

# **CHAPTER ONE: INTRODUCTION AND LITERATURE REVIEW**

## **1. INTRODUCTION**

### **1.1 Background/Rationale**

The HIV/AIDS pandemic is one of the single most important challenges facing the global public Health community. Countries are focusing on a comprehensive response. According to the 2009 Zimbabwe estimates on HIV and AIDS, 1, 189, 279 (1, 078, 758 – 1, 312, 981) were living with the HIV virus (MoHCW, 2010). The same document stated the HIV prevalence among the most affected age-group (15-49 years) as 14.26%. The World Health Organisation (WHO) and UNAIDS launched the "3 by 5" initiative in December 2003 whose main objective was to get three million people on ARVs by end of 2005 (WHO, 2003). In 2003 342 000 people in Zimbabwe were in urgent need for the drugs (MoHCW, 2004). At the end of 2009, more than 500 000 people were estimated to be in need of ARVs and an estimated 308 000 are currently accessing the drugs (MoHCW, 2011).

The increase in the number of patients in urgent need is mainly due to the new WHO treatment guidelines that recommend that all HIV positive people with a CD4 count of 350 and below be commenced on ART regardless of their clinical stage. It is anticipated that the number will continue to increase as a result of the cumulative effect of increased survival rates on ART (MoHCW, 2010). Zimbabwe's HIV and AIDS care plan for the nationwide provision of Antiretroviral Therapy (ART) 2005- 7 (MoHCW, 2004) reflected Government's commitment to provide ARVs to all people who needed them. The Ministry of Health and Child Welfare opened several opportunistic Infections (OI) clinics countrywide where the drugs are provided. There are also a number of clinical trials taking place in the country. According to the 2008-2012 HIV and AIDS CARE, the government of Zimbabwe is still continuing with its efforts to reduce HIV-related morbidity and mortality, improve the survival of persons with HIV and AIDS, and to improve the quality of life for persons living with HIV and AIDS (MoHCW, 2008).

According to the same document, the ART program is undertaken in the context of a comprehensive care and support package that addresses medical, social and emotional needs of PLWHA.

Although rehabilitation input may be required in mitigating the impact of the pandemic especially in terms of prevention of disability and improving quality of life, it appears it has been completely left out in the HIV and AIDS Care Plan (MoHCW, 2008). The possible reasons may be the lack of appreciation by influential policy makers in the health sector, lack of appreciation of its impact by rehabilitation personnel, lack of knowledge by rehabilitation personnel on their role with this group of people or lack of knowledge and appreciation by PLWHA themselves on the benefits of rehabilitation. The silence on rehabilitation may be a reflection of a lack of awareness on the field as a whole in the country. Although there is evidence to the effect that rehabilitation can play an important role in improving the quality of life of PLWHA, there are situations in this country where all other services are provided as a package for free except for rehabilitation services. PLWHA requiring rehabilitation are therefore not receiving it as a result.

Despite a pivotal role that can be played by rehabilitation in improving the quality of life of PLWHA through minimizing impairments of body functions and structures, activity limitations, participation restrictions and addressing environmental barriers (O'Brien et al, 2006), it has not been considered that way. This is probably because traditionally scientists have measured the outcomes of health conditions by relying on mortality data. Outcome of ARVs has been cited in terms of increased CD4 count and quantity of life but not in terms of quality of life (WHO, 2001). However, more recently, the international concern about health care outcomes has shifted to the assessment of functioning at the level of the whole human being in day-to-day life (WHO, 2001).

HIV/AIDS is associated with episodic disability and multi-systems involvement and this makes persons living with the condition experience a range of impairments, activity limitations and participation restrictions (disabilities) affecting multi-systems including musculoskeletal, neurological and cardio-respiratory systems (O'Brien et al , 2006;

O'Brien, 2008). The availability of ARVs also mean that HIV is now a chronic illness and people are living longer with the day-to-day health-related consequences and challenges associated with it. Individuals on ARVs have also been found to experience adverse events from the medication that may affect the physical, social and/or psychological components of a person's health (O'Brien, et al, 2006) and the prolonged survival associated with physical disability can compromise the functional independence of patients, their capacity for self-care and mobility, and their capacity for work and productivity. As the number of persons with symptomatic HIV infection increases, more attention to the management of the functional disability is necessary to provide a better quality of life (Zonta, et al, 2003). The need to identify the activity limitations and participation restrictions faced by people living with HIV/AIDS cannot be underscored in our Zimbabwean community where approximately 14% of adults are living with the virus and above 500 000 PLWA are estimated to be in urgent need of ARVs (MoHCW, 2010).

In 2001, the World Health Assembly adopted the International Classification of Functioning, Disability and Health (ICF) as the newest member of the WHO family of classifications. The ICF provides a universally applicable classification and assessment tool, both for activity levels and overall levels of participation in basic areas and roles of social life (WHO, 2001a). The ICF acknowledges that every human being can experience a decrement in health and thereby experience some disability. It thus "mainstreams" the experience of disability and recognizes it as a universal human experience. By shifting the focus from cause to impact, it places all health conditions on an equal footing allowing them to be compared using a common metric.

According to WHO's 2002 document "Towards a Common Language for Functioning, Disability and Health", studies have shown that diagnosis alone does not predict service needs, length of hospitalization, level of care or functional outcomes. It has also been found that the presence of disease or disorder is not an accurate predictor of receipt of disability benefits, work potential, performance, potential to return to work, or likelihood of social integration (WHO, 2002). Therefore, the purpose of this study was to assess the quality of life (functional status) in adults living with HIV/AIDS at various periods of

taking ARVs in order to determine the impact on various activity and participation domains. The study was also aimed at determining factors that are associated with quality of life as measured by one's level of functioning based on the ICF.

## **1.2. REVIEW OF LITERATURE**

### **1.2.1 Antiretroviral Therapy**

Anti-Retroviral Therapy (ART) is the administration of at least three different types of medications known as Anti-Retroviral drugs (ARVs) in order to suppress the replication of the Human Immunodeficiency Virus (HIV) (NDTPAC, 2005; Barlett and Gallant, 2003; <http://www.etharc.org/plwha/faq/art>, 2007). Treatment with these combinations of drugs is also known as Highly Active Anti-retroviral Therapy (HAART). ART is not a cure, must be taken for life and is costly. ART is delivered as part of a comprehensive care, which includes voluntary counseling and testing (VCT), the diagnosis and treatment of Sexually Transmitted Diseases, Tuberculosis, Opportunistic Infections and the prevention of mother to child transmission (PMTCT) (MoHCW, 2004; <http://www.etharc.org/plwha/faq/art>, 2007). If used successfully, ART can suppress HIV viral replication thereby slowing down disease progression, improving immunity and delaying mortality (<http://www.etharc.org/plwha/faq/art>, 2007). Although ART is not a cure, it is believed that it prolongs and enhances the quality of life of people living with HIV and AIDS (PLWHA). Thus, HIV replication and immune deterioration can be delayed and survival and quality of life improved (WHO, 2007). Once started, it has to be taken for life with better than 95% adherence (WHO, 2007). Up until mid 2010, in Zimbabwe, HIV infected patients were started on ART when they manifested signs and symptoms of WHO stage III or AIDS defining illnesses and/or had CD4 count of 200 or less (NDTPAC, 2005; <http://www.etharc.org/plwha/faq/art>, 2007). WHO recommended that in ARV treatment programs in resource-limited settings, HIV infected adolescents and adults should start ARV therapy when they had clinical AIDS regardless of CD4 count (WHO, 2007). When total lymphocyte count could be assessed, in addition people with WHO stage II or III HIV disease should be offered treatment. When CD4 counts were available, all HIV infected people with less than 200 CD4 cells/mm<sup>3</sup> were supposed to be offered treatment (NDTPAC, 2005; WHO, 2007). WHO has recently updated its

guidelines for ART and now recommends that all PLWHA with CD4 count of 350 or less be started on ARVs regardless of their WHO clinical stage. Member countries including Zimbabwe have started following the new guidelines (NDTPAC and MoHCW, 2010).

In the Zimbabwean context, the Opportunistic Infection Clinic is where people knowingly living with HIV/AIDS or suspecting that they might have go for voluntary counseling and testing and also for treatment of opportunistic infections. The same clinic also assesses patients for eligibility for ARVs. Those eligible to be on ARVs are commenced on treatment and the monitoring process for adherence, adverse effects and treatment failure begins (NDTPAC and MoHCW, 2003). Assessment for eligibility is done using two methods; CD4 count and WHO clinical staging. At the time of data collection, those with a CD4 count of 200 cell/mm<sup>3</sup> or less or those on stage 3 or 4 of WHO clinical staging were considered eligible to commence on ARVs (NDTPAC and MoHCW, 2003). Ideally, both methods of assessment should be used but when the machine to measure CD4 count is down the clinicians can only use the WHO clinical staging.

Those initiated on ARVs are required to come for review after two weeks initially, then after one month, two months and thereafter every three months. Those who would be found to be complying with their treatment for six months and have no candidiasis or cryptococcal meningitis are referred for treatment at their local clinic (decentralization).

At the time of data collection, the 1<sup>st</sup> line drugs used were Stavudine, Lamivudine and Nevirapine (Stalanev) (NDTPAC & MoHCW, 2003; EDLIZ, 2006). The newly recommended 1<sup>st</sup> line is Tenofovir, lamivudine and nevirapine (or efavirenz) (NDTPAC & MoHCW, 2010).

Despite the medical benefits of HAART, the complex and demanding schedules for these medications may interfere with performance of daily life tasks, including personal care and employment. Also, a number of adverse effects have been reported among PLWHA who are on HAART (NDTPAC and MoHCW, 2010; The Herald, 2011). This is also consistent with previous researchers who noted that persons with HIV may experience a

range of physical, social, and psychological consequences associated with HIV and its associated conditions and treatments (Rusch et al, 2004; O'Brien et al, 2008).

### **1.2.2 HIV related disabilities**

HIV/AIDS is associated with episodic disability and multi-systems involvement (Rusch, et al, 2004; O'Brien et al, 2008). This makes persons living with the condition experience a range of impairments, activity limitations and participation restrictions (disabilities) affecting multi-systems including musculoskeletal, neurological and cardio-respiratory systems (Rusch, et al, 2004; O'Brien et al , 2006; O'Brien et al, 2008). Owing to the availability of antiretroviral drugs, rather than an illness that traditionally resulted in a gradual progression to death, HIV can now present as a chronic illness characterized by fluctuating episodes of wellness and illness for people who can access and tolerate the drugs. Increased longevity associated with HAART means that a greater number of individuals are living longer with the day-to-day, health-related consequences and challenges associated with HIV (Rusch, et al, 2004; O'brien et al , 2006). A range of health problems may arise from the HIV disease itself, but individuals also commonly experience adverse events from the medications that may affect the physical, social, and/or psychological components of a person's health (Bopp et al, 2003).

It has been documented that even individuals on HAART experience adverse events from the medication that may affect various components of a person's health (O'Brien, et al, 2006; Rusch, et al, 2004). The prolonged survival associated with physical disability can compromise the functional independence of patients, their capacity for self-care and mobility, and their capacity for work and productivity (O'Brien, et al, 2006).

Chronic HIV infection is also associated with muscle weakness, fatigue, impaired functional work capacity, depression, and decreased quality of life, which lead to disability and mortality (Bopp et al, 2003; O'Brien et al, 2008).

Diarrhea, poor diet, and poor nutrient absorption place HIV patients at risk for dehydration and electrolyte abnormalities, both of which can lead to muscle cramps and cardiac dysrhythmias (Bopp et al, 2003). Anaemia and muscle wasting have also been

reported and can cause increased fatigue and further limit exercise and functional capacity. According to Bopp et al (2003), special care should be taken if a patient has had previous pneumocystis pneumonia because residual lung scarring may decrease alveolar volume, leading to oxygen desaturation at moderate exercise intensities, further limiting exercise capacity. This may explain the issue of getting tired easily or low endurance often complained about by a number of PLWHA (Rusch et al, 2004; The Zimbabwean, 2010; Bopp et al, 2003). Results from Rusch et al (2004)'s survey found remarkably high prevalence of disablement, with at least 80% of respondents having experienced at least one impairment, activity limitation, or participation restriction within the previous month. Examples of disablement included pain and generalized weakness, difficulty carrying out vigorous activities and household chores, and difficulty engaging in employment or leisure activities. O'Brien, et al (2006) also found similar results. Mental health issues were also found to be remarkably prevalent among persons living with HIV, with almost 60% of respondents having reported being diagnosed with depression by a physician (O'Brien, 2006).

Results from the above cited studies demonstrated an increased need for rehabilitation professionals to play their role in addressing the disabilities experienced by this population. In Zonta et al, (2003)'s study, 91% reported impaired physical activity; a complaint about various degrees of weakness was made by 81%, 49% indicated that they maintained all of their activities, although at a slower pace, with stops for rest and 49% left their professions for reasons related to the infection. The most common complain about disabling neurological involvement were: parasthesia (30%), balance impairment (16%) and hemiparesis (11%) (Zonta et al, 2003). Changes in body composition as seen in lipodystrophy are also believed to influence a person's self-esteem related to his/her body image. This lipodystrophy has also been associated with elevated triglycerides and low-density lipoproteins which place these individuals at risk of cardiovascular disease and consequently to myocardial infarction or stroke (Mutimura et al, 2008; Bopp et al, 2003). As the number of persons with symptomatic HIV infection increases, more attention to the management of the functional disability will be necessary to provide a better quality of life and rehabilitation can play a major role there.

### **1.2.3 Role of Rehabilitation in HIV/AIDS**

Therapeutic exercise is reported to have been used successfully in the treatment of diabetes, dyslipidemias, hypertension, cardiovascular disease and certain type of cancers. These benefits are believed to also extend to people infected with HIV (Bopp et al, 2003). Zonta, et al (2003) rightly noted that as the number of persons with symptomatic HIV infection increases, more attention should be put on the management of the functional disability in order to provide a better quality of life. The ultimate goal of rehabilitative interventions has always been to enable people with disabling conditions to achieve their maximum level of functioning (Radomski and Trombly Latham, 2008; Pedretti, Pendleton and Schultz-Kron, 2006). In the same way, rehabilitation interventions can be designed to prevent the decline in functional ability in PLWHA. It has been noted in previous studies that for PLWHA, these interventions should be individualized on the basis of functional capacity and individual symptomatology of each client, hence no one exercise program can adequately deal with the special needs of all HIV-infected patients (Bopp et al, 2003; O'Brien et al, 2006).

Higher CD4 count and slower progression to AIDS have been reported in exercisers compared to non-exercisers (Mustafa et al, 1999). Exercise has also been reported to positively affect many aspects of the physical and mental health of HIV-infected patients (Bopp et al, 2003). However, according to the same author, the effects of prolonged, high-intensity exercise, or overtraining, have also been well documented to increase the severity of infections and to negatively affect immune function in humans and increase mortality in animal models. It is thought that for these reasons many physicians still instruct their HIV-infected clients to avoid physical exertion, despite evidence that moderate-intensity exercise can decrease symptoms of HIV infection and positively affect immune measures (Bopp et al, 2003). According to Nieman, Johanssen, Lee, and Arabatzis (1990) cited in Bopp et al (2003), high intensity exercise sessions decrease the effectiveness of the immune system, leading to more opportunistic infections among HIV-free individuals. For this reason high-intensity exercise has been avoided, and moderate-intensity exercise has been recommended for HIV-infected individuals. The

need to work closely with the client's physician in deciding the intensity of the exercise program has therefore been emphasized (Bopp et al, 2003).

Maximal oxygen consumption, VO<sub>2</sub>max is a common measure of functional work capacity. As physical fitness increases, so too does VO<sub>2</sub>max in healthy adults free of HIV infection. Pothoff, Wassermann, and Ostmann (1994) cited in Bopp et al (2003) found that VO<sub>2</sub>max values both at the anaerobic threshold and at maximal exercise were reduced in HIV-infected individuals compared to a control group of uninfected individuals. Therapeutic exercise has also been found to increase functional capacity in HIV-infected individuals. This according to Bopp et al (2003) may decrease HIV-related disability and allow for longer independent living. Both aerobic and resistance exercise were found to positively affect body composition in HIV infected patients (Smith et al, 2001).

