PLWHA is imperative to appropriately guide the formation and initiation of interventions which aim to enhance the overall health-related quality of life of the HIV positive individuals.

Chapter 6

Conclusion and Recommendations

The purpose of this study was to develop a profile of the level of ability of the outpatient cohort using the ICF Checklist as an assessment tool.

The results of this study demonstrated a high prevalence of mild to moderate physical impairments, activity limitations and participation restrictions of an HIV positive outpatient cohort. Body impairments that were found to be of importance included mental functions, sensory functions and pain, functions relating to the cardiovascular, haematological, immunological and respiratory systems as well as neuromusculoskeletal functions. Activity limitations of importance to PLWHA include general tasks and demands, mobility, interpersonal interactions and relationships and major life areas. The statistical analysis showed that impairments of body functions are strongly associated with activity limitations as indicated by the literature. Sensory dysfunction and pain as well as neuromusculoskeletal impairments were found to be associated with problems with mobility. Major life areas like remunerative employment and economic self-sufficiency remained problematic, even at a participatory level, which may indicate that environmental and sociodemographic variables have important influence upon activity limitations and participation restrictions. Regression analysis showed that impairments of sensory functions and pain, functions of the digestive, metabolic and endocrine systems as well as neuromusculoskeletal problems were the greatest predictors of activity limitations and participation restrictions.

The results revealed that aspects of the environment have both facilitatory and impeding influences on this cohort. The most common barriers to function included problems with services, systems and policies and perceived negative attitudes. Strong facilitators of function included support and relationships and perceived positive attitudes. This study supports research that indicates that contextual and environmental factors influence function at a body, activity and social level.

The results of this study are of use as they identify chief areas of physical impairments, activity limitations and participation restrictions in a South African HIV positive outpatient cohort. Impairments of body function and the impact of the compound burden of disease manifestations have a robust influence on activity limitations and participation restrictions. The results emphasise the need for awareness and holistic assessment of problems and impending disabilities in order to inform the appropriate management which embraces prevention, primary care and rehabilitation of PLWHA. Such proactive interventions may prevent physical and functional shortcomings and enhance health-related quality of life.

With the information gathered from this study as well as from future larger studies, research may be guided to explore more aspects of assessment that are important in the lives of people living with HIV and AIDS in South Africa. This study may also assist future research exploring appropriate and beneficial interdisciplinary rehabilitation interventions which improve function for PLWHA. This would contribute to an informed response to the continuum of prevention, treatment and care promoted as an umbrella approach to the management of PLWHA by UNAIDS.

Recommendations from the study:

- It is recommended that, in the assessment of PLWHA, rehabilitation workers should include the assessment of mental functions, sensory functions such as pain and sight, respiratory functions as well as neuromusculoskeletal functions such as muscle strength.
- In line with holistic functional assessment, therapists involved in the management of PLWHA should take cognisance of areas such as mobility, interpersonal interactions and financial remuneration. In addition, assessment of activity limitations and participation restrictions should be focused at an individual level.
- In working with PLWHA, rehabilitation professionals should aim to deal with impairments, activity limitations and participation restrictions and should pay particular attention to the associated environmental and contextual factors such as employment and socioeconomic status.
- Adequate understanding and assessment of the full health experience will help to strengthen the interdisciplinary referral system within the medical field as well as within social, labour, education, water and sanitation, and developmental sectors.

- Health professionals must assess patients from an impairment, activity, participation and contextual point of view in order to move from a medical and rehabilitation model to a biopsychosocial model of care.

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Appendices

Appendix 1 – The International Classification of Function Checklist

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ICF CHECKLIST

Version 2.1a, Clinician Form

for International Classification of Functioning, Disability and Health (ICF)

This is a checklist of major categories of the International Classification of Functioning, Disability and Health (ICF) of the World Health Organization. The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarized for case records (for example, in clinical practice or social work). The checklist should be used along with the ICF or ICF Pocket version.

H 1. When completing this checklist, use all information available. Please check those used:

[1] written records [2] primary respondent [3] other informants [4] direct observation

If medical and diagnostic information is not available it is suggested to complete

appendix 1: Brief Health Information (p 9-10) which can be completed by the respondent.

H 2. Date ____/____/____ H 3. Case ID ____ H 4. Participant No. ____

Day Month Year CE or CS Case No. 1a or 2a Exclin FTC Site Participant

A. DEMOGRAPHIC INFORMATION

A.1 NAME (optional) First _____ FAMILY _____

A.2 SEX (1) ☐ Female (2) ☐ Male

A.3 DATE OF BIRTH ____/____/____ (date/month/year)

A.4 ADDRESS (optional)

A.5 YEARS OF FORMAL EDUCATION ____

A.6 CURRENT MARITAL STATUS: (Check only one that is most applicable)

- (1) Never married ☐ (4) Divorced ☐
- (2) Currently Married ☐ (5) Widowed ☐
- (3) Separated ☐ (6) Cohabiting ☐

A.7 CURRENT OCCUPATION (Select the single best option)

- (1) Paid employment ☐ (6) Retired ☐
- (2) Self-employed ☐ (7) Unemployed (health reason) ☐
- (3) Non-paid work, such as volunteer/charity ☐ (8) Unemployed (other reason) ☐
- (4) Student ☐ (9) Other ☐
- (5) Keeping house/House-maker ☐ (please specify) _____

A.8 MEDICAL DIAGNOSIS of existing Main Health Conditions, if possible give ICD Codes.

1. No Medical Condition exists

2. ICD code: ____

3. ICD code: ____

4. ICD code: ____

5. A Health Condition (disease, disorder, injury) exists, however its nature or diagnosis is not known

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PART 1a: IMPAIRMENTS of BODY FUNCTIONS

Body functions are the physiological functions of body systems (including psychological functions).

Impairments are problems in body function as a significant deviation or loss.

Qualifier: 0 No impairment, 1 Mild impairment, 2 Moderate impairment

Extent of impairments 3 Severe impairment, 4 Complete impairment, 8 Not specified

9 Not applicable

<i>Short List of Body Functions</i>	<i>Qualifier</i>
b1. MENTAL FUNCTIONS	
b110 Consciousness	
b114 Orientation (<i>time, place, person</i>)	
b117 Intellectual (<i>incl. Retardation, dementia</i>)	
b130 Energy and drive functions	
b134 Sleep	
b140 Attention	
b144 Memory	
b152 Emotional functions	
b156 Perceptual functions	
b164 Higher level cognitive functions	
b167 Language	
b2. SENSORY FUNCTIONS AND PAIN	
b210 Seeing	
b230 Hearing	
b235 Vestibular (<i>incl. Balance functions</i>)	
b280 Pain	
b3. VOICE AND SPEECH FUNCTIONS	
b310 Voice	
b4. FUNCTIONS OF THE CARDIOVASCULAR, HAEMATOLOGICAL, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS	
b410 Heart	
b420 Blood pressure	
b430 Haematological (<i>blood</i>)	
b435 Immunological (<i>allergies, hypersensitivity</i>)	
b440 Respiration (<i>breathing</i>)	
b5. FUNCTIONS OF THE DIGESTIVE, METABOLIC AND ENDOCRINE SYSTEMS	
b515 Digestive	
b525 Defecation	
b530 Weight maintenance	
b555 Endocrine glands (<i>hormonal changes</i>)	
b6. GENITOURINARY AND REPRODUCTIVE FUNCTIONS	
b620 Urination functions	
b640 Sexual functions	
b7. NEUROMUSCULOSKELETAL AND MOVEMENT RELATED FUNCTIONS	
b710 Mobility of joint	
b730 Muscle power	
b735 Muscle tone	
b765 Involuntary movements	
b8. FUNCTIONS OF THE SKIN AND RELATED STRUCTURES	
ANY OTHER BODY FUNCTIONS	
ICF Checklist © World Health Organization, September 2001. Page 3	

Part 1 b: IMPAIRMENTS of BODY STRUCTURES

Body structures are anatomical parts of the body such as organs, limbs and their components.