Stress management has been indicated to delay disease progression and ward off secondary infections in HIV-sero-positive individuals (Antoni et al, 2002; Cruess et al, 2000). It was also found that aerobically trained HIV-infected men were protected from stress-related impairments in immune function compared to sedentary controls. The authors however noted that appropriately trained persons must monitor all exercise sessions involving an HIV-infected patient until the patient demonstrates the ability to tolerate the prescribed workload. The goals of the exercise prescription according to (Mutimura et al, 2008) should include the improvement of functional work capacity and increases in muscular strength. Exercise must be performed at a moderate intensity: from 11 to 14 on the Borg Rating of Perceived Exertion Scale, at 50% to 85% of peak heart rate, or at 45% to 85% VO<sub>2</sub>max (Ainsworth et al, 2000).

Because patients present with varying types and intensities of symptoms, no one exercise program can adequately deal with the special needs of all HIV-infected patients. Suggested exercise modalities include moderate-intensity aerobic activity using large muscle groups, such as walking, cycling, and rowing. Ainsworth et al (2000) compiled a compendium of physical activities and their associated metabolic equivalent (MET)

levels. The MET level of an activity can be determined by dividing its metabolic cost (in mL/kg/min) of oxygen consumption by 3.5 mL/kg/min, the metabolic cost at rest. With even asymptomatic HIV-infected individuals having reduced functional capacities ( $VO_{2max} = 28\text{mL/kg/min}$ . 8 METs), it is recommended that individuals exercise at an intensity between 3 and 6 METs. Activities in this intensity range include bicycling at speeds less than 10mph; water aerobics; routine gardening; walking at 3mph on level surface; low intensity jogging; and low intensity sports such as badminton, fencing, and golf (Ainsworth et al, 2000).

Therapeutic exercise has the potential to increase functional work capacity and muscular strength and endurance while reversing muscle and fat wasting and improving several psychological measures in the HIV-infected population (O'Brien et al, 2006; Bopp et al, 2003; Mutimura et al, 2008). It was noted that exercise derives these benefits without the high cost and potentially severe side effects of medical and pharmacological interventions (Mutimura et al, 2008).

Because persons living with HIV may simultaneously experience a range of impairments, activity limitations and participation restrictions affecting multiple systems, including the musculoskeletal, neurological and cardio-respiratory systems, requiring rehabilitation intervention (O'Brien, 2006), rehabilitation professionals working in outpatient, inpatient, rehabilitative, or community care settings have a role to play in working with this population. Similar to all clients living with lifelong illnesses, rehabilitation interventions can be designed to prevent the decline in functional ability.

According O'Brien et al (2006), rehabilitation professionals require no special training in the field of HIV to work with this population. The authors argued that assessment and treatment strategies used with this population are not different from those used with other populations. The same tools can be drawn but applied in a different context, keeping in mind the multi-systemic, episodic, and unpredictable nature of the infection. (O'Brien et al, 2006).

#### **1.2.4 Quality of Life in people living with HIV/AIDS**

A number of studies have been carried out on the quality of life among people living with HIV/AIDS (Lubeck and Fries, 1992; Hughes, Jelsma, Maclean, Darder and Tinise, 2004; Ichikawa and Natpratan, 2004; Jelsma, Maclean, Hughes, Tinise and Darder, 2005).

Most of the studies used either a cross-sectional design or a cases-control design.

In Northern Thailand a study was done to determine the quality of life among people living with HIV/AIDS (Ichikawa and Natpratan, 2004). The design was a cross sectional survey of 200 subjects with HIV/AIDS attending self-help groups in the municipal area. Data was collected through face to face interviews. Hughes et al (2004), also did a study in South Africa looking at health –related quality of life among people living with HIV/AIDS. This was a case-control (123 cases and 108 controls) study where subjects were recruited from a population of beneficiaries of HIV/AIDS clinics that provided ART to PLWHA within a resource poor community. Subjects were in WHO stage 3 or 4 of the disease and/or had CD4 count of less than 200 cell/mm<sup>3</sup> blood. The assessment of the health-related quality of life was done before subjects were commenced on ARVs. Controls were randomly selected from the community in the same area and were in the same age range. They used EuroQoL-5 Dimensions (EQ-5D) measure of Health related quality of life (HRQoL). The results showed a significant difference in quality of life between the cases and controls in the following areas/domains: mobility, usual activity, pain/discomfort. On a visual analogue scale, PLWHA reported significantly lower scores compared to the community sample.

Santos, Junior and Lopes (2004) also did a similar study in Sao Paulo in Brazil. They used WHO-QOL –bref for PLWA. The results showed that women presented the lowest scores for the psychological and socio-demographic characteristics, life style and clinical conditions. This was a cross-sectional study based on consecutive sampling and was conducted in a University specialized AIDS service at the Faculty of Medicine, University of Sao Paulo. The sample consisted of 365 PLWA aged 18 years and older who were followed up by infectologist. Socio-demographic and life style variables and the clinical conditions were collected using a questionnaire. Quality of Life was

estimated using a WHOQOL-bref. Descriptive analysis was performed using SPSS. Women, blacks, individuals with lower income, as well as individuals with CD4+ cell counts below 200 cell/mm<sup>3</sup> blood and individuals under psychiatric care had lower quality of life (Santos et al, 2004).

### **1.2.5 The research instrument- the ICF**

ICF is a multipurpose classification intended for a wide range of uses in different sectors (WHO, 2002). It classifies functioning and disability associated with health conditions. The health and health-related domains used help to describe changes in body function and structure, what a person with a health condition can do in a standard environment (their level of capacity), as well as what they actually do in their usual environment (their performance). The domains are classified from body, individual and societal perspectives by means of two lists; a list of body functions and structure, and a list of domains of activity and participation. ICF is WHO's framework for health and disability and it provides health and health related outcomes information (WHO, 2001a; WHO, 2001b). It allows WHO to go beyond the old traditional mortality and morbidity measures by including measures of functional domains of health. Because of its flexible framework, the detail and completeness of its classifications and the fact that each domain is operationally defined, with inclusions and exclusions, the ICF can be used for a myriad of uses to answer a wide range of questions involving clinical research and policy development issues. In this study the ICF was used for the assessment of individuals (What is the person's level of functioning?) although in general it can also be used for the evaluation of treatment (what are the outcomes of ARV treatment? How useful are the interventions?). Thus, the ICF can be used as a valuable tool by institutions for management and outcome evaluation answering such questions as “How useful are the services we are providing?” (WHO, 2002).

Hence ICF can be used for policy development, economic analyses, research, intervention studies and evaluation of environmental factors. It can also be used for economic analyses to ensure that society can effectively prevent limitations on activities and restrictions on participation by costing the economic impact of functional limitations

viz-viz the costs of modifying the built and social environments. In terms of research uses, ICF provides a framework or structure for interdisciplinary research in disability and for making research comparable.

To quantify the magnitude or severity of the problem in each of the ICF categories, WHO proposes the qualifiers scale. The categories are scored by the researcher during an interview with the patient. The severity of the patient's problem in each of the ICF categories is quantified with the qualifiers' scale which has 5 response levels ranging from 0 to 4, corresponding to:

- 0.....no difficulty (none, absent, negligible)
- 1.....mild difficulty (slight, low)
- 2.....moderate difficulty (medium, fair)
- 3.....severe difficulty (high, extreme)
- 4.....complete difficulty (total) in performing a certain activity or daily task.

In addition there are response options "8, not specified" and "9 not applicable" (WHO, 2001a; WHO, 2001b; WHO, 2002b; Uhlig, Lillemo, Moe et al, 2007).

In his review of the conceptualization, measurement, and research findings on quality of life of individuals with spinal cord injuries, Djikers (2005) noted that quality of Life measures have various applications some of which are; assessing the patient, especially identifying commonly overlooked functional and psychosocial problems; prioritizing problems; tracking functional changes over time,; monitoring quality of care and monitoring treatment effects including evaluating the efficacy of competing medical and psychosocial interventions. The International Classification of Functioning, Disability and Health (ICF) was published by WHO in 2001. It integrates both the medical and social models of health and adopts a bio-psychosocial approach which views biological, psychological and social processes as integral to and interactive with physical health and illness (WHO, 2001). WHO also published an ICF Checklist (WHO, 2001b) that gives guidelines on the use of the instrument as a data collection tool. The validity of the instrument was tested on other conditions and in different environments but has not been tested on HIV/AIDS patients. The domains can be used together or separately. This

study used the activities and participation domain to assess the impact of ARVs on the quality of life of people living with HIV/AIDS using the performance qualifier. The environmental factors were also assessed.

This study is going to identify common functional problems faced by adults living with HIV/AIDS who are on ARVs. Dijkers (2005) cited some shortcomings of quality of life studies/measures that also apply to the current study. According to this author, clinicians do not know what specific Health related/quality of life scores mean in the same way that they know the meaning of a specific blood pressure reading for example (in terms of risks, potential for intervention etc). Also for monitoring purposes, it is not known what a "clinically significant" change in quality of life score is. Another question that remains unanswered according to Dijkers (2005) is; When does a difference make a difference? The "clinically important difference" or "minimal clinically important difference" received extraordinary attention with conflicting views where some researchers discussed various methods of determining these values while others argued that a single value cannot validly be determined. In this study, quality of life was assessed in terms of the level of difficulty a person experienced in executing activities or getting involved in life situations. The purpose of this study was to assess the extent of activity limitation and participation restrictions among people living with HIV/AIDS receiving antiretroviral therapy.

### **1.3 STATEMENT OF THE PROBLEM**

There has been limited documentation of the extent of the activity limitations or participation restrictions experienced by people living with HIV/AIDS in Zimbabwe. This is further supported by very little if any government response in terms of mitigating HIV-related disabilities as shown by the lack of a national stance on the provision of rehabilitation services to HIV-infected individuals. There are certain situations where the only service a patient has to pay for is rehabilitation in institutions where every other service to do with HIV/AIDS treatment and care is free. Does it mean that rehabilitation has no role especially when one is on antiretroviral therapy?

## **1.4 SIGNIFICANCE OF THE STUDY**

There has been a commendable national response to the HIV/AIDS pandemic by the Government of Zimbabwe in terms of prevention, testing, counseling and treatment (ART), but very little response in terms of provision of rehabilitation services to HIV-infected individuals. Why this researcher says so is because of the provision of all other HIV related services freely under the auspices of OI clinics except Rehabilitation services

It is therefore important to assess the Zimbabwean situation in terms of activity limitations and participation restrictions (disabilities) experienced by people living with HIV/AIDS and determine the extent of problem.

Findings from this study may lead us to analyze institutional capacity of the MoHCW to mitigate in terms of provision of appropriate and adequate rehabilitation services to this group of people as a way of improving quality of life as well as maximizing participation of people living with HIV/AIDS and assisting in identifying enabling responses of society to increase independence and bringing an awareness of social practices that facilitate or hinder performance.

This is going to be one of the few studies addressing quality of life of patients on ARVs in a Zimbabwean context, providing the much needed HIV-related disability data. The fact that one's CD4 count has increased may not necessarily translate into increased performance in activities of daily living. Thus, the information can be used to formulate intervention strategies that aim to maximize one's level of functioning (quality of life).

If we are to holistically improve the quality of life of PLWHA, it is highly desirable that the activity limitations and participation restrictions faced by these people be registered and characterized in terms of their relationship to period one has been on ARVs, type of ARVs and other demographic characteristics. The study will contribute to the body of knowledge for the care and support for PLWHA. Strategies meant to minimize these disabilities can be adopted. Occupational therapists, physiotherapists and other professionals involved in rehabilitation of PLWHA can benefit by way of in-depth understanding of the limitations and restrictions faced by PLWHA in their day-to-day lives. This in turn will enable them to plan interventions to address the problems.

## **1.5 RESEARCH QUESTIONS**

What is the functional status (quality of life) of adults living with HIV/AIDS who are on ARVs?

Which factors are associated with quality of life in adults living with HIV/AIDS who are on ARVs?

## **1.6 OBJECTIVES**

### **1.6.1 Broad Objective**

To determine the activity limitations and participation restrictions (disabilities) experienced by adults living with HIV/AIDS who are on ARVs and the factors associated with quality of life as assessed by the ICF.

### **1.6.2 Specific Objectives:**

1. To describe the sample in terms of demographic and clinical characteristics.
2. To determine the prevalence of activity limitations and participation restriction (disability) among adults living with HIV/AIDS who are on ARVs.
3. To determine the activity/participation domains which are most/least affected in adults living with HIV/AIDS who are on ARVs
4. To determine factors which are predictive of a higher/lower quality of life in adults living with HIV/AIDS who are on ARVs
5. To determine the barriers and facilitators experienced by persons living with HIV/AIDS

## **CHAPTER TWO: METHODOLOGY**

### **2.1 Study Design**

This was a cross sectional analytical study design in which socio-demographic, clinical information and participants' level of functioning were collected only once and statistical tests were used to explore variables that explained participants' level of functioning/quality of life.

### **2.2 Subjects and sampling**

Patients who presented at Parirenyatwa Opportunistic infection clinic for ARVs either for first time prescription of ARVs or had been on ARVs were recruited into the study on a voluntary basis and with informed consent. Consecutive sampling for those meeting the inclusion criteria who presented on the days of the interviews was adopted.

#### **2.2.1 Reference Population**

Zimbabwean adults (18 years and above) living with HIV and AIDS.

#### **2.2.2 Source Population**

Adults living with HIV/AIDS who were getting their 1<sup>st</sup> prescription for ARVs on the day of interviews or those who had been on ARVs.

#### **2.2.3 Sampling Frame**

Adults living with HIV and AIDS at Parirenyatwa Group of Hospitals' Opportunistic Infection Clinic who were already on ARVs or were starting on the days of interviews.

#### **2.2.4 Inclusion criteria**

- HIV positive male or female
- Eighteen years old or above
- Has been on first or second line ARVs or has been confirmed eligible for ARVs and was starting on the day

- Those who gave their consent to participate in the study

### 2.2.5 Exclusion criteria

- Less than 18 years of age
- Those not confirmed eligible to start on ARVs
- Those who refused to give their consent to participate in the study

## 2.3 Setting

The study was done at the adult Opportunistic Infection Clinic at Parirenyatwa Group of Hospitals. Parirenyatwa Hospital OI clinic is situated within the main hospital grounds.

## 2.4 Sample size

The sample size calculation to estimate the prevalence of activity/activity limitations and participation/participation restrictions (disabilities) and the quality of life among adults living with HIV who were on ARVs was calculated using Cochran's simple formula for categorical data based on the assumption of normal approximation (Appendix 4).

$$n = \frac{Z^2 P(1-P)}{d^2}$$

Where n= sample size

Z= Z statistic for the level of confidence

P= expected prevalence or proportion

d = precision or margin of error

Therefore, the Z statistic for the level of confidence of 95%, that is, 1.96 was used.

The expected prevalence (P) of activity limitations and participation restrictions among people living with HIV/AIDS was based on previous studies among people living with HIV/AIDS and assumed to be between 50% and 84%. The precision d or acceptable margin of error of the proportion estimated was set at 0.10. Based on the prevalence range 50% to 84%, the upper limit of 84% was used to calculate the required sample size.

The minimum required sample size at analysis stage was **52**.

Statistical power of the study is not usually calculated in this type of study (cross sectional – prevalence studies) because we do not have beta in the formula.

## **2.5 Study factors**

- Socio-demographic characteristics i.e Gender, age, level of education, marital status, occupation,
- Clinical characteristics i.e last CD4 Count, period since last CD4 count, type of ARVs, period on ARVs, use of other medication
- Physical health,
- Emotional and mental health,
- Previous injury
- Use of assistive devices
- Having an assistant
- Environmental factors

## **2.6 Outcome factors**

The main outcome variable was extent of activity limitation and participation restriction (quality of life) as indicated by:

- Total instrument score (Sum of the following domains; mobility, self-care, domestic life, interpersonal relationships, major life areas and Community & civic life)
- Individual domain total scores (mobility, self-care, domestic life, interpersonal relationships, major life areas and Community & civic life)

Additional outcome variables were;

- Reduction of usual activities
- Stopping usual activities

## **2.7 Indicators**

Number of participants with at least some limitation/restriction

## **2.8 The Data Collection Instrument**

The adapted ICF (Appendix 1) was used for data collection, and it consisted of three parts. Part 1 had two sections. Section A collected demographic information on the participant as in the original ICF and in addition collected information on the WHO clinical stage, Last CD4 Count and date, ARVs participant was taking and the date ARVs were initiated. Section B collected the participant's brief health information.

Part 2 collected information on activity limitations and participation restrictions faced by participants in their day-to-day life using the ICF scoring. The performance qualifier which looks at the extent of participation restriction by describing the person's actual performance of a task or action in his or her current environment was adopted. This qualifier was chosen because of its emphasis of the current environment which also brings in the societal context. The following short list of Activity and Participation domains found to be applicable in the Zimbabwean situation were assessed: Mobility, Self care, Domestic life, Interpersonal interactions and relationships, Major life areas and Community, social and civic life. An opportunity was given for participants to state any other activity and participation domain they felt necessary. Part 3 of the questionnaire was looking at environmental factors that were acting as either facilitators or barriers to the participant's involvement in life situations. The physical environment was excluded from this questionnaire as it required an actual physical evaluation of the participant's environment a task which was not feasible in this study. The following domains of environmental factors were included: Support and relationships, Attitudes and Services, systems and policies.

## **2.9 Procedure**

Permission was first sought from the Doctor and matron in charge of the adult Opportunistic infection clinic at Parirenyatwa Hospital before asking the Clinical Director of the same institution for permission to carry out the study. After getting permission from the Clinical Director of Parirenyatwa hospital, ethical approval was

sought from the Institutional Review Board of the College of Health Sciences Joint Research Ethics Committee (JREC).

### **2.9.1 Pretesting and Pilot study**

The instrument (Appendix 1) was pre-tested on five participants. This was meant to address issues of clarity as well as ensuring that domains relevant to the Zimbabwean setting were included in the interview questionnaire. The pilot study was also meant to assess the feasibility of the study in the setting. The researcher was able to determine the time required per participant and the possible feasibility problems with the study.

### **2.9.2 Data collection for main study**

The researcher had three days of the week to collect data from participants as allocated by the clinic matron. The available days were Monday, Wednesday and Friday. On days of data collection, the researcher would wait for participants to see the doctor first and then get those who were waiting to collect their medication to participate in the study. Groups of patients were therefore addressed as they were waiting for their turn to collect their medication. The researcher and her assistant would be introduced by the sister-in-charge and explain the purpose of the study to the patients as well as asking for their informed consent. The consenting process involved explaining the purpose of the study to possible participants, tell them that participation was voluntary and there was no penalty for not participating i.e they would continue to receive the usual services from the clinic. Participation in the study had no anticipated risks to participants, no monetary benefits, they had an option to write or not to write their name on the interview questionnaire and information would be kept confidentially. They were told that the results would be used to come up with methods aimed at improving the quality of life (activity and participation) of people living with HIV and AIDS who are on ARVs. Those who agreed to participate were asked to sign an informed consent form (Appendix 3a and 3b) and were invited into the allocated room for interviews. Those who agreed to participate were assessed on their functional status using the ICF based questionnaire (Appendix 1). Participants' records were also used to confirm information on the last CD4 count and date, date of initiation of ARVs and the medications they were getting.

## **2.10 Data management and analysis**

Statistical Packages Intercool Stata version 10 and SAS were used to analyse the data. Data was captured on to an excel data sheet first and was imported into the Stata format (data editor) and SAS format. Data was cleaned (checked for any missing values and incorrectly entered data and necessary corrections made) and exploratory data analysis was done to check for outliers and errors, normality of data etc.

Descriptive statistics were used to describe the distribution of the sample according to demographic, clinical and functional variables. The level of significance was set at 5%. 95% confidence intervals were calculated and stated. Graphs and tables were used to represent the data.

To determine the prevalence of activity limitations/participation restrictions, new variables were created where items within the major domains were re-coded as follows: 0- no difficulty, 1- minimum to complete difficulty (1-4) and not specified and not applicable were coded as missing.

Total scores for each domain were calculated and a mean score derived. A total score for all the domains was also calculated. Item-item and item-total correlations were computed to check if each item measured what the domain was intended to and whether all the items were measuring the same thing. Poorly performing items were dropped and univariate and multivariate analysis were done before carrying out to determine factors that were predictive of quality of life.

## **2.12 Ethical Considerations**

1. Ethical approval was granted by the Institutional Review Board of the College of Health Sciences (Appendix 2).
2. Participants signed an informed consent form (Appendix 3a and 3b).
3. Participation was on a voluntary basis and refusal to participate did not

disadvantage the participants in any way and this was made clear during the informed consent process.

4. Confidentiality and privacy of the participants were strictly observed i.e though participants had an option to give their names or not, no names were going to be used in any write-up (a coding system was used) and interviews were held away from other patients and staff.
5. Information collected was kept under lock and key and was only accessible to the researcher and her supervisors.
6. Those who had urgent needs that could benefit from rehabilitation were counseled, given advice and were also given information on where they could access rehabilitation services and the benefits of rehabilitation. Getting the services would however be at a cost to the participant.

## **CHAPTER THREE: RESULTS**

### **3.0 Introduction**

A total of 59 out of the 75 participants who had gone through the consent process agreed to take part in the study giving a response rate of about 79%.

### 3.1 Socio-demographic characteristics of participants

**Table 3.1: Distribution of participants according to socio-demographic characteristics**

| <b>Variable</b>                  | <b>Number</b>    | <b>Percentage</b> |
|----------------------------------|------------------|-------------------|
| <b>Sex</b>                       |                  |                   |
| Male                             | 26               | 44                |
| Female                           | 33               | 56                |
| <b>Marital Status</b>            |                  |                   |
| Never married                    | 2                | 3                 |
| Married                          | 32               | 54                |
| Divorced                         | 7                | 12                |
| Widowed                          | 18               | 31                |
| <b>Employment status</b>         |                  |                   |
| Paid employment                  | 15               | 25                |
| Self employed                    | 20               | 34                |
| House maker                      | 3                | 5                 |
| Retired                          | 1                | 2                 |
| Unemployed (health reason)       | 15               | 25                |
| Unemployed (other reason)        | 4                | 7                 |
| other                            | 1                | 2                 |
| <b>Highest educational level</b> |                  |                   |
| Primary Grade 7                  | 13               | 22                |
| Secondary O-Level                | 39               | 66                |
| Tertiary- Diploma                | 6                | 10                |
| Tertiary –Degree                 | 1                | 2                 |
|                                  |                  |                   |
| Mean age (S.D)                   | 42 years (S.D 9) |                   |

From Table 3.1 above, the mean age of participants was 42 years (+/- 9), 56% were female, 25% were in paid employment, 54% were married and 31% were widowed. The majority of participants had attained Ordinary level.

### 3.1.1 Distribution of participants according to gender and marital status

**Table 3.2: Distribution according to gender and marital status**

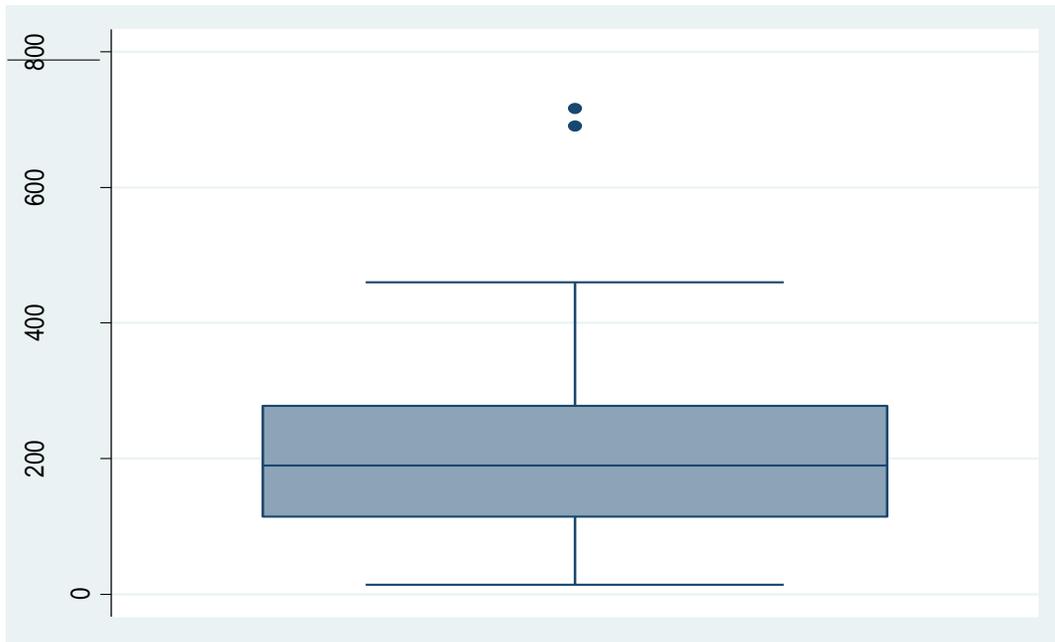
| <b>Gender</b> | <b>Marital status</b> |                |                 |                | <b>Total</b> |
|---------------|-----------------------|----------------|-----------------|----------------|--------------|
|               | <b>Never married</b>  | <b>Married</b> | <b>Divorced</b> | <b>Widowed</b> |              |
| <b>Female</b> | 1                     | 12             | 4               | 16             | <b>33</b>    |
| <b>Male</b>   | 1                     | 20             | 3               | 2              | <b>26</b>    |
| <b>Total</b>  | <b>2</b>              | <b>32</b>      | <b>7</b>        | <b>18</b>      | <b>59</b>    |

Sixteen (89%) of those widowed were female, 63% of those currently married were male and 57% of those divorced were female (Table 3.2).

## 3.2 Clinical Profile of Participants

### 3.2.1 Distribution of participants according to last CD4 count

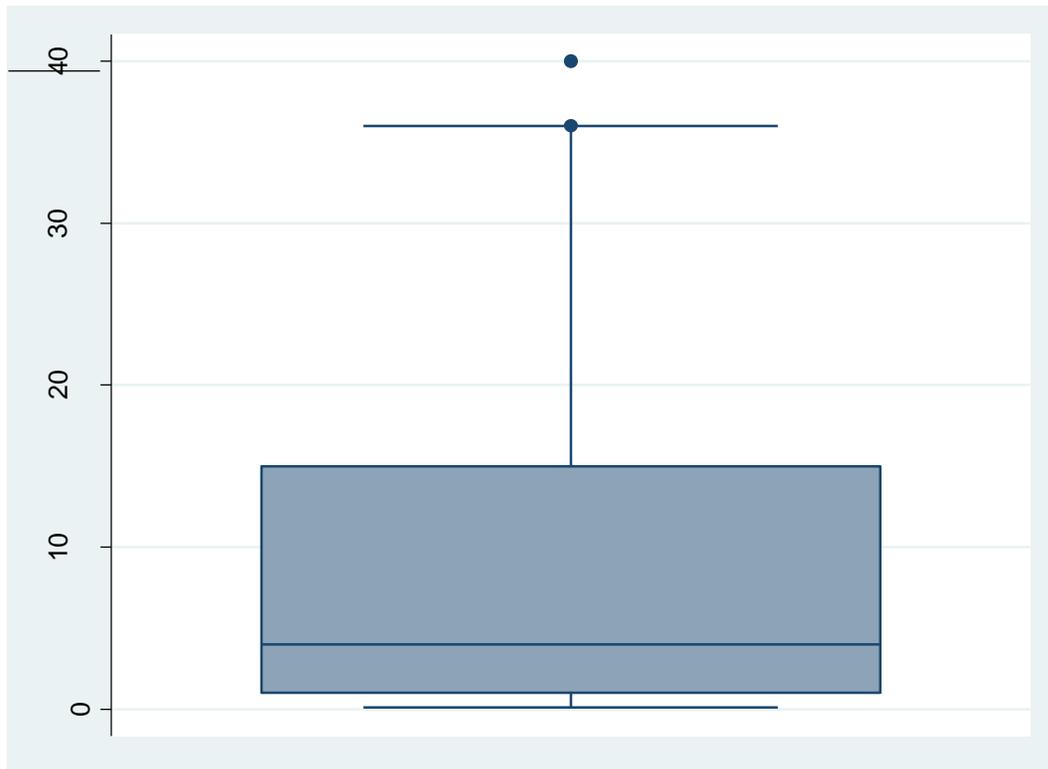
*Figure 3.1: Box plot showing the distribution of participants according to last CD4 count*



From the table above the median last CD4 count was 189.5 (I.Q 114; 278). The distribution according to last CD4 count is skewed due to few very high outliers (Figure 3.1).

### 3.2.2 Period since last CD4 Count in months

*Figure 3.2: Box plot for distribution of participants according to period since last CD4 count.*



The mean number of months since last CD4 was 8.9 months with a standard deviation of 10.3. The median is four months (I.Q 1; 15) (Figures 3.2).

### 3.2.3: Type of Antiretroviral drugs

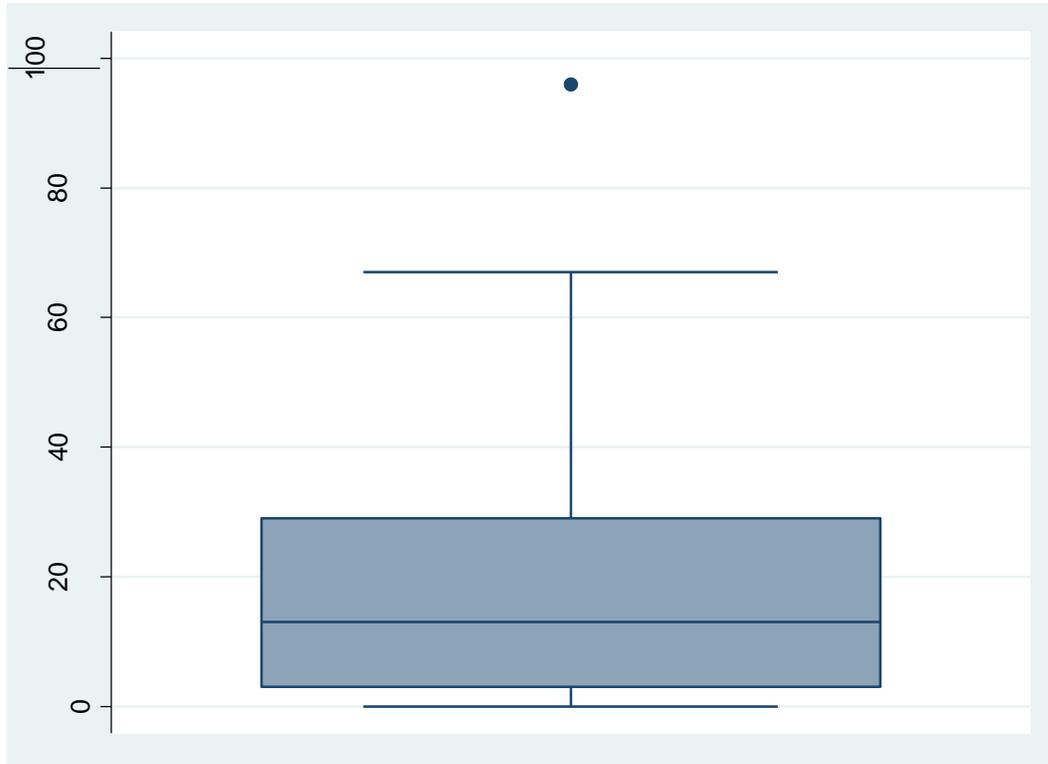
**Table 3.3: Distribution of participants according to type of ARVs**

| <b>Drug Combination</b>           | <b>Number</b> | <b>Percentage</b> |
|-----------------------------------|---------------|-------------------|
| Stalanev                          | 32            | 54.2              |
| Combivir and nevirapine           | 4             | 6.8               |
| Combivir and efavirenz            | 3             | 5.1               |
| Zidolam and nevirapine            | 4             | 6.8               |
| Douvir and nevirapine             | 2             | 3.4               |
| Coviro and efavirenz              | 3             | 5                 |
| Aluvia, lamuvudine and nevirapine | 1             | 1.7               |
| Alluvia, tinofovir and lamuvudine | 2             | 3.4               |
| Starter pack                      | 6             | 10.2              |
| Incorrectly captured              | 2             | 3.4               |
| <b>TOTAL</b>                      | <b>59</b>     | <b>100</b>        |

The majority of participants were on Stavudine, lamuvidine and nevirapine (Stalanev), six participants were starting and two participants were incorrectly captured (Table 3.3).