Impairments are problems in structure as a significant deviation or loss.

First Qualifier: <i>Extent of impairment</i>	Second Qualifier: <i>Nature of the change</i>	Third Qualifier (suggested): <i>Location</i>
0 No impairment 1 Mild impairment 2 Moderate impairment 3 Severe impairment 4 Complete impairment 8 Not specified 9 Not applicable	0 No change in structure 1 Total absence 2 Partial absence 3 Additional part 4 Aberrant dimensions 5 Discontinuity 6 Deviating position 7 Qualitative changes in structure, including accumulation of fluid 8 Not specified 9 Not applicable	0 More than one region 1 right 2 left 3 both sides 4 front 5 back 6 proximal 7 distal

<i>Short List of Body Structures</i>	First Qualifier: <i>Extent of impairment</i>	Second Qualifier: <i>Nature of the change</i>	Third Qualifier: <i>Location</i>
s1. STRUCTURE OF THE NERVOUS SYSTEM			
s110 Brain			
s120 Spinal cord and peripheral nerves			
s2. THE EYE, EAR AND RELATED STRUCTURES			
s3. STRUCTURES INVOLVED IN VOICE AND SPEECH			
s4. STRUCTURE OF THE CARDIOVASCULAR, IMMUNOLOGICAL AND RESPIRATORY SYSTEMS			
s410 Cardiovascular system			
s430 Respiratory system			
s5. STRUCTURES RELATED TO THE DIGESTIVE, METABOLISM AND ENDOCRINE SYSTEMS			
s6. STRUCTURE RELATED TO GENITOURINARY AND REPRODUCTIVE SYSTEM			
s610 Urinary system			
s630 Reproductive system			
s7. STRUCTURE RELATED TO MOVEMENT			
s710 Head and neck region			
s720 Shoulder region			
s730 Upper extremity (arm, hand)			
s740 Pelvis			
s750 Lower extremity (leg, foot)			
s760 Trunk			
s8. SKIN AND RELATED STRUCTURES			
ANY OTHER BODY STRUCTURES			

PART 2: ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTION

Activity is the execution of a task or action by an individual. Participation is involvement in a life situation.

Activity limitations are difficulties an individual may have in executing activities. Participation restrictions are problems an individual may have in involvement in life situations.

The Performance qualifier describes what an individual does in his or her current environment. Because the current environment brings in the societal context, performance can also be understood as "involvement in a life situation" or "the lived experience" of people in the actual context in which they live. This context includes the Environmental Factors. The Capacity qualifier describes an individual's ability to execute a task or an action. This construct indicates the highest probable level of functioning that a person may reach in a given domain at a given moment. To assess the full ability of the individual, one would need to have a "standardized" environment to neutralize the varying impact of different environments on the ability of the individual. As standardized environment may be: (a) an actual environment commonly used for capacity assessment in test settings; or (b) where this is not possible, a hypothetical environment a uniform impact.

Note: Use Appendix 2 if needed to elicit information on the Activities and Participation of the individual

First Qualifier: Performance extent of participation restriction	Second Qualifier: Capacity (without assistance) Extent of Activity limitation
0 No difficulty 1 Mild difficulty 2 Moderate difficulty 3 Severe difficulty 4 Complete difficulty 8 Not specified 9 Not applicable	0 No difficulty 1 Mild difficulty 2 Moderate difficulty 3 Severe difficulty 4 Complete difficulty 8 Not specified 9 Not applicable

Short List of A&P domains

	Performance Qualifier	Capacity Qualifier
d1. LEARNING AND APPLYING KNOWLEDGE		
d110 Watching		
d115 Listening		
d140 Learning to read		
d145 Learning to write		
d150 Learning to calculate (arithmetic)		
d175 Solving problems		
d2. GENERAL TASKS AND DEMANDS		
d210 Undertaking a single task		
d220 Undertaking multiple tasks		
d3. COMMUNICATION		
d310 Communicating with -- receiving -- spoken messages		
d315 Communicating with -- receiving -- non-verbal messages		
d330 Speaking		
d335 Producing non-verbal messages		
d350 Conversation		

Short List of A&P domains

d4. MOBILITY	Performance qualifier	Capacity qualifier
d430 Lifting and carrying objects		
d440 Fine hand use (<i>picking up, grasping</i>)		
d450 Walking		
d465 Moving around using equipment (<i>wheelchair, skates, etc.</i>)		
d470 Using transportation (<i>car, bus, train, plane, etc.</i>)		
d475 Driving (<i>riding bicycle and motorcycle, driving car, etc.</i>)		
d5. SELF CARE		
d510 Washing oneself (<i>bathing, drying, washing hands, etc.</i>)		
d520 Caring for body parts (<i>brushing teeth, shaving, grooming, etc.</i>)		
d530 Toileting		
d540 Dressing		
d550 Eating		
d560 Drinking		
d570 Looking after one's health		
d6. DOMESTIC LIFE		
d620 Acquisition of goods and services (<i>shopping, etc.</i>)		
d630 Preparation of meals (<i>cooking, etc.</i>)		
d640 Doing housework (<i>cleaning house, washing dishes laundry, ironing, etc.</i>)		
d660 Assisting others		
d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS		
d710 Basic interpersonal interactions		
d720 Complex interpersonal interactions		
d730 Relating with strangers		
d740 Formal relationships		
d750 Informal social relationships		
d760 Family relationships		
d770 Intimate relationships		
d8. MAJOR LIFE AREAS		
d810 Informal education		
d820 School education		
d830 Higher education		
d850 Remunerative employment		
d860 Basic economic transactions		
d870 Economic self-sufficiency		
d9. COMMUNITY, SOCIAL AND CIVIC LIFE		
d910 Community Life		
d920 Recreation and leisure		
d930 Religion and spirituality		
d940 Human rights		
d950 Political life and citizenship		

ANY OTHER ACTIVITY AND PARTICIPATION

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PART 3: ENVIRONMENTAL FACTORS

Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives.

Qualifier in environment: 0 No barriers 0 No facilitator

Barriers or facilitator 1 Mild barriers +1 Mild facilitator

2 Moderate barriers +2 Moderate facilitator

3 Severe barriers +3 Substantial facilitator

4 Complete barriers +4 Complete facilitator

Short List of Environment

Qualifier

barrier or facilitator

e1. PRODUCTS AND TECHNOLOGY	
e110 For personal consumption (<i>food, medicines</i>)	
e115 For personal use in daily living	
e120 For personal indoor and outdoor mobility and transportation	
e125 Products for communication	
e150 Design, construction and building products and technology of buildings for public use	
e155 Design, construction and building products and technology of buildings for private use	
e2. NATURAL ENVIRONMENT AND HUMAN MADE CHANGES TO ENVIRONMENT	
e225 Climate	
e240 Light	
e250 Sound	
e3. SUPPORT AND RELATIONSHIPS	
e310 Immediate family	
e320 Friends	
e325 Acquaintances, peers, colleagues, neighbours and community members	
e330 People in position of authority	
e340 Personal care providers and personal assistants	
e355 Health professionals	
e360 Health related professionals	
e4. ATTITUDES	
e410 Individual attitudes of immediate family members	
e420 Individual attitudes of friends	
e440 Individual attitudes of personal care providers and personal assistants	
e450 Individual attitudes of health professionals	
e455 Individual attitudes of health related professionals	
e460 Societal attitudes	
e465 Social norms, practices and ideologies	
E5. SERVICES, SYSTEMS AND POLICIES	
e525 Housing services, systems and policies	
e535 Communication services, systems and policies	
e540 Transportation services, systems and policies	
e550 Legal services, systems and policies	
e570 Social security, services, systems and policies	
e575 General social support services, systems and policies	
e580 Health services, systems and policies	
e585 Education and training services, systems and policies	
e590 Labour and employment services, systems and policies	
ANY OTHER ENVIRONMENTAL FACTORS	