### 3.2.4 Distribution of participants according to period they had been on ARVs (in months).

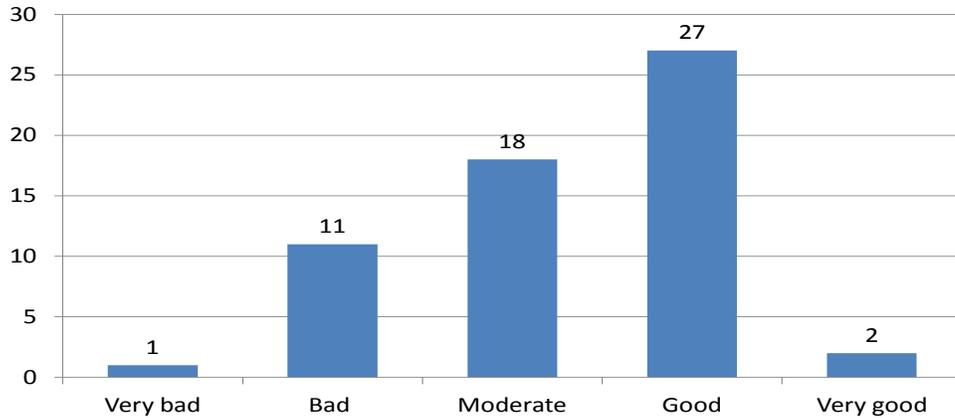
*Figure 3.3: Box plot showing the distribution participants according to period on ARVs.*



Period participants had been on ARVs ranged from zero to 96 months. The median period was 13 months (I.Q 3;29).

### 3.2.5 Participants' rating of own Physical Health

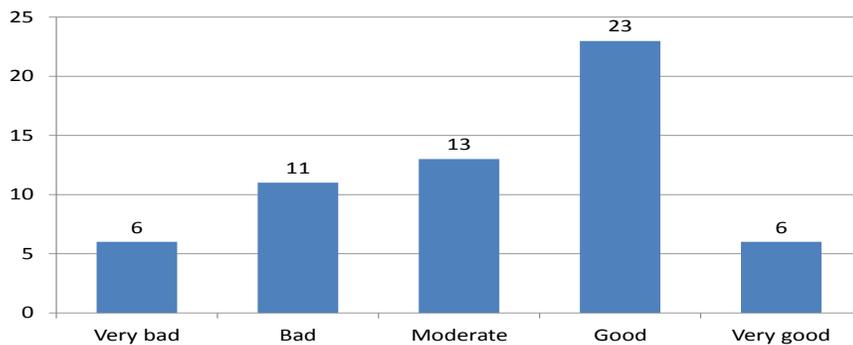
*Figure 3.4: Distribution according to physical health*



Forty-nine percent of the participants rated their physical health as good to very good, 51% as moderate very bad (Figure 3.4).

### 3.2.6 Participants' rating of own Mental and emotional health

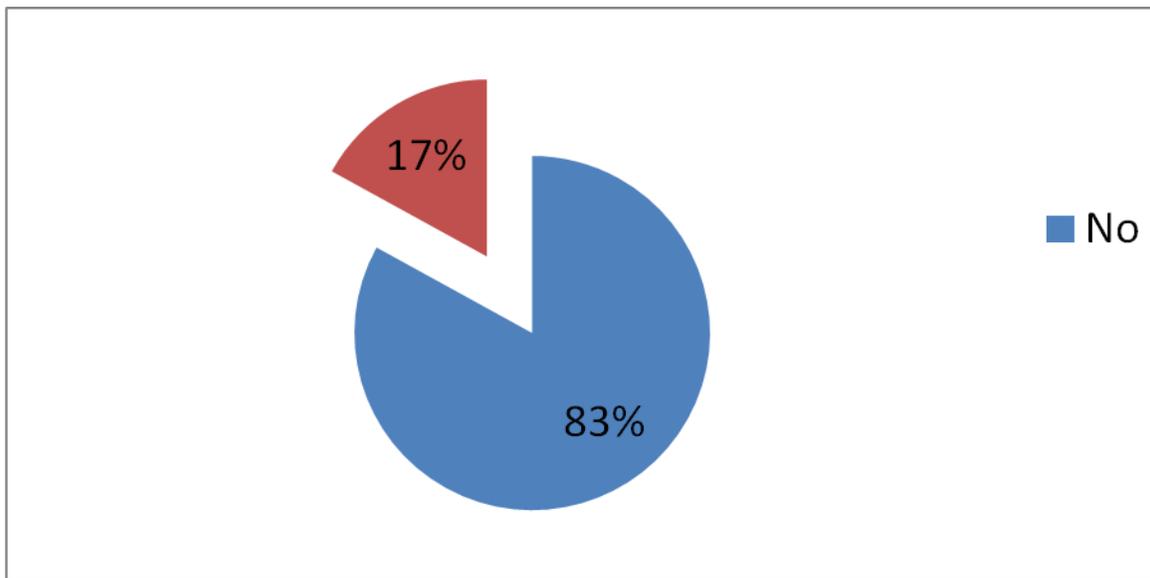
*Figure 3.5: Participants' mental and emotional health.*



From the diagram above, forty-nine percent rated their mental and emotional health as good to very good, 22% as moderate and 29% as bad to very bad (Figure 4.5).

### 3.2.7 Previous injuries

*Figure 3.6: Distribution of participants according to previous injury.*

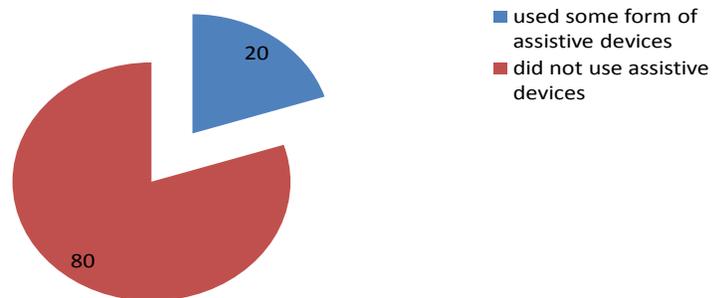


Forty-nine (83%) had no previous injuries (Fig 3.6).

### 3.3 Other factors

#### 3.3.1 Use of assistive devices

Figure 3.7: Distribution of participants according to use of assistive devices



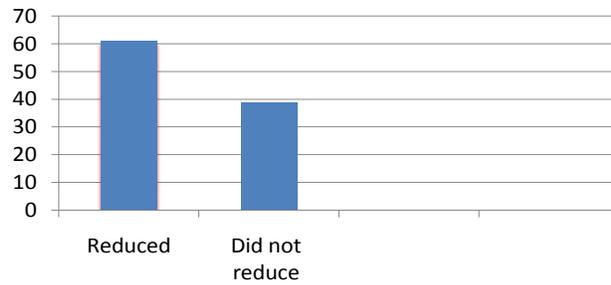
Twelve (20%) used some form of assistive devices (Fig 3.7).

#### 3.3.2 Personal assistant

Thirty-two (54%) had someone assisting them because of limitations in their performance of activities of daily living. Of those who had assistance, wife (37.5%) and children (28%) were providing the assistance. Only one participant cited husband.

### 3.3.3 Reduction of usual activities

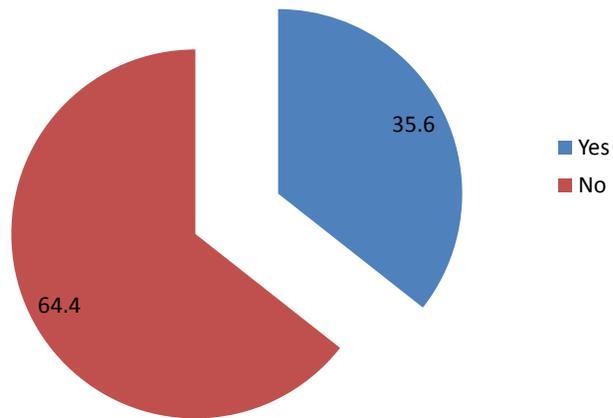
*Figure 3.8: Distribution of participants according to reduction of usual activities*



Thirty-six (61%) reported that they had reduced their usual activities or work because of their health condition (Fig 3.8).

### 3.3.4 Stopped usual activities

*Figure 3.9: Distribution of participants according to stopping of usual activities*



Twenty-one (35.6%) had been totally unable to carryout usual activities or work because of their condition (Fig 3.9).

### 3.4 Prevalence of Activity limitations/Participation restrictions

The prevalence of activity limitations/participation restrictions were calculated as percentages of those who specified the extent of limitation/restriction they experienced in their day-to-day life. Those for whom a certain item was not applicable were not included. For purposes of data presentation in this section activity limitation/participation restriction was grouped into two categories, that is, **no difficulty** for those who rated their level of activity limitation/participation restriction as 0, and **some to complete difficulty** if a participant rated their level of difficulty as 1 to 4 (minimum to complete difficulty). Therefore, for each activity or participation area, a proportion of those with minimum to complete difficulty were calculated as the prevalence of activity limitation/participation restriction (Tables 3.4 -.3.9).

#### 3.4.1 Mobility domain

**Table 3.4: Distribution of participants according to limitations and restrictions in the mobility domain**

| Activity                | No difficulty | Some to complete difficulty | Total |
|-------------------------|---------------|-----------------------------|-------|
| Lifting and carrying    | 17            | 41                          | 58    |
| Fine hand use           | 41            | 17                          | 58    |
| Walking                 | 17            | 41                          | 58    |
| Moving with equip       | -             | 7                           | 7     |
| Use of public transport | 37            | 21                          | 58    |
| Driving                 | 8             | 11                          | 19    |

Of 58 participants who specified their activity and participation in mobility domain, the following proportions had some to complete difficulty with the following activities; 71% with lifting and carrying and 71% with walking. All the seven who used some equipment for moving about reported some to complete difficulty in using the equipment. Of the 19 licensed drivers in the study, 58% had some to complete difficulty with driving (Table 3.4).

The reasons given by participants for problems in this domain were parasthesia/tingling sensation/numbness in feet and hands (peripheral neuropathy), low endurance/general body weakness, pain, shortness of breath, swelling/oedema, spasticity and paralysis, concentration problems, visual problems, in-coordination, and negative comments from the public.

### 3.4.2 Self-care Domain

**Table 3.5: Distribution of participants according to limitations and restrictions in the self-care domain**

| Activity                 | No difficulty | Some to complete difficulty | Total |
|--------------------------|---------------|-----------------------------|-------|
| Bathing                  | 41            | 17                          | 58    |
| Caring for body parts    | 46            | 12                          | 58    |
| Toileting                | 48            | 10                          | 58    |
| Dressing                 | 48            | 10                          | 58    |
| Eating                   | 56            | 2                           | 58    |
| Drinking                 | 57            | 1                           | 58    |
| Looking after own health | 52            | 4                           | 56    |

|  |  |  |  |
|--|--|--|--|
|  |  |  |  |
|--|--|--|--|

Of the 58 participants who specified the level of difficulty they experienced carrying out self-care activities, the following reported some to complete difficulty performing the activities; 29% with bathing, 21% with caring for body parts (grooming), 17% with toileting, 17% with dressing, 3% with eating and 2% with drinking (Table 3.5).

The reasons given for some of the limitations in self-care domain were low endurance, pain, peripheral neuropathy, poor hand function, problems assuming certain positions, hemiplegia and incontinence.

### 3.4.3 Limitations and restrictions experienced in the domestic life

**Table 3.6: Distribution of participants according to limitations in Domestic life domain**

| Activity         | No difficulty | Some to complete difficulty | Total |
|------------------|---------------|-----------------------------|-------|
| Shopping         | 25            | 31                          | 56    |
| Cooking          | 34            | 22                          | 56    |
| Housework        | 25            | 30                          | 55    |
| Assisting others | 24            | 12                          | 36    |

Of the 56 participants who indicated the level of difficulty they experience with shopping, 55% indicated that they had some to complete difficulty. Thirty-nine percent had some to complete difficulty with cooking and about 55% with housework (Table: 3.6).

The reasons given for limitations in the domestic life domain were low endurance, mobility problems, peripheral neuropathy, backache, visual problems and swelling of the face attracting the attention of the public.

### 3.4.5 Interpersonal relationships

**Table 3.7: Distribution according to limitations in Interpersonal interactions and relationships**

| Activity        | No difficulty | Some to complete difficulty | Total |
|-----------------|---------------|-----------------------------|-------|
| Basic           | 51            | 7                           | 58    |
| Complex         | 46            | 7                           | 53    |
| Strangers       | 48            | 10                          | 58    |
| Formal          | 39            | 7                           | 46    |
| Informal        | 49            | 8                           | 57    |
| Family (d760)   | 47            | 11                          | 58    |
| Intimate (d770) | 27            | 14                          | 41    |

Fifty-one (88%) of 58 participants who indicated level of difficulty they experienced with basic interpersonal relationships indicated that they had no difficulty at all in this regard (Table 3.7). Thirty-four percent had some to complete difficulty with their intimate relationships. It is also important to note that 18 (31%) of the 59 participants felt that the question on intimate relationships was either not applicable to them or they just did not want to say.

The reasons given by participants for having problems with interpersonal relationships were speech problems, spouse/participant's pain, poor sensation, poor bed mobility, shyness, low endurance, low libido, discordance among couples, negative attitudes towards people living with HIV/AIDS and feeling discriminated against.

### 3.4.6 Major life areas

**Table 3.8: Distribution of participants according to limitations in Major life domain**

| <b>Activity</b>                           | <b>No difficulty</b> | <b>Some to complete difficulty</b> | <b>Total</b> |
|---|----------------------|------------------------------------|--------------|
| <b>Informal education (d810)</b>          | 11                   | 5                                  | 16           |
| <b>Formal education (d820)</b>            | 10                   | 5                                  | 15           |
| <b>Remunerative employment (d850)</b>     | 14                   | 31                                 | 45           |
| <b>Basic economic transactions (d860)</b> | 49                   | 8                                  | 57           |
| <b>Economic self sufficiency (d870)</b>   | 12                   | 45                                 | 57           |
|   |                      |                                    |              |

About 79% of participants reported being restricted in their participation in economic self sufficiency and 69% were restricted in participating in remunerative employment. Eight-three percent of the participants had no difficulty in participating in basic economic transactions. Only 27% and 25% of participants were participating or felt that informal education and formal education were applicable to them respectively (Table 3.8).

The reasons given for restrictions felt in involvement in major life areas were low endurance, pain, mobility problems, lack of financial resources, bad mental and

emotional state, time constraints, illness, peripheral neuropathy, memory problems and negative reactions from the public.