Part 4: OTHER CONTEXTUAL INFORMATION

4.1 Give a thumbnail sketch of the individual and any other relevant information.

4.2 Include any *Personal Factors* as they impact on functioning (e.g. lifestyle, habits, social background, education, life events, race/ethnicity, sexual orientation and assets of the individual).

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Appendix 1:

BRIEF HEALTH INFORMATION

☐ Self Report ☐ Clinician Administered

X.1 Height : / / cm (or inches)

X.2 Weight: / / kg (or pounds)

X.3 Dominant Hand (prior to health condition): Left ☐ Right ☐ Both hands equally ☐

X.4 How do you rate your physical health in the past month?

Very good ☐ Good ☐ Moderate ☐ Bad ☐ Very bad ☐

X.5 How do you rate your mental and emotional health in the past month?

Very good ☐ Good ☐ Moderate ☐ Bad ☐ Very bad ☐

X.6 Do you currently have any disease(s) or disorder(s) ?

☐ NO ☐ YES

If YES, please specify: _____

X.7 Did you ever have any significant injuries that had an impact on your level of functioning?

☐ NO ☐ YES

If YES, please specify: _____

X.8 Have you been hospitalized in the last year?

☐ NO ☐ YES

If YES, please specify reason(s) and for how long?

1. _____ days

2. _____ days

3. _____ days

X.9 Are you taking any medication (either prescribed or over the counter)?

☐ NO ☐ YES

If YES, please specify major medications

1. _____

2. _____

3. _____

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X.10 Do you smoke?

☐ NO ☐ YES

X.11 Do you consume alcohol or drugs?

☐ NO ☐ YES

If YES, please specify average daily quantity

Tobacco: _____

Alcohol: _____

Drugs: _____

X.12 Do you use any assistive device such as glasses, hearing aid, wheelchair, etc.?

☐ NO ☐ YES

If YES, please specify

X.13 Do you have any person assisting you with your self care, shopping or other daily activities?

☐ NO ☐ YES

If YES, please specify person and assistance they provide

X.14 Are you receiving any kind of treatment for your health?

☐ NO ☐ YES

If YES, please specify: _____

X.15 Additional significant information on your past and present health:

X.16 IN THE PAST MONTH, have you cut back (i.e. reduced) your usual activities or work because of your *health condition?* (a disease, injury, emotional reasons or alcohol or drug use)
☐ NO ☐ YES If yes, how many days? _____

X.17 IN THE PAST MONTH, have you been totally unable to carry out your usual activities or work because of your *health condition?* (a disease, injury, emotional reasons or alcohol or drug use)
☐ NO ☐ YES If yes, how many days? _____

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Appendix 2:

GENERAL QUESTIONS FOR PARTICIPATION & ACTIVITIES

The following probes are proposed as a guide to help the examiner when interviewing the respondent about problems in functioning and life activities, in terms of the distinction between capacity and performance. Take into account all personal information known about the respondent and ask any additional probes as necessary. Probes should be rephrased as opened questions if necessary to elicit greater information.

Under each domain there are two kinds of probes:

The first probe tries to get the respondent to focus on his or her capacity to do a task or action, and in particular to focus on limitations in capacity that are inherent or intrinsic features of the person themselves. These limitations should be direct manifestations of the respondent's health state, without the assistance. By assistance we mean the help of another person, or assistance provided by an adapted or specially designed tool or vehicle, or any form of environmental modification to a room, home, workplace and so on. The level of capacity should be judged relative to that normally expected of the person, or the person's capacity before they acquired their health condition.