### 3.4.7 Community, social and civic life domain

**Table 3.9: Distribution of participants according to limitations in Community, social and civic life**

| Activity                              | No difficulty | Some to complete difficulty | Total |
|---------------------------------------|---------------|-----------------------------|-------|
| Community life (d910)                 | 31            | 19                          | 50    |
| Recreation and leisure (d920)         | 26            | 18                          | 44    |
| Religion and spirituality (d930)      | 43            | 13                          | 56    |
| Human rights (d940)                   | 11            | 8                           | 19    |
| Political life and citizenship (d950) | 10            | 8                           | 19    |

Of those who were involved in Human rights and Politics, 42% and 44% experienced some to complete difficulty in participating respectively. Of those who were participating in religion and spirituality, community life and in recreation and leisure; 23%, 38% and 41% experienced some to complete difficulty respectively (Table 3.9).

The reasons given for participation restrictions in the community, social and civic life were upbringing, mobility problems, bad emotional and mental state, no interest, lack of transport, other commitments and stigma.

### **3.5 Environmental factors**

The ICF includes an environmental factor classification that makes it possible to identify environmental barriers and facilitators for capacity and performance of actions and tasks in daily living. Interventions that focus on an individual's performance may seek environmental modifications which can be achieved by either eliminating the barrier or creating environmental facilitators for improved performance of actions and tasks in daily living (WHO, 2002).

**Table 3.10: Distribution of participants according to experienced Environmental Facilitators and barriers**

|             | <b>Environmental factor</b>   | <b>Facilitator</b> | <b>Barrier</b> |
|-------------|---|--------------------|----------------|
| <b>E3</b>   | <b>Support and relationships</b>  | n (%)              | n (%)          |
| <b>e310</b> | Immediate family  | 44 (75%)           | 10 (17%)       |
| <b>e320</b> | Friends   | 36 (61%)           | 7 (12%)        |
| <b>e325</b> | Acquaintances, peers, colleagues, neighbours and community members      | 33 (56%)           | 12 (20%)       |
| <b>e330</b> | People in position of authority   | 19 (32%)           | 11 (19%)       |
| <b>e340</b> | Personal care providers and personal assistants                         | 15 (25%)           | 0 (0%)         |
| <b>e355</b> | Health professionals  | 51 (86%)           | 3 (5%)         |
| <b>e360</b> | Health related professionals  | 40 (68%)           | 0 (0%)         |
| <b>E4</b>   | <b>Attitudes</b>  |                    |                |
| <b>e410</b> | Individual attitudes of immediate family members                        | 46 (78%)           | 7 (12%)        |
| <b>e420</b> | Individual attitudes of friends   | 37 (63%)           | 10 (17%)       |
| <b>e440</b> | Individual attitudes of personal care providers and personal assistants | 12 (20%)           | 1 (2%)         |
| <b>e450</b> | Individual attitudes of health professionals                            | 52 (88%)           | 3 (5%)         |
| <b>e455</b> | Individual attitudes of health related professionals                    | 41 (69%)           | 1 (2%)         |
| <b>e460</b> | Societal attitudes  | 23 (39%)           | 22 (37%)       |
| <b>e465</b> | Social norms, practices and ideologies                                  | 4 (7%)             | 14 (24%)       |
| <b>E5</b>   | <b>Services, systems and policies</b>                                   |                    |                |
| <b>e525</b> | Housing services, systems and policies                                  | 9 (15%)            | 23 (39%)       |
| <b>e535</b> | Communication services, systems and policies                            | 14 (24%)           | 8 (14%)        |
| <b>e540</b> | Transportation services, systems and policies                           | 16 (27%)           | 17 (29%)       |
| <b>e550</b> | Legal services, systems and policies                                    | 7 (12%)            | 14 (24%)       |
| <b>e570</b> | Social security, services, systems and policies                         | 7 (12%)            | 19 (32%)       |
| <b>e575</b> | General social support services, systems and policies                   | 8 (14%)            | 9 (15%)        |
| <b>e580</b> | Health services, systems and policies                                   | 40 (68%)           | 5 (8%)         |
| <b>e585</b> | Education and training services, systems and policies                   | 15 (25%)           | 3 (5%)         |
| <b>e590</b> | Labour and employment services, systems and policies                    | 6 (10%)            | 18 (31%)       |

***NB: All percentages are to the nearest whole number.***

The environmental factors cited most as facilitators were the support and relationships of health professionals (86%), immediate family (75%), health-related professionals (68%) and friends (61%); the attitudes of health professionals (88%), immediate family (78%), health related professionals (69%) and friends (63%) and health services, systems and

policies (68%). The most cited barriers were societal attitudes (37%), housing services, systems and policies (39%), social security, services and policies (32%) and labour and employment services, systems and policies (31%) (Table 3.10).

### 3.6 Activity/Participation domains most/least affected

**Table 3:11: Domains least/most affected**

| Variable | No. responded | Mean | S.D  | Median |
|----------|---------------|------|------|--------|
| Totmob   | 58            | 4.9  | 4.1  | 4      |
| Totself  | 58            | 1.9  | 3.7  | 0      |
| Totdom   | 57            | 3.7  | 3.9  | 3      |
| Totinter | 58            | 2.3  | 4.8  | 0      |
| Totmaj   | 58            | 4.8  | 4.4  | 4      |
| Totcomm  | 56            | 3.4  | 5.5  | 0      |
| totscore | 58            | 20.8 | 19.8 | 15     |
| D430     | 58            | 1.7  | 1.4  | 2      |
| D440     | 58            | 0.7  | 1.2  | 0      |
| D450     | 58            | 1.7  | 1.4  | 2      |
| D465     | 7             | 2.9  | 0.4  | 3      |
| D470     | 58            | 0.8  | 1.2  | 0      |
| D475     | 19            | 1.8  | 1.8  | 2      |
| D510     | 58            | 0.6  | 1.1  | 0      |
| D520     | 58            | 0.4  | 0.8  | 0      |
| D530     | 58            | 0.3  | 0.8  | 0      |
| D540     | 58            | 0.3  | 0.8  | 0      |
| D550     | 58            | 0.1  | 0.3  | 0      |
| D560     | 58            | 0.03 | 0.3  | 0      |
| D570     | 56            | 0.1  | 0.6  | 0      |
| D620     | 56            | 1.3  | 1.4  | 1      |
| D630     | 56            | 0.8  | 1.2  | 0      |
| D640     | 55            | 1.3  | 1.4  | 1      |
| D660     | 36            | 0.5  | 0.9  | 0      |
| D710     | 58            | 0.2  | 0.8  | 0      |
| D720     | 53            | 0.3  | 0.8  | 0      |
| D730     | 58            | 0.3  | 0.7  | 0      |
| D740     | 46            | 0.3  | 0.9  | 0      |
| D750     | 57            | 0.2  | 0.7  | 0      |
| D760     | 58            | 0.4  | 1.1  | 0      |
| D770     | 41            | 0.9  | 1.4  | 0      |
| D810     | 16            | 1.1  | 1.7  | 0      |
| D820     | 15            | 1.3  | 1.7  | 0      |
| D850     | 45            | 2.2  | 1.7  | 2      |
| D870     | 57            | 2.2  | 1.4  | 2      |
| D910     | 50            | 1.1  | 1.6  | 0      |
| D920     | 44            | 1.3  | 1.7  | 0      |
| D930     | 56            | 0.7  | 1.4  | 0      |
| D950     | 18            | 1.1  | 1.6  | 0      |

To determine the most affected domain, the Statistical package SAS was used to calculate the totals, means, medians and standard deviations for individual items, domains and the total score for all domains. The most affected domains were mobility, domestic life and major life (Table 4.11). The least affected domains were self-care and interpersonal interactions and relationships. The most affected items under mobility were moving around using equipment (d465), driving (d475), lifting and carrying (d430) as well as walking (d440). The most affected items in the major life domain were participation in remunerative employment (d850) and economic self sufficiency (d870). The least affected items were eating (d550) and drinking (d560) under self-care domain and basic interpersonal interactions (d710) and informal social relationships (d750) under interpersonal interactions and relationships (Table 3:11).

### **3.7 Internal Consistency and Reliability**

Before any associations were tested internal consistency and scale reliability (Cronbach's alpha) were calculated. The standardized alpha coefficient provides information about how each variable reflects the reliability of the scale with standardized variables. If the standardized alpha decreases after removing a variable from the construct, then the variable is strongly correlated with other variables in the scale. On the other hand, if the standardized alpha increases after removing a variable from the construct, then removing this variable from the scale makes the construct more reliable.

#### **3.7.1 Domain- total correlation and Cronbach Coefficient alpha**

For the domain- total correlation, the raw and standardized Cronbach Coefficient Alpha was 0.86. The Cronbach Coefficient Alphas with the deleted variable were as shown on Table 3.12 below.

**Table 3.12: Cronbach Coefficient Alpha with Deleted Variable**

| Deleted variable | Variable Correlation with total | Cronbach alpha |
|------------------|---------------------------------|----------------|
| Totmob           | 0.75                            | 0.82           |
| Totself          | 0.71                            | 0.83           |
| Totdom           | 0.73                            | 0.83           |
| Totinter         | 0.39                            | 0.89           |
| Totmaj           | 0.64                            | 0.84           |
| Totcomm          | 0.75                            | 0.82           |

Key :

totmob- total mobility score

totself- total self-care score

totdom- total domestic life score

totinter- total interpersonal score

totmaj- total major life score

totcomm- total community and civic life score

All domains had a Reliability correlation coefficient of 0.70 and above except the domains for interpersonal interactions and relationships (0.41) and major life (0.64). The Cronbach Coefficient alpha for all domains decreased with the deletion of each of the domain variables except for interpersonal interactions and relationships which slightly increased the Cronbach alpha coefficient. Therefore, there is high internal consistency for all the domains.

### **3.7.2 Domain- Domain Correlation (Item-item)**

When the Pearson Correlation Coefficients were computed to determine how the specific domains correlated with each other, the item-item correlation was high for all domains

and was statistically significant ( $p < 0.05$ ) except for interpersonal interactions which was weakly correlated with the domains of self care (0.22) and domestic life (0.16) and the correlation was also not statistically significant ( $p = 0.1$  and  $0.24$ ) respectively (Table 3.13). On Table 3.13 below, the number on the top depicts the Correlation Coefficient whereas the one at the bottom is the p-value for statistical significance of the correlation between the domains.

**Table 3.13** **Pearson Correlation Coefficients, N = 55**  
 Prob > |r| under H0: Rho=0

|          | totmob            | totself           | totdom            | totinter          | totmaj            | totcomm           |
|----------|-------------------|-------------------|-------------------|-------------------|-------------------|-------------------|
| totmob   | 1.00000           | 0.77327<br><.0001 | 0.76673<br><.0001 | 0.28105<br>0.0377 | 0.51969<br><.0001 | 0.51944<br><.0001 |
| totself  | 0.77327<br><.0001 | 1.00000           | 0.69230<br><.0001 | 0.22407<br>0.1001 | 0.46248<br>0.0004 | 0.57623<br><.0001 |
| totdom   | 0.76673<br><.0001 | 0.69230<br><.0001 | 1.00000           | 0.16203<br>0.2373 | 0.50628<br><.0001 | 0.66010<br><.0001 |
| totinter | 0.28105<br>0.0377 | 0.22407<br>0.1001 | 0.16203<br>0.2373 | 1.00000           | 0.42270<br>0.0013 | 0.51836<br><.0001 |
| totmaj   | 0.51969<br><.0001 | 0.46248<br>0.0004 | 0.50628<br><.0001 | 0.42270<br>0.0013 | 1.00000           | 0.58719<br><.0001 |
| totcomm  | 0.51944<br><.0001 | 0.57623<br><.0001 | 0.66010<br><.0001 | 0.51836<br><.0001 | 0.58719<br><.0001 | 1.00000           |

**Key:**

totmob- total mobility score

totself- total self-care score

totdom- total domestic life score

totinter- total interpersonal score

totmaj- total major life score

totcomm- total community and civic life score

## **3.8 Internal Consistency and Reliability of items within each domain**

### **3.8.1 Mobility**

All items in the mobility domain were internally consistent except for d440 which caused Cronbach Coefficient alpha to increase when it was deleted. The Cronbach Coefficient alpha was however 0.80 for the domain. All items were significantly correlated ( $p < 0.01$ ) with each other indicating high reliability and internal consistency of the items.

### **3.8.2 Self care**

All items were correlating well with the domain total (Correlation coefficient of 0.4 and above). All items also showed internal consistency except for d550 which increased the Cronbach alpha slightly when the item was deleted. Cronbach alpha for all items was 0.85. Item-item correlation within the domain showed Pearson Correlation Coefficients of 0.23 to 0.89 with most items statistically significantly correlated ( $p \leq 0.04$ ) except d550 & d510 ( $p = 0.07$ ) and d550 & d530 ( $p = 0.09$ ).

### **3.8.3 Domestic life**

All items were correlating highly with each other (Pearson's Correlation coefficient of 0.81 to 0.89) and they were all statistically significant ( $p < 0.0001$ ). The Cronbach alpha was 0.94 with each of the items deleted a figure which is below both the raw and standardized alpha. Therefore, there is high internal consistency and good reliability.

### **3.8.4 Interpersonal interactions and relationships**

All the Cronbach Coefficient alphas went down with deletion of each item except for d770 which increased the Cronbach alpha. The items were all correlating well (Pearson's Correlation Coefficient 0.42 to 0.97) and the correlation was statistically significant ( $p = 0.01$  to  $p < 0.0001$ ). Therefore the items have high internal consistency and reliability.

### **3.8.5 Major life areas**

All Cronbach Coefficient alphas decreased following deletion of all items except for item d860 which slightly increased the Cronbach Coefficient alpha. The Cronbach Coefficient

alpha ranged from 0.91 to 0.96. The major life domain items except d860 and d870 (Pearson's correlation coefficient of 0.46 and  $p = 0.1$ ) were also highly correlated with each other (Pearson's correlation coefficient of 0.63 to 0.95 and  $p = 0.02$  to  $p < 0.0001$ ). Therefore the internal consistency and reliability was high.

### **3.8.6 Community, social and civic life**

All items correlated highly with the domain total (0.86 to 0.94) and Cronbach Coefficient alphas for all items except d940 decreased when the item was deleted showing good internal consistency. Pearson's Coefficient Correlation ranged from 0.79 to 0.98 and  $p < 0.0001$ ).

### **3.9 Factors that predict quality of life.**

A higher total score or domain score indicates a lower quality of life (0= no difficulty, 4= complete difficulty). The main outcome variables were total instrument score and domain total score which are both continuous variables. Additional outcome variables were reduction of usual activities and stopping of usual activities due to the health condition. The main independent variables were last CD4 count, period on ARVs and type of ARV. The covariates were age, sex, educational level, marital status, current occupation, period since last CD4 count, physical health, mental health, previous injuries, use of other medication, use of assistive devices as well as having someone assisting with daily activities. Both unadjusted and adjusted analysis were done to determine the relationship between Last CD4 count and domain totals and last CD4 count and total score, and the relationship between period on ARVs and domain totals and period on ARVs and total score. Correlation and simple regression analyses were done.

### 3.9.1 Unadjusted analysis (Univariate analysis)

**Table 3.14: Relationship between Period on ARVs and quality of life**

| Variable                 | Mean | SD   | Pearson's Correlation Coefficient | P-value |
|--------------------------|------|------|-----------------------------------|---------|
| Total score              | 20.8 | 19.8 | -0.19                             | 0.16    |
| Mobility                 | 4.9  | 4.1  | -0.06                             | 0.6     |
| Self-care                | 1.9  | 3.7  | -0.17                             | 0.2     |
| Domestic life            | 3.7  | 3.9  | -0.24                             | 0.08    |
| Interpersonal            | 2.3  | 4.8  | 0.04                              | 0.74    |
| Major life               | 4.8  | 4.4  | -0.17                             | 0.20    |
| Community and civic life | 3.40 | 5.5  | -0.27                             | 0.04*   |

\*Statistically significant

Period one had been on ARVs was statistically negatively associated with one's participation in community and civic life ( $p= 0.04$ ), that means the lower the period one had been on ARVs the higher the total score (the greater the difficulty one experienced in participating in community and civic life). Period on ARVs was not statistically significantly associated with one's mobility, self-care, participation in domestic life, interpersonal interactions and major life (Table 3.14).