The second probe focuses on the respondent's actual performance of a task or action in the person's actual situation or surroundings, and elicits information about the effects of environmental barriers or facilitators. It is important to emphasize that you are only interested in the extent of difficulty the respondent has in doing things, assuming that they want to do them. Not doing something is irrelevant if the person chooses not to do it.

I. Mobility

(Capacity)

(1) In your present state of health, how much difficulty do you have walking long distances (such as a kilometer or more) without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?")
(Performance)

(1) In your present surroundings, how much of a problem do you actually have in walking long distances (such as a kilometer or more)?

(2) Is this problem walking made worse, or better, by your actual surroundings?

(3) Is your capacity to walk long distances without assistance more or less than what you actually do in your present surroundings?

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II. Self Care

(Capacity)

(1) In your present state of health, how much difficulty do you have washing yourself, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?")
(Performance)

- (1) In your own home, how much of a problem do you actually have washing yourself?
- (2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?
- (3) Is your capacity to wash yourself without assistance more or less than what you actually do in your present surroundings?

III. Domestic Life

(Capacity)

- (1) In your present state of health, how much difficulty do you have cleaning the floor of your where you live, without assistance?
- (2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?")
(Performance)

- (1) In your own home, how much of a problem do you actually have cleaning the floor?
- (2) Is this problem made worse, or better, by the way your home is set up or the specially adapted tools you use?
- (3) Is your capacity to clean your floor without assistance more or less than what you actually do in your present surroundings?

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IV. Interpersonal Interactions

(Capacity)

- (1) In your present state of health, how much difficulty do you have making new friends, without assistance?
- (2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?")
(Performance)

- (1) In your present situation, how much of a problem do you actually have making friends?
- (2) Is this problem making friends made worse, or better, by anything (or anyone) in your surroundings?

- (3) Is your capacity to make friends, without assistance, more or less than what you actually do in your present surroundings?

V. Major Life Areas

(Capacity)

- (1) In your present state of health, how much difficulty do you have getting done all the work you need to do for your job, without assistance?
- (2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?")
(Performance)

- (1) In your present surroundings, how much of a problem do you actually have getting done all the work you need to do for your job?
- (2) Is this problem fulfilling your job requirements made worse, or better, by the way the work environment is set up or the specially adapted tools you use?
- (3) Is your capacity to do your job, without assistance, more or less than what you actually do in your present surroundings?

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VI. Community, Social and Civic Life

(Capacity)

(1) In your present state of health, how much difficulty do you have participating in community gatherings, festivals or other local events, without assistance?

(2) How does this compare with someone, just like yourself only without your health condition?

(Or: "...than you had before you developed your health problem or had the accident?") (Performance)

(1) In your community, how much of a problem do you actually have participating in community gatherings, festivals or other local events?

(2) Is this problem made worse, or better, by the way your community is arranged or the specially adapted tools, vehicles or whatever you use?

(3) Is your capacity to participate in community events, without assistance, more or less than what you actually do in your present surroundings?

ICF Checklist © World Health Organization, September 2001. Page 14

Appendix 3:

GUIDELINES FOR THE USE OF ICF CHECKLIST VERSION 2.1A

1. This is a checklist of major categories of International Classification of Functioning, Disability and Health (ICF) of the World Health Organization. The ICF Checklist is a practical tool to elicit and record information on the functioning and disability of an individual. This information can be summarized for case records (for example, in clinical practice or social work).

2. This version (2.1a) is for use by a clinician, health or social care professional.

3. The checklist should be used along with the ICF full or short version which is scheduled for publication in September 2001. Until then the ICDH-2 Final Draft, full version, WHO, 2001 will serve as reference document for the ICF checklist. The raters should familiarize themselves with the ICDH-2 Final Draft by attending a brief educational programme or self-taught curriculum.

4. All information from written records, primary respondent, other informants and direct observation can be used to fill in the checklist. Please record all sources of information used on the first page.

5. Parts 1 to 3 should be filled in by writing the qualifier code against each of the function, structure, activity and participation term that shows some problem for the case being evaluated. Appropriate codes for the qualifiers are given on the relevant pages.

6. Comments can be made regarding any information that can serve as the additional qualifier or that is thought to be significant for the case being evaluated.

7. Part 4 (Environment) has both negative (barrier) and positive (facilitator) qualifier codes. For all positive qualifier codes, please use a plus (+) sign before the code.

8. The categories given in the checklist have been selected from the ICF and are not exhaustive. If you need to use a category that you do not find listed here, use the space at the end of each dimension to record these.

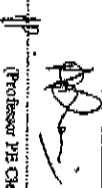
Appendix 2 - Ethical Clearance Certificate

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R1449 Van As

CLEARANCE CERTIFICATE	PROTOCOL NUMBER M06011
PROJECT	The Level of Activity and Associated Impairments Activity Limitations and Participation Restrictions of Adult HIV+
INVESTIGATORS	Ms Mj Van As
DEPARTMENT	Physiotherapy Department
DATE CONSIDERED	06.03.31
DECISION OF THE COMMITTEE	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 06.03.10 CHAIRPERSON  (Professor PE Cleaton-Jones)

*Guidelines for writers 'informed consent' attached where applicable

cc: Supervisor : Ms H Meyerwa

DECLARATION OF INVESTIGATORS

To be completed in duplicate and ONE COPY returned to the Secretary at Room 14005, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I and we are authorized to carry out the above-mentioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. I agree to a submission of a yearly progress report.

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES



Appendix 3 - Gauteng Department of Health Permission Letter

Appendix 4 - Letters supplied to participants and hospital staff

Appendix 4.1 – Information sheet seeking initial permission to access patients and records

Information sheet seeking initial permission to access patients and records

To the HIV clinic management team,

Dear

I, Melissa Van As, am a physiotherapist who is currently registered as a Masters student at the University of the Witwatersrand. The title of my study is, "The International Classification of Function (ICF) in adults visiting the HIV outpatient clinic at Helen Joseph Hospital."

The aim of the study is to interview HIV positive adults attending the HIV clinic with regards to their physical abilities, activity and participation limitations as well as their environmental, vocational, emotional and societal situations. Such information may enable us, as rehabilitation workers, to broaden our knowledge and improve our assessment and treatment of people living with HIV/AIDS in South Africa. Permission to carry out the study has been granted by the superintendent of the hospital.

I will be using the International Classification of Function, Disability and Health (ICF) Checklist in order to assess the patients.

I am not a member of the clinical team so I appeal to you, as a person who has established rapport with the patients, to:

- Approach the patient on the day of potential assessment.
- Explain to the patient that he/she is invited to take part in a research project investigating their level of ability.
- Explain that a researcher, Melissa Van As, wishes to conduct an assessment with them involving asking questions about themselves, their abilities and difficulties with activities and participation within society. The researcher will use their medical records for information should they agree to take part.
- They are in no way obliged to take part in the study.
- They will be reimbursed for their transport (R30) if the time taken by the study inconveniences them.
- Obtain permission for the researcher, Melissa Van As, to explain the study further, answer all questions and obtain written consent should they agree to participate.

If the patient agrees that the researcher may speak to him/her and have access to his/her medical records, please let him/her tick the appropriate box below.

I,..... (Patient's Name), give my permission for the researcher to give me more information about the study before I make my decision about participating.

☐

YES

Signature:.....