**Table 3.15: Relationship between Last CD4 Count and quality of life**

| Variable                 | Mean | SD   | Pearson's Correlation Coefficient | P-value |
|--------------------------|------|------|-----------------------------------|---------|
| Total score              | 20.8 | 19.8 | 0.06                              | 0.9     |
| Mobility                 | 4.9  | 4.1  | 0.05                              | 0.7     |
| Self-care                | 1.9  | 3.7  | 0.008                             | 1       |
| Domestic life            | 3.7  | 3.9  | 0.04                              | 0.8     |
| Interpersonal            | 2.3  | 4.8  | -0.000                            | 1       |
| Major life               | 4.8  | 4.4  | 0.07                              | 0.6     |
| Community and civic life | 3.40 | 5.5  | -0.1                              | 0.5     |

**\*Statistically significant**

Last CD4 count was not statistically significantly associated with any of the domains or the total score ( $p > 0.5$ ) (Table 3.15).

### **Relationship between type of ARV and quality of life**

Table 3.16: Relationship between type of ARV and quality of life

| Variable                 | P-value |
|--------------------------|---------|
| Total score              | 0.02*   |
| Mobility                 | 0.2     |
| Self-care                |         |
| Domestic life            | 0.1     |
| Interpersonal            | 0.03*   |
| Major life               | 0.09    |
| Community and civic life | 0.04*   |

**\*Statistically significant**

Type of ARV was statistically significantly associated with quality of life (total score) ( $p = 0.02$ ), interpersonal interactions and relationships ( $p = 0.03$ ) and participation in community and civic life ( $p = 0.04$ ) in an unadjusted analysis (Table 3.16).

### 3.9.2 Adjusted analysis (Multivariate analysis)

This was done to take care of possible confounding factors.

**Table 3.17: P- values for adjusted analysis**

|                                   | Total/<br>Overall<br>score | Mobility | Self-<br>care | Domesti<br>c<br>life | Interpersonal<br>interactions | Major<br>life | Commu<br>nity life |
|-----------------------------------|----------------------------|----------|---------------|----------------------|-------------------------------|---------------|--------------------|
| <b>Type of<br/>ARV</b>            | 0.7                        | 0.6      | 0.6           | 0.7                  | 0.4                           | 0.6           | 0.9                |
| <b>Period on<br/>ARV</b>          | 0.4                        | 0.3      | 1             | 0.4                  | 1                             | 0.1           | 0.2                |
| <b>Last CD4</b>                   | 0.1                        | 0.8      | 0.8           | 0.5                  | 0.2                           | 0.06          | 0.3                |
| <b>Age</b>                        | 0.6                        | 0.2      | 0.6           | 0.6                  | 0.7                           | 0.8           | 0.7                |
| <b>Sex</b>                        | 1                          | 0.9      | 1             | 0.7                  | 0.8                           | 1             | 0.6                |
| <b>Education</b>                  | 0.3                        | 0.7      | 0.6           | 0.2                  | 0.8                           | 0.3           | 0.2                |
| <b>Marital<br/>status</b>         | 0.6                        | 0.6      | 0.4           | 0.9                  | 0.6                           | 1             | 0.7                |
| <b>Occup</b>                      | 0.06                       | 0.3      | 0.1           | 0.2                  | 0.7                           | 0.06          | 0.1                |
| <b>Periodsinc<br/>elastCD4</b>    | 0.8                        | 1        | 0.3           | 0.3                  | 0.2                           | 0.7           | 0.3                |
| <b>Physical<br/>health</b>        | 0.01*                      | 0.0002*  | 0.1           | 0.04*                | 0.2                           | 0.4           | 0.3                |
| <b>Mental<br/>health</b>          | 0.04*                      | 0.5      | 0.9           | 0.9                  | 0.0002*                       | 0.3           | 0.2                |
| <b>Previous<br/>injuries</b>      | 0.4                        | 0.3      | 0.3           | 0.8                  | 0.8                           | 0.3           | 0.6                |
| <b>Other<br/>medication<br/>s</b> | 0.1                        | 0.4      | 0.8           | 0.8                  | 0.04*                         | 0.1           | 0.02*              |
| <b>Ass device</b>                 | 0.02*                      | 0.02*    | 0.4           | 0.05*                | 0.2                           | 0.3           | 0.006*             |
| <b>assistant</b>                  | 0.1                        | 0.2      | 0.05*         | 0.04*                | 0.4                           | 0.2           | 0.1                |

\*Statistically significant

When all other variables were controlled for, type of ARV, period one has been on ARVs, last CD4 count, age, sex, education, marital status, previous injuries and current occupation were not statistically significantly associated with either the total score or the specific domains. One's rating of their physical health was statistically significantly associated with the total score ( $p= 0.01$ ), mobility ( $p= 0.0002$ ), and domestic ( $p= 0.04$ ). It is important to note that one's rating of their physical health was not significantly associated with one's involvement in self-care activities ( $p= 0.1$ ), major life ( $p= 0.4$ ) and community and civic life activities ( $p= 0.3$ ).

One's rating of their mental and emotional health was statistically significantly associated with the overall score ( $p= 0.04$ ) and interpersonal interactions and relationships ( $p= 0.0002$ ). Use of assistive devices were predictive of the overall score (quality of life) ( $p= 0.02$ ), mobility ( $p= 0.02$ ), domestic ( $p= 0.05$ ) and involvement in community and civic activities ( $p= 0.006$ ). Use of other medications was statistically significantly associated with one's interpersonal interactions and relationships ( $p= 0.04$ ) and involvement in community and civic life ( $p= 0.02$ ). Having an assistant was statistically significantly associated with extent of difficulties experienced with self-care activities ( $p= 0.05$ ) and domestic life ( $p= 0.04$ ).

Other associations which are worth mentioning although not statistically significant are that between occupation and overall score ( $p= 0.06$ ), occupation and major life ( $p=0.06$ ) and last CD4 count and major life ( $p= 0.06$ ) (Table 3.17).

### 3.10 Predictors of one reducing or stopping usual activities

#### 3.10.1 Factors predicting reduction of usual activities

Table 3.18 below shows the factors that were associated with one reducing their usual activities. These were indicated as Odds Ratios.

**Table 3.18: Predictive Factors for reducing usual activities**

| Variable              | Odds ratio | 95% C.I for odds ratio | p-value |
|-----------------------|------------|------------------------|---------|
| Period on ARV         | 0.96       | 0.909-1.008            | 0.09    |
| Last CD4              | 1.00       | 0.997-1.012            | 0.24    |
| ARV                   | 0.53       | 0.074-3.752            | 0.52    |
| Age                   | 0.98       | 0.874-1.104            | 0.76    |
| Male                  | 21.90      | 1.073-446.8            | 0.04    |
| Education             | 0.18       | 0.007-4.567            | 0.3     |
| Marital status        | 0.51       | 0.245-1.068            | 0.07    |
| Occupation            | 0.89       | 0.602-1.326            | 0.58    |
| Period since last CD4 | 0.96       | 0.849-1.073            | 0.43    |
| Physical health       | 0.35       | 0.074-1.674            | 0.19    |
| Mental health         | 1.33       | 0.525-3.353            | 0.55    |
| Previous injuries     | 0.2        | 0.015-2.618            | 0.22    |
| Other medications     | 0.36       | 0.005-25.354           | 0.64    |
| Assistive device      | 24.67      | 1.225-496.8            | 0.04    |
| Assistant             | 0.59       | 0.085-4.060            | 0.59    |

One's gender (O.R 21.9) and use of assistive devices (O.R 24.67) statistically significantly predicted reduction of usual activities due to the illness. Marital status (O.R 0.5) though not statistically significantly associated with reduction of usual activities may need further exploration in larger samples.

### 3.10.2 Factors that predicted stopping of usual activities

Table 3.19 below shows the factors that were associated with one completely stopping their usual activities.

**Table 3.19: Predictive factors for stopping usual activities**

| <b>Variable</b>              | <b>Odds ratio</b> | <b>95% C.I for odds ratio</b> | <b>p-value</b> |
|------------------------------|-------------------|-------------------------------|----------------|
| <b>Period on ARV</b>         | 0.92              | 0.843; 0.998                  | 0.05           |
| <b>Last CD4</b>              | 1.01              | 0.998; 1.020                  | 0.09           |
| <b>ARV</b>                   | 0.10              | 0.007; 1.367                  | 0.08           |
| <b>Age</b>                   | 0.95              | 0.806; 1.112                  | 0.51           |
| <b>Sex</b>                   | 0.58              | 0.045; 7.411                  | 0.67           |
| <b>Education</b>             | 0.03              | <0.001; 2.228                 | 0.11           |
| <b>Marital status</b>        | 0.94              | 0.420; 2.096                  | 0.88           |
| <b>Occupation</b>            | 1.75              | 1.064; 2.873                  | 0.03           |
| <b>Period since last CD4</b> | 0.99              | 0.862; 1.127                  | 0.84           |
| <b>Physical health</b>       | 0.94              | 0.197; 4.485                  | 0.94           |
| <b>Mental health</b>         | 0.46              | 0.149 1.451                   | 0.19           |
| <b>Previous injuries</b>     | 0.24              | 0.005; 12.829                 | 0.48           |
| <b>Other medications</b>     | 0.01              | <0.001; 1.495                 | 0.07           |
| <b>Assistive device</b>      | 26.8              | 0.872; 825.1                  | 0.06           |
| <b>Assistant</b>             | 0.46              | 0.052; 4.061                  | 0.48           |

Period one has been on ARVs (O.R 0.92) and one's occupation (O.R 1.75) were statistically significant in explaining stopping of usual activities as shown by the p-values and 95% Confidence intervals of the odds ratios which do not include a one (Table 3.19).

## **CHAPTER FOUR: DISCUSSION**

### **4.1 Discussion of Methodology**

The instrument used for data collection is not validated on HIV/AIDS patients. However, it was validated on other conditions (Uhlig et al, 2007) and the developers of the instrument meant that it be used to collect health related functional status data across all conditions (WHO, 2001).

There is likely to be volunteer bias as those who volunteer to participate may be systematically different in terms of their quality of life from those who refused. Those who took part may be the survivors of the pandemic (survivor bias). External validity may be limited due to the fact that the study was done at only one institution that may be catering for a certain type of clientele. However, the same researcher assessed all participants, thus intra observer variation limited.

Participants were drawn from one setting which is a referral setting, and since the services were decentralized to districts and local clinics by the time of the data collection, those who continued to receive services at the institution may differ from those referred to their local clinics in terms of their response to treatment, activity limitations and participation restrictions.

Consecutive sampling was used to enroll patients for the study, that is, all the patients available on the days of data collection had a chance to be involved in the study.

Interviewer bias cannot be ruled out. Respondents may have exaggerated the extent of their activity limitations and participation restrictions if they felt it could enhance their chances of benefiting from free services.

A sample size of 59 is large enough to make conclusions on the prevalence and extent of activity limitations and participation restrictions experienced by PLWHA.

## **4.2 Demographic profile of participants**

### **4.2.1 Age**

The ages of participants ranged from 22 years to 63 years with a mean age of 41.6 years (S.D 9.3 years). The median age was 40 years. According to Zimbabwean HIV positive population based literature, age range 15- 49 years is the most affected constituting about 88% of HIV positive people 15 years old and above (MoHCW, 2010). This group constitutes the reproductive and most sexually active age group.

### **4.2.2 Gender**

Fifty-four percent of respondents were female. A higher proportion of women is consistent with the last census results which showed that 52% of the Zimbabwean population was female (CSO, 2002). The Zimbabwe Demographic Health Survey of 2005- 2006 also showed that the prevalence of HIV was higher in women (21.1%) than in men (14.5%)(CSO and MoHCW, 2007) . This was true in both rural and urban settings. This was also supported by the 2009 HIV estimates which gave 59% as the proportion of women infected among the 15 years and above age category (MoHCW, 2010). Women are vulnerable to HIV due to various reasons including biological factors, socio-economic factors leading women to fail to negotiate for safer sex as well as cultural beliefs and practices (NAC and UNPFA, 2006). In other previous studies (Zonta et al, 2003) the participants were mainly male homosexual and intravenous drug users. In Zimbabwe the main (over 90%) mode of HIV transmission is heterosexual intercourse (NAC and UNPFA, 2006). It is also important to note that the age of those infected is steadily increasing, and this is most likely to be due to the availability of antiretroviral drugs which are prolonging life.

### **4.2.3 Education**

Sixty-six percent had gone up to Ordinary level and only 12% had tertiary education. It is important to note that the least educated participant had primary education up to Grade 7 and all participants were able to read and write. These findings are consistent with high literacy rates (92%) reported on Zimbabwe. The entry point into formal employment or

tertiary education is a pass at Ordinary level hence the majority of the participants having reached Ordinary level. Those who failed to get to Ordinary level cited financial constraints. The possible reason for few (12%) participants having tertiary education is probably because the study was done at a Government institution where the services were highly subsidized. The more educated and presumably the more affluent may have visited private institutions. Results of the 2005-2006 demographic health survey revealed that in Zimbabwe, HIV prevalence was lowest among women and men with more than secondary education (CSO and MoHCW, 2007).

#### **4.2.4 Marital status**

Fifty-four percent of participants were married, 18% were widowed, 12% were divorced and 3% were single. About 63% of the married were male and 89% of the widowed were women. The proportion of those single and divorced was almost similar among male and female. The reasons for a high proportion of females among the widowed may be that infected men die earlier from HIV leaving their wives widowed or the widowed men get married more easily compared to widowed women. The same reason may explain a higher percentage of males in the married category.

#### **4.2.5 Current occupation**

In this sample, about 25% were formally employed and an equal number were unemployed due to their HIV-related illnesses. Previous studies noted that prolonged survival can compromise one's capacity for work and productivity (O'Brien et al, 2006; Bopp et al, 2003). In Zonta et al's (2003) study, 49% had left their profession due to reasons related to their HIV-infection. This has important implications in terms of crafting ways of retaining these people on their jobs and at the same time maximizing their performance at work to avoid short changing employers. Occupational therapists are trained to work with clients with health problems with an ultimate goal of helping them to function at their maximum level by addressing the problem from various levels i.e impairment, activity limitation, participation restriction and addressing environmental factors that may be working against them as barriers while capitalizing on the facilitating aspects of the environment (Kielhofner, 2008; Pegretti et al, 2006; Radomski and

Trombly Latham, 2008). Thirty-four percent were self-employed, the majority not out of choice but due to lack of jobs. This may be due to high unemployment rates during the period of data collection as the country had gone through more than a decade of hard economic conditions. It is also important to note that the majority of participants had ordinary level and below and they had not necessarily passed five subjects hence the high unemployment rate.

### **4.3 Clinical profile of participants**

#### **4.3.1 Last CD4 Count and period on ARVs**

The last CD4 count of participants ranged from 14 to 716 with a mean of 223 and S.D of 153.9 and median of 189.5. The distribution was skewed due to few very high outliers. The distribution was wide due to the fact that the participants had been on ARVs for various periods of time ranging from less than a day to 96 months and a mean period of 19.5 months and median period of 13 months. Period since last CD4 ranged from less than a month to 40 months with mean period 8.9 months (S.D 10.3) and a median period of four months. Therefore, one's last CD4 count did not necessarily reflect one's present condition at the time of interview.

#### **4.3.2 Physical and mental & emotional health**

Fifty-one percent of participants rated their physical health as moderate to very bad. The major complains given for poor physical health were; general body weakness, low endurance, numbness and tingling in hands and feet (peripheral neuropathy), pain and shortness of breath. These complains are consistent with findings of previous studies by O'Brien et al (2006) and Rusch et al (2004). The same proportion rated their mental and emotional health as moderate to very bad with 29% of all participants rating it as very bad.

#### **4.3.3 Other factors**

The majority (83%) of participants had no previous injuries that affected their functioning implying that any present limitations in function were related to their HIV –related condition. Twenty percent used some form of assistive device and most of the devices

were meant to assist them with walking. Some of the assistive devices were improvised and not properly prescribed.