☐

NO

4.2 – Letter to patients

Dear Patient,

Hi. My name is Melissa Van As. I'm a physiotherapist currently doing my Masters course through the University of the Witwatersrand. I'm conducting a research study and I would be very grateful if you would consider taking part. The title of my research is "The International Classification of Function (ICF) in adults visiting the HIV outpatient clinic at Helen Joseph Hospital." I'm researching the problems that HIV positive people have as well as other environmental factors that affect people living with HIV/AIDS.

If you are between 18 and 49 years of age and HIV positive, you are invited to take part in the study. You will not be able to assist in participating if you are younger than 18 yrs old or if you had a level of disability before the diagnosis of HIV infection. The study involves you completing a questionnaire called the International Classification of Function, Disability and Health Checklist (ICF Checklist) with the assistance of a researcher. It will take approximately 1 hr to complete the questionnaire. Information about the study and the methods by which it will commence are on an attached information sheet. If there are any questions regarding the study, please don't hesitate to speak to me or the research assistant.

You will be given bus fare or taxi money (R30) should the time taken by the interview inconvenience you.

If you have any questions please contact me at the Wits Physiotherapy Department (011 717 3702) or on 083 334 2330.

Thank you for your time,
Melissa Van As
(Physiotherapist)

Appendix 4.3– Information sheet supplied to patients

Information Sheet

Dear Patient

To help you make an informed decision about taking part in the study I have prepared a few questions and answers to assist you.

Why am I doing this study?

The aim of the study is to better understand the problems and limitations that are experienced by people living with HIV/AIDS in South Africa. With your help, the difficulties that HIV positive people have can be investigated and be better understood so we, as health care workers, can try to improve the services available to help people with HIV/AIDS.

What do I expect from those who decide to participate in the study?

If you decide to take part, I will ask you to sign a consent form indicating that I (or a research assistant) may interview you and look at your medical records for information. I will ask you questions about your abilities with daily chores, employment, physical and emotional problems and your situation outside of the hospital. I might test how strong your muscles are and how much your joints can move. I will be using questions and tests that have been prepared by the World Health Organisation called the International Classification of Function (ICF). The interview will take approximately 1 hour.

Are there benefits to participants?

Yes. If we find that you are in need of physiotherapy and you are not already receiving it, we will provide you with treatment or refer you to the physio department at the hospital. There are no risks attached to taking part in the study. Your participation may influence the improvement of selected services available to assist people living with HIV/AIDS in South Africa.

Will my information be confidential?

The study will take place in an area that is private. Personal details will be kept private at all times during and after the interview. No names will be recorded on the questionnaires. You will be given a number which will be recorded on the ICF questionnaire. Only the researchers will have access to the list linking the names to the numbers. All information gathered will be kept anonymous and confidential and will be destroyed after the study is completed.

May I stop the interview at any time?

Yes. You may stop the interview at any time for any reason and you will not be affected in any way. You will still get the same treatment and services.

Thank you for your time,
Melissa Van As
(Physiotherapist)

Appendix 4.4 – Informed Consent Form – Study participants

Informed Consent Form – Study participants

I..... (name of participant),
I.D. number....., hereby accept the invitation to join the
research entitled, “The International Classification of Function (ICF) in adults visiting the HIV
outpatient clinic at Helen Joseph Hospital.” conducted by Melissa Van As, a Masters student
from the University of the Witwatersrand.

I give my permission to be interviewed by a researcher and for my medical records to be
used on (date) at.....(place).

I am aware that I am taking part in the study at my own free will and that I may stop the
interview at any time and continue to receive routine treatment. I understand that my
personal details and information collected at the interview will be kept confidential at all
times. I will have access to any information that relates to my health status. I give my
permission for information gathered to be used to compile a research report that may be
written up in a journal (No names included).

The details of the study have been explained to me. I am aware of what is required of me to
assist with the research. I know that I will not receive any direct payment for my participation
in the study except that my transport costs will be covered should the duration of the
interview inconvenience me.

I have been informed adequately about my involvement in the study and agree to participate
in the study.

Participant's name and signature:.....

Investigator's name and signature:.....