Fifty-four percent of participants were getting assistance for their daily activities and assistance was mostly coming from the family with wife (37.5%) and children (28%) mainly providing the assistance. Only one participant cited husband as the assistant. This reflects the caring and nurturing role played by women in our society. The implications are that women may be prevented from pursuing personal goals when someone gets sick in the home. Men should also be encouraged to participate in caring for sick family members.

Sixty-one percent of participants had reduced their usual activities and work while about 36% had stopped their usual activities and work due to their condition. This is consistent with O'Brien et al's (2006) findings. The role of rehabilitation professionals, especially occupational therapists to enable people to function at their maximum level come in handy. It is important to note that none of the participants were receiving any form of rehabilitation. Chances are that these people's participation in certain activities could be improved through exercise, energy conservation and work simplification techniques since most of them were limited by weakness, shortness of breath, pain and peripheral neuropathy

#### **4.4 Prevalence of Activity limitations and participation restriction**

The most affected domains were mobility, domestic life and major life. The least affected areas were self-care and interpersonal interactions and relationships. Mobility problems were caused by peripheral neuropathy, pain and low endurance. The aspects under mobility which were most affected were; moving around with equipment (using assistive devices) probably because the devices were not appropriately prescribed and there was no training done in using them, driving due to peripheral neuropathy and pain, lifting and carrying due to shortness of breath, low endurance and general body weakness, and walking due to general body weakness, shortness of breath, pain and peripheral neuropathy. Peripheral neuropathy, pain, low endurance and shortness of breath were

reported in previous studies as impairments associated with activity limitations in the mobility domain (Rusch et al, 2004). Peripheral neuropathy has also been suspected to be one of the adverse reactions of the antiretroviral drugs especially Stavudine (NDTPAC and MoHCW, 2010; The Herald, 2011). As a result regimens containing stavudine are being phased out in Zimbabwe (NDTPAC and MoHCW, 2010) in response to WHO's recommendation following evidence of its adverse effects from multicenter trials. In this study, 59% (35) of the participants were on stavudine containing regimens.

Participation in remunerative employment and economic self-sufficiency were major life challenges and these two are linked. In-order for one to participate in remunerative employment, one should be physically and mentally fit.

Interpersonal interactions and relationships and self-care were the least affected areas probably because these do not require much physical strength. It is however important to note that quite a significant proportion of participants (34%) reported some to complete difficulties in their intimate relationships due to low endurance, decreased libido, discordance, pain and neuropathy.

Rehabilitation practitioners are trained to help people increase their cardiovascular fitness through carefully selected exercises, activities and aerobic exercises (Bopp et al, 2003). Occupational therapists are especially trained to analyse activities of daily living and identify the specific performance components necessary for performance (Kielhofner, 2008; Radomski and Trombly Latham, 2008; Pedretti et al, 2006). According to the same authors, occupational therapists are also trained to adapt the environment and the way activities are done can be simplified and be done in energy conserving ways. Although this may appear simple, these interventions can enable someone to maximize their level of participation.

#### **4.5 Barriers and facilitators to activity and participation**

The environmental factors cited most as facilitators were the support and relationships of health professionals, immediate family, health-related professionals and friends; the attitudes of health professionals, immediate family, health-related professionals and friends and health services, systems and policies. These findings are not surprising as all the participants were beneficiaries of the government's free antiretroviral programs and the professionals are well trained to serve this population hence their support and relationships and attitudes being rated as facilitating by the majority of the participants. The support, relationships and attitudes of the immediate family were also highly rated as facilitating and this is consistent with findings from previous studies where the family has been identified as the major support system these people have. Factors cited by the least number of participants as facilitating were social norms, practices and ideologies (7%), and the following services, systems and policies; legal (12%), social security (12%) and labour and employment (10%). The most cited barriers were societal attitudes, housing, social security and labour & employment services, systems and policies. Least cited barriers were the support and relationships of the following; personal care providers (0%), health-related professionals (0%) and health professionals (5%). The attitudes of personal care providers (2%), health professionals (5%) and health-related professionals (2%) as well the education services, systems and policies were the least cited barriers. Societal attitudes towards PLWA although improving needs to be addressed as some participants were victims of stigma and discrimination. A lot has been done in Zimbabwe in an effort to foster positive attitudes in individuals and the society as a whole. These have bore some fruits but are not adequate. On services, systems and policies, this study was done at a period when the country was coming out of a decade long economic downturn where most workers had lost all their savings and their pensions had been eroded by inflation. Services like legal were inaccessible because of costs. Unemployment rate was also very high due to the shrinkage of the economy.

#### **4.6 Factors predicting quality of life**

Before adjusting for other possible explanatory variables, the type of ARV (categorized as stavudine containing and non- stavudine containing regimens) statistically

significantly predicted the total score (quality of life) ( $p= 0.02$ ), interpersonal interactions and relationships ( $0.03$ ) as well as community and civic life ( $p=0.04$ ). However, in an adjusted analysis which took into account the effect of all the other explanatory variables, type of ARV was not statistically significantly associated with either the total score or any of the domains. In an unadjusted analysis, time one had been on antiretroviral drugs did not predict one's overall score (quality of life) ( $p= 0.16$ ) but statistically significantly predicted one's participation in community and civic life ( $p=0.04$ ). It also predicted one's participation in domestic life events ( $p=0.08$ ) although the association was not statistically significant. In the adjusted analysis, period on antiretroviral drugs was neither associated with the overall score nor any of the domains. There might have been possible confounding by other explanatory variables. Possible reasons for no or weak association with quality of life is that this particular sample was recruited from one of the major referral OI clinics and chances are that those who had been on antiretroviral drugs for longer and continued to attend this centre even after decentralization were likely to be experiencing adverse events although this was beyond the scope of this study to confirm. These findings however imply that regardless of period one has been on antiretroviral drugs, there is need to continue helping these people to perform at their maximum level in order for them to experience the best possible quality of life.

In both the adjusted and unadjusted analysis, last CD4 count neither predicted overall score nor participation in any of the domains. This is inconsistent with the expected since CD4 count is expected to predict quality of life. Two possible reasons are: firstly, the CD4 count recorded in this study did not necessarily reflect the person's current CD4 count since the period since the last CD4 count ranged from 0-40 months with a mean period of 8.9 months (S.D 10.3). This period is long enough for one's CD4 count or condition to change significantly. The second possible but unlikely reason is that an increase in CD4 count does not necessarily translate to improved quality of life. The same study needs to be done with a more representative and larger sample to confirm these findings.

In an adjusted analysis, the following variables statistically significantly explained the overall score; physical health, mental health and use of assistive devices. Mobility was statistically significantly explained by physical health and use of assistive devices. Self-care was only statistically significantly explained by having someone assisting. Participation in domestic life was statistically significantly explained by physical health, use of assistive device and having an assistant. Interpersonal interactions and relationships were statistically significantly explained by one's rating of their mental and emotional health and use of other medications. None of the variables statistically significantly explained participation in major life events. Participation in community and civic life was statistically significantly explained by use of other medications and use of assistive devices.

Rehabilitation can therefore play an important role in terms of treatment of HIV-related impairments and minimizing activity limitations and participation restrictions, mitigating against the socio-economic challenges through enabling someone to remain at work and ensuring productivity at work by appropriate placement. The psychological effect of being in control of one's life at home and at work can play an important role in improving one's quality of life (Radomski and Trombly Latham, 2008; Pedretti et al, 2006). Assessment can focus on motor, sensory, cognitive, perceptual, interpersonal and intrapersonal, self-maintenance, work and leisure and community and environment. Treatment programs should be according to patients' needs and abilities, must be continuously adjusted as aims are met and altered ((Radomski and Trombly Latham, 2008; Pedretti et al, 2006). Treatment may include provision of equipment, home assessment, advice on energy conservation and time management, introduction of new methods for personal ADL and practice skills (Barwood, Barnett, Davies and Hancock, 1993). Individual and /or group treatments may aid stress management and relaxation skills, reality orientation, safety, increase confidence and self-esteem, assertion training, leisure counseling, retraining domestic skills, improve social skills, provide enjoyment and expression

The ultimate goal of rehabilitative interventions is to enable people with disabling conditions to achieve their maximum level of functioning. In the same way, rehabilitation interventions can be designed to prevent the decline in functional ability. Interventions should be individualized on the basis of functional capacity and individual symptomatology of each client, hence no one exercise program/intervention can adequately deal with the special needs of all HIV-infected patients (Mustafa et al, 1999). A need to work closely with the client's physician in deciding the intensity of the exercise program was noted. Mustafa et al found that HIV-infected individuals self-reporting exercise participation had 107.5% higher CD4 cell counts when compared to their counterparts who denied exercise participation. Exercisers also displayed slower disease progression to AIDS compared to non-exercisers.

#### **4.7 Limitations of the study**

Originally the researcher wanted to do a prospective cohort study with data collected at initiation of ARVs and after four months of ARVs. From the pilot study it emerged that it was going to be difficult to follow-up the subjects due to the decentralization of the provision of ARVs. It also emerged that some patients were presenting at Parirenyatwa for the first time but had been taking ARVs from somewhere else. The researcher was of the opinion that the subjects will be more honest if she only asked them the period they had been on ARVs whether from Parirenyatwa or somewhere else. Also the fact that only those who would have been initiated on ARVs were to be interviewed meant that participants would be more honest as there will not be any threat of being denied access to ARVs from Parirenyatwa Opportunistic Infection clinic. The study was done at only one centre making it difficult to generalize the results to all PLWA on ARVs.

## **CHAPTER FIVE: CONCLUSION AND RECOMMENDATIONS**

### **5.1 Conclusions**

The mean age of participants was 41 years (+/- 9.3), 56% were female, 54% were married and 30.5% were widowed. Median period on ARVs was 13 months (I.Q.R 3-29) and median last CD4 count was 189.5 (I.Q.R 114-278). Thirty-two (54%) were on Stalanev (Stavudine, Lamuvidine and Nevirapine). About 36% and 61% had stopped or reduced their usual activities due to the illness respectively. Most affected aspects were walking (71%), fine hand use (41%), lifting & carrying objects (71%), shopping (55%), housework (55%), remunerative employment (56%) and economic self-sufficiency (79%). The support and relationships and attitudes of health professionals (86% and 88%) and immediate family (75% and 78%) were the cited major environmental facilitators. Factors statistically significantly associated with quality of life were physical health ( $p= 0.01$ ), mental & emotional health ( $p= 0.04$ ), and use of assistive devices ( $p= 0.02$ ). Period on ARVs and last CD4 count were not statistically significantly associated with quality of life after adjusting for possible confounding variables.

HIV-related disabilities are prevalent even among those on antiretroviral drugs and their quality of life is reduced, hence the need to scale up rehabilitation services for them.

### **5.2 Recommendations**

#### **To Government**

The national response to the HIV pandemic should include rehabilitative interventions, that is, rehabilitation services should be part of the comprehensive care and support services and should be reflected in the Zimbabwe national strategic plan for HIV/AIDS. Rehabilitation services for PLWHA should be accessible and affordable in the same way that counseling, testing and ARVs are.

The researcher therefore recommend that the subject be explored further at a national level, and that HIV and AIDS policies in Zimbabwe respond adequately to the

rehabilitation needs of people living with HIV/AIDS. A uniform rehabilitation protocol should also be designed for HIV-infected persons.

### **To Educators of Rehabilitation and other Health professionals**

Educational curricula for rehabilitation professionals, particularly Occupational therapists and physiotherapists must embrace the ICF as a guideline for problem identification and intervention planning for PLWHA. Other health professionals' curricula should also include rehabilitation needs of PLWHA and should clarify when to refer PLWHA for rehabilitation. PLWHA should be informed on the problems that require rehabilitation intervention.

There is need for in-depth understanding of the role of rehabilitation in the era of HIV and AIDS.

### **5.3 Suggestions for Further Research**

There is need for follow-up studies on a larger scale to gain in-depth knowledge on HIV related impairments, activity limitations and participation restrictions experienced by PLWHA as well as to confirm the trends observed in this study.

The effect of rehabilitation interventions on PLWHA who are experiencing impairments, activity limitations and participation restrictions also needs to be studied.

The researcher also undertook and is still advocating for the scaling up of rehabilitation services for PLWHA. In that spirit, she has already made presentations at various fora on HIV/AIDS, Disability and Rehabilitation. The findings will be used to enrich the newly introduced HIV and AIDS module for students in the rehabilitation fraternity.

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APPENDICES

**APPENDIX 1**

**Questionnaire to assess the quality of life of adults living with HIV/AIDS based on the International Classification of Functioning, Disability and Health.**

Date: ...../...../..... Case ID ..... Participant number..... Participant name.....

**PART 1: DEMOGRAPHIC AND HEALTH INFORMATION**

**Section A: Demographic Information**

- 1. Sex: [ ] Female [ ] Male
2. Date of Birth: ...../...../..... (day/month/year)
3. Address (optional).....
4. Years of formal education...../Highest level of education.....
5. Current marital status: (Check only one that is most applicable)
Never married [ ] currently married [ ] Separated [ ] Divorced [ ] Widowed [ ] Cohabiting [ ]
6. Current Occupation (Select the single best option)
Paid employment [ ] Self-employed [ ] Non-paid work such as volunteer/charity [ ] Student [ ] Keeping house/House-maker [ ] Retired [ ] Unemployed (health reason) [ ] Unemployed (other reason) [ ] Other [ ] (Please specify) .....
7. Medical Diagnosis of existing Main Health Conditions, if possible give ICD Codes.
a. No medical condition exists [ ]
b. .... ICD Code.....
c. .... ICD Code.....
d. .... ICD Code.....
e. A health condition exists, however its nature or diagnosis is not known
8. WHO clinical stage.....
9. CD4 Counts and dates.....
10. ARVs .....

**Section B: Brief Health Information**

[ ] Self Report [ ] Clinician Administered

- 1. How do you rate your physical health?
Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]
2. How do you rate your mental and emotional health?
Very good [ ] Good [ ] Moderate [ ] Bad [ ] Very bad [ ]

3. Did you ever have any significant injuries that had an impact on your level of functioning?  
 Yes [ ] No [ ]  
 If Yes, please specify reason(s) and for how long  
 a. ....: days  
 b. ....: days  
 c. ....: days
4. Are you taking any medication (either prescribed or over the counter) besides your ARVs?  
 Yes [ ] No [ ]  
 If Yes, please specify major medications  
 a. ....  
 b. ....  
 c. ....
5. Do you use any assistive devices such as hearing aids, glasses, wheelchair etc?  
 Yes [ ] No [ ]  
 If Yes, please specify  
 .....
6. Do you have any person assisting you with your self care, shopping or other daily activities?  
 Yes [ ] No [ ]  
 If Yes, please specify person and assistance provided  
 .....
7. Are you receiving any kind of treatment for your health?  
 Yes [ ] No [ ]  
 If Yes, please specify  
 .....
8. In the past month, have you cut back (i.e reduced) your usual activities or work because of your health condition?  
 Yes [ ] No [ ]  
 If Yes, how many days? .....
9. In the past month, have you been totally unable to carry out your usual activities or work because of your condition?  
 Yes [ ] No [ ]  
 If Yes, how many days? .....

**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 indicates the extent of Participation restriction by describing the person's actual performance of a task or action 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 – all aspects of the physical, social and attitudinal world that can be coded using the Environmental. The Performance qualifier measures the difficulty the respondent experiences in doing things, assuming that they want to do them.*

**Note:** Use attached interview guide to elicit information on the Activities and Participation of the individual

|   |  |
|---|--|
| <p><b>Qualifier: Performance</b><br/>Extent of Participation Restriction</p>  |  |
| <p><b>0 No difficulty</b> means the person has no problem<br/> <b>1 Mild difficulty</b> means a problem that is present 25% of the time, with an intensity a person can tolerate and which happens rarely over the last 30 days.<br/> <b>2 Moderate difficulty</b> means that a problem that is present less than 50% of the time, with an intensity, which is interfering in the persons day to day life and which happens occasionally over the last 30 days.<br/> <b>3 Severe difficulty</b> means that a problem that is present more than 50% of the time, with an intensity, which is partially disrupting the persons day to day life and which happens frequently over the last 30 days.<br/> <b>4 Complete difficulty</b> means that a problem that is present more than 95% of the time, with an intensity, which is totally disrupting the persons day to day life and which happens every day over the last 30 days.<br/> <b>8 Not specified</b> means there is insufficient information to specify the severity of the difficulty.<br/> <b>9 Not applicable</b> means it is inappropriate to apply a particular code (e.g. b650 Menstruation functions for woman in pre-menarche or post-menopause age).</p> |  |

| Short list of A&P domains  | Performance Qualifier |
|--|-----------------------|
| <b>d4. MOBILITY</b>  |                       |
| <b>d430</b> Lifting and carrying objects   |                       |
| <b>d440</b> Fine hand use ( <i>picking up, grasping</i> )                            |                       |
| <b>d450</b> Walking  |                       |
| <b>d465</b> Moving around using equipment ( <i>wheelchair, skates, etc.</i> )        |                       |
| <b>d470</b> Using transportation ( <i>car, bus, train, plane, etc.</i> )             |                       |
| <b>d475</b> Driving ( <i>riding bicycle and motorbike, driving car, etc.</i> )       |                       |
| <b>d5. SELF CARE</b>   |                       |
| <b>d510</b> Washing oneself ( <i>bathing, drying, washing hands, etc</i> )           |                       |
| <b>d520</b> Caring for body parts ( <i>brushing teeth, shaving, grooming, etc.</i> ) |                       |
| <b>d530</b> Toileting  |                       |
| <b>d540</b> Dressing   |                       |
| <b>d550</b> Eating   |                       |
| <b>d560</b> Drinking   |                       |
| <b>d570</b> Looking after one`s health   |                       |

|  |  |
|--|--|
| <b>d6. DOMESTIC LIFE</b>   |  |
| <b>d620</b> Acquisition of goods and services ( <i>shopping, etc.</i> )                      |  |
| <b>d630</b> Preparation of meals ( <i>cooking etc.</i> )                                     |  |
| <b>d640</b> Doing housework ( <i>cleaning house, washing dishes laundry, ironing, etc.</i> ) |  |
| <b>d660</b> Assisting others   |  |
|  |  |
| <b>d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS</b>                                      |  |
| <b>d710</b> Basic interpersonal interactions   |  |
| <b>d720</b> Complex interpersonal interactions   |  |
| <b>d730</b> Relating with strangers  |  |
| <b>d740</b> Formal relationships   |  |
| <b>d750</b> Informal social relationships  |  |
| <b>d760</b> Family relationships   |  |
| <b>d770</b> Intimate relationships   |  |
|  |  |
| <b>d8. MAJOR LIFE AREAS</b>  |  |
| <b>d810</b> Informal education   |  |
| <b>d820</b> School education   |  |
| <b>d830</b> Higher education   |  |
| <b>d850</b> Remunerative employment  |  |
| <b>d860</b> Basic economic transactions  |  |
| <b>d870</b> Economic self-sufficiency  |  |
|  |  |
| <b>d9. COMMUNITY, SOCIAL AND CIVIC LIFE</b>  |  |
| <b>d910</b> Community Life   |  |
| <b>d920</b> Recreation and leisure   |  |
| <b>d930</b> Religion and spirituality  |  |
| <b>d940</b> Human rights   |  |
| <b>d950</b> Political life and citizenship   |  |
|  |  |
| <b>ANY OTHER ACTIVITY AND PARTICIPATION</b>  |  |
|  |  |
|  |  |
|  |  |
|  |  |

**PART 3: ENVIRONMENTAL FACTORS**

*Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. In this questionnaire the physical environment has been excluded.*

Qualifier in environment: Barrier or facilitator

- |                     |                            |
|---------------------|----------------------------|
| 0 No barriers       | +0 No 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    |

| <b>Short List of Environment</b>   | <b>Barrier</b> | <b>Facilitator</b> |
|--|----------------|--------------------|
| <b>e3. SUPPORT AND RELATIONSHIPS</b>   |                |                    |
| 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  |                |                    |
|  |                |                    |
| <b>e4. ATTITUDES</b>   |                |                    |
| 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                                  |                |                    |
|  |                |                    |
| <b>e5. SERVICES, SYSTEMS AND POLICIES</b>                                    |                |                    |
| 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                    |                |                    |
|  |                |                    |
| <b>ANY OTHER ENVIRONMENTAL FACTORS</b>                                       |                |                    |
|  |                |                    |
|  |                |                    |
|  |                |                    |

## **APPENDIX 2: JREC APPROVAL**

**INFORMED CONSENT FORM**

APPENDIX 3a: INFORMED CONSENT FORM

ENGLISH VERSION

I willingly agree to participate in the study being carried out by Mrs Tecla Mlambo. The study is meant to assess the areas in my day-day life where I'm having problems and see which areas I am having problems in my day-to-day functioning. The findings will assist our health service providers to come up with ways that are meant to maximise my functioning in day-to-day life. Thus, the information will benefit me and other people in my situation. I understand that my participation is voluntary, I can withdraw any time without having my treatment withdrawn. The information I give will strictly be treated as confidential and there will be no mentioning of my name in any publication.

Should I require any information or clarification on the study or findings, I can contact Mrs T Mlambo at the following address and telephone numbers:

University of Zimbabwe College of Health Sciences

Department of Rehabilitation

New Health Sciences Buildings –Parirenyatwa Hospital Grounds.

Telephone numbers: Business 04 797 800 (direct), 04 707 887/707 707/791 631

ext 2175/6

Cell 0772 263 521

Signature..... Dated.....

## APPENDIX 3b: INFORMED CONSENT FORM

### SHONA VERSION

Ini ndinobvuma pasina kumanikidzwa kutora chikamu mutsvakiridzo irikuitwa naMai Tecla Mlambo veku Rehabilitation department ku College of Health Sciences ye University ye Zimbabwe. Tsvakiridzo iyi irikuongorora nzvimbo mumaramiro angu ezuva nezuva dzingangodero ndichisangana nedambudziko mukuita mabasa kana kugarisana nevamwe zvichikonzerwa neurwere hweHIV/AIDS kana mishonga yandirikunwa. Zvichabuda mutsvakiridzo iyi zvichashandiswa kutsvaga nzira dzingabatsira kuti ini kana vamwe vangave nedambudziko vabatsirwe kurarama nenzira yebamusorosa ingakwanisike. Ndinonzwisisa kuti kutora chikamu mutsvakiridzo iyi hakumanikidzwi, uye kusava chikamu hazvikanganisi mamwe marapirwo angu pachipatara chino.

Zvinyorwa zvinogona kubuda mutsvakiridzo ino hazvizovi ne zita rangu.

Kana ndichida kuziva zvimwe kana kunyatsojekeserwa nezve tsvakiridzo iyi kana kuwana chinyorwa chichabuda mutsvakiridzo ino, ndinoona kana kunyorera kana kuridza nhare kuna Mai Tecla Mlambo pakero nenhamba dzinotevera:

University of Zimbabwe College of Health Sciences

Department of Rehabilitation

New Health Sciences Buildings –Parirenyatwa Hospital Grounds.

Nhare: Dzokubasa 04 797 800 (direct), 04 707 887/707 707/791 631  
ext 2175/6

Nharembozha 0772 263 521

Signature..... Date.....

#### APPENDIX 4: SAMPLE SIZE CALCULATION

The sample size calculation to estimate the prevalence of activity/activity limitations and participation/participation restrictions (quality of life) among adults living with HIV who on ARVs was calculated using Cochran's simple formula for categorical data based on the assumption of normal approximation;

$$n = \frac{Z^2 P(1-P)}{d^2}$$

Where n= sample size

Z= Z statistic for the level of confidence

P= expected prevalence or proportion

d = precision or margin of error

Therefore, the Z statistic for the level of confidence of 95%, that is, 1.96 was used.

The expected prevalence (P) of activity limitations and participation restrictions among people living with HIV/AIDS was based on previous studies among people living with HIV/AIDS and assumed to be between 50% and 84%. The precision d or acceptable margin of error of the proportion estimated was set at 0.10.

Based on the prevalence range 50% to 84%, the upper limit of 84% was used to calculate the required sample size.

$$n = \frac{1.96^2 \times 0.84(1-0.84)}{0.10^2}$$

$$n = 51.63$$

Since we cannot have a fraction of a person, the minimum required sample size at analysis stage is **52**.

Statistical power of the study is not usually calculated in this type of study (cross sectional – prevalence studies) because we do not have beta in the formula.

## APPENDIX 5: CODE BOOK/DATA DICTIONARY

### Questionnaire to assess the quality of life of adults living with HIV/AIDS based on the International Classification of Functioning, Disability and Health.

Date: ...../...../.....

Interview site: 1- OI Clinic 2- KS Clinic

#### **DEMOGRAPHIC AND HEALTH INFORMATION**

##### **Section A: Demographic Information**

###### **11. Sex:**

- 1- Female
- 2- 2-Male

###### **12. Age in years**

###### **13. Highest level of education:**

- 1- Primary education grade 7
- 2-Secondary O-level
- 3-Secondary A-level
- 4-Tertiary Diploma
- 5- Tertiary University degree

###### **14. Marital status:**

- 1-Never married
- 2- Currently married
- 3- Separated
- 4- Divorced
- 5- Widowed
- 6-Cohabiting

###### **15. Current Occupation:**

- 1-Paid employment
- 2- Self-employed
- 3- Non-paid work such as volunteer/charity
- 4 -Student
- 5- Keeping house/House-maker
- 6- Retired
- 7- Unemployed (health reason)

8- Unemployed (other reason)

9- Other (Please specify) .....

16. CD4 Counts and dates.....

17. ARVs .....

**Section B: Brief Health Information**

10. Physical health

5-Very good

4-Good

3-Moderate

2-Bad

1-Very bad

11. Mental and emotional health

5-Very good

4-Good

3-Moderate

2-Bad

1-Very bad

12. Previous injury

1-Yes

0-No

13. Any other medication (either prescribed or over the counter) besides your ARVs

1-Yes

0-No

14. Use of assistive devices

1-Yes

0-No

15. Any person assisting you with your self care, shopping or other daily activities

1-Yes

0-No

16. Cut back (i.e reduced) your usual activities or work because of your health condition?

1-Yes

0-No

17. Been totally unable to carry out your usual activities or work because of your condition

1- Yes

0-No

**PART 2: ACTIVITY LIMITATIONS & PARTICIPATION RESTRICTION**

**Qualifier:** *Performance*

Extent of Activity Limitation and Participation Restriction

**0 - No difficulty**

**1 - Mild difficulty**

**2- Moderate difficulty**

**3- Severe difficulty.**

**4 -Complete difficulty.**

**. Not specified**

**. Not applicable**

| Short list of A&P domains  | Performance Qualifier |
|--|-----------------------|
|  |                       |
| <b>d4. MOBILITY</b>  |                       |
| <b>d430</b> Lifting and carrying objects   |                       |
| <b>d440</b> Fine hand use ( <i>picking up, grasping</i> )                                    |                       |
| <b>d450</b> Walking  |                       |
| <b>d465</b> Moving around using equipment ( <i>wheelchair, skates, etc.</i> )                |                       |
| <b>d470</b> Using transportation ( <i>car, bus, train, plane, etc.</i> )                     |                       |
| <b>d475</b> Driving (riding bicycle and <i>motorbike, driving car, etc.</i> )                |                       |
|  |                       |
| <b>d5. SELF CARE</b>   |                       |
| <b>d510</b> Washing oneself ( <i>bathing, drying, washing hands, etc</i> )                   |                       |
| <b>d520</b> Caring for body parts ( <i>brushing teeth, shaving, grooming, etc.</i> )         |                       |
| <b>d530</b> Toileting  |                       |
| <b>d540</b> Dressing   |                       |
| <b>d550</b> Eating   |                       |
| <b>d560</b> Drinking   |                       |
| <b>d570</b> Looking after one`s health   |                       |
|  |                       |
| <b>d6. DOMESTIC LIFE</b>   |                       |
| <b>d620</b> Acquisition of goods and services ( <i>shopping, etc.</i> )                      |                       |
| <b>d630</b> Preparation of meals ( <i>cooking etc.</i> )                                     |                       |
| <b>d640</b> Doing housework ( <i>cleaning house, washing dishes laundry, ironing, etc.</i> ) |                       |
| <b>d660</b> Assisting others   |                       |
|  |                       |
| <b>d7. INTERPERSONAL INTERACTIONS AND RELATIONSHIPS</b>                                      |                       |
| <b>d710</b> Basic interpersonal interactions   |                       |
| <b>d720</b> Complex interpersonal interactions   |                       |
| <b>d730</b> Relating with strangers  |                       |
| <b>d740</b> Formal relationships   |                       |
| <b>d750</b> Informal social relationships  |                       |
| <b>d760</b> Family relationships   |                       |
| <b>d770</b> Intimate relationships   |                       |
|  |                       |

|   |  |
|---|--|
| <b>d8. MAJOR LIFE AREAS</b>                 |  |
| <b>d810</b> Informal education              |  |
| <b>d820</b> Education                       |  |
| <b>d850</b> Remunerative employment         |  |
| <b>d860</b> Basic economic transactions     |  |
| <b>d870</b> Economic self-sufficiency       |  |
|   |  |
| <b>d9. COMMUNITY, SOCIAL AND CIVIC LIFE</b> |  |
| <b>d910</b> Community Life                  |  |
| <b>d920</b> Recreation and leisure          |  |
| <b>d930</b> Religion and spirituality       |  |
| <b>d940</b> Human rights                    |  |
| <b>d950</b> Political life and citizenship  |  |
|   |  |
| <b>ANY OTHER ACTIVITY AND PARTICIPATION</b> |  |
|   |  |
|   |  |
|   |  |
|   |  |

**PART 3: ENVIRONMENTAL FACTORS**

*Environmental factors make up the physical, social and attitudinal environment in which people live and conduct their lives. In this questionnaire the physical environment has been excluded.*

**Qualifier in environment: Barrier or facilitator**

**All facilitators have an “f” at the end of the code and all barriers have a “b”.**

**1 Mild barriers**

**2 Moderate barriers**

**3 Severe barriers**

**4 Complete barriers**

**1 Mild facilitator**

**2 Moderate facilitator**

**3 Substantial facilitator**

**4 Complete facilitator**

| <b>Short List of Environment</b>  | <b>Barrier (b)</b> | <b>Facilitator (f)</b> |
|---|--------------------|------------------------|
| <b>e3. SUPPORT AND RELATIONSHIPS</b>  |                    |                        |
| <b>e310</b> Immediate family  |                    |                        |
| <b>e320</b> Friends   |                    |                        |
| <b>e325</b> Acquaintances, peers, colleagues, neighbours and community members      |                    |                        |
| <b>e330</b> People in position of authority   |                    |                        |
| <b>e340</b> Personal care providers and personal assistants                         |                    |                        |
| <b>e355</b> Health professionals  |                    |                        |
| <b>e360</b> Health related professionals  |                    |                        |
|   |                    |                        |
| <b>e4. ATTITUDES</b>  |                    |                        |
| <b>e410</b> Individual attitudes of immediate family members                        |                    |                        |
| <b>e420</b> Individual attitudes of friends   |                    |                        |
| <b>e440</b> Individual attitudes of personal care providers and personal assistants |                    |                        |
| <b>e450</b> Individual attitudes of health professionals                            |                    |                        |
| <b>e455</b> Individual attitudes of health related professionals                    |                    |                        |
| <b>e460</b> Societal attitudes  |                    |                        |

|  |  |  |
|--|--|--|
| e465 Social norms, practices and ideologies                |  |  |
|  |  |  |
| <b>e5. SERVICES, SYSTEMS AND POLICIES</b>                  |  |  |
| 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  |  |  |
|  |  |  |
| <b>ANY OTHER ENVIRONMENTAL FACTORS</b>                     |  |  |
|  |  |  |
|  |  |  |
|  |  |  